UTS UNIVERSITY OF TECHNOLOGY SYDNEY

AN EMPIRICAL INVESTIGATION OF OLDER ADULTS' AND PROFESSIONALS' PERSPECTIVES AND EXPERIENCES OF ADVANCE PERSONAL PLANNING

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Thesis submitted in fulfilment of the requirements for the degree of

Doctor of Philosophy

Under the supervision of Professor Nola Ries, Associate Professor Jane Wangmann and Dr Amy Waller

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CERTIFICATE OF ORIGINAL AUTHORSHIP

I, Briony Johnston, declare that this thesis is submitted in fulfilment of the requirements for the award of Doctor of Philosophy, in the Faculty of Law at the University of Technology Sydney.

This thesis is wholly my own work unless otherwise referenced or acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

This document has not been submitted for qualifications in any other academic institution.

This research is supported by the Australian Government Research Training Program.

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FORMAT OF THESIS

My research is formatted as a conventional thesis.

Original published works arising from research during my candidature are included in appendices.

LIST OF PUBLICATIONS INCLUDED

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STATEMENT OF CONTRIBUTION OF AUTHORS

The graduate research student, Briony Johnston, is the sole author of 'A Revised Approach to Advance Personal Planning: The Role of Theory in Achieving "The Good Result"'. This paper was submitted for consideration of, and was subsequently awarded, the John McPhee (Law) Student Essay Prize at the 2021 Australasian Association of Bioethics and Health Law.

The graduate research student, Briony Johnston, is the first listed author of 'Key Informant Perspectives on Barriers to Advance Personal Planning: Results from a Qualitative Interview Study'. She was responsible for data collection, drafting, editing and facilitating publication of the paper. Dr Nola Ries and Dr Amy Waller, supervisors of the graduate research student, contributed to the paper by providing feedback relating to the interpretation and presentation of results, and reviewing the various iterations of the publication. All authors were in agreement with the content of the submitted manuscript.

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ABSTRACT

While many Australians may be familiar with Advance Care Planning, which relates to the process of thinking about and discussing future wishes regarding healthcare, the full range of instruments that form the broader legal process of Advance Personal Planning (APP) is less recognised. APP allows individuals to consider, discuss and record their values and preferences about future financial, health and personal matters in anticipation of a period of incapacity or death.

This thesis presents an original study that investigates the experiences and perspectives of APP from three cohorts: people aged 65 years or older living in regional areas of New South Wales; lawyers working in regional areas of New South Wales; and professional key informants working within the fields of health, ageing and law. Their experiences are examined holistically, offering an informed perspective of existing barriers to engagement, factors affecting the quality of prepared instruments, and barriers that may prevent the successful implementation of an older person's APP instruments during a period of incapacity in future.

The deliberate combination of these cohorts, rather than the continued siloing of legal and health professionals, provides a unique contribution to understanding how APP processes are currently operating, and facilitates informed perspectives on opportunities for improvement. Findings are analysed through the integrated lens of Preventive Law and Therapeutic Jurisprudence, known as 'theralaw', and applied within the field of Elder Law. Integrating the respective foci of proactively preventing risks from occurring through communication and planning, and prioritising the wellbeing of older people when interacting with the legal system, produces a new appreciation for the benefits of APP. Perspectives of how the law supports, or fails to support, people as they age come to the fore, offering an examination of how APP can facilitate the realisation of autonomy and empowerment, while protecting the wellbeing and guarding against the vulnerability of older people.

Recommendations are made at individual, professional and structural levels, offering informed suggestions for how APP processes can be improved. Reframing APP as an ongoing, routine, interprofessional and communication-based process between an older person, their support

community and relevant professional advisors helps to promote the recognition of APP as a vital component of planning for the rest of life, rather than the end of life.

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1 INTRODUCTION

1.1 INTRODUCTION

Advance Personal Planning (APP) is a process that allows an individual to act on their legal rights by considering, discussing and recording their values and preferences about future financial, health and personal matters in anticipation of a later loss of capacity or death.[1] This doctoral research is an original study that comprehensively investigates and integrates the experiences and perspectives of three key cohorts: older people living in regional areas of New South Wales (NSW); lawyers working in regional areas of NSW, Australia; and professional key informants working in the fields of law, health and ageing. My research highlights points of convergence and divergence between the experiences of these cohorts. Barriers are identified at three main stages of APP: initial barriers to engaging with available legal planning instruments; factors affecting the quality of prepared instruments; and barriers to successfully implementing instruments in the future. The integration of the theoretical perspectives of Preventive Law and Therapeutic Jurisprudence, and their application within the field of Elder Law, allows for new insights to be gained from the study results. Finally, this holistic examination of APP leads to the development of informed recommendations for improvement at individual, professional and structural levels. My research was supported by an Australian Research Council Discovery Project Grant, entitled 'Taking Action: Increasing Advance Personal Planning by Community-dwelling Older Adults' (DP190100861). This chapter will

[1] Karen M Detering et al, 'The Impact of Advance Care Planning on End of Life Care in Elderly Patients: Randomised Controlled Trial' (2010) 340 *BMJ* c1345:1-9 ('The Impact of Advance Care Planning on End of Life Care'); Rebecca L Sudore et al, 'Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel' (2017) 53(5) *Journal of Pain and Symptom Management* 821; Amy Waller et al, 'Increasing Advance Personal Planning: The Need for Action at the Community Level' (2018) 18(1) *BMC Public Health* 606:1–8.

provide a brief overview of the difference between APP and Advance Care Planning, as well as outlining the legal significance of planning instruments. I will state my research questions and outline the original contributions of my research to the existing knowledge base. Finally, I will provide an overview of the structure of my thesis.

1.2 THE LEGAL IMPORTANCE OF ADVANCE PERSONAL PLANNING

1.2.1 Advance Personal Planning

APP aims to ensure that a person's health, legal and financial wishes are known and respected during periods of incapacity and after death.[2] Such planning may fulfil several purposes: consideration of the potential changes an individual may face towards the end of life; encouragement of an awareness of dying and a chance to record values and preferences and share these with relevant parties; legally planning for a future loss of capacity and any impact this may have on a person's wishes; and assigning responsibility to other individuals to ensure these wishes are acted upon.[3] More generally, APP is not limited to individuals who are not nearing the end of life.[4] It provides a means for any older person to consider their values and preferences with the goal of planning ahead for the future with regard to their legal, financial, personal and health-related wellbeing.

APP is an umbrella term that encompasses the full range of available legal planning mechanisms. For the purposes of my research, I have adopted the terminology for the relevant instruments and appointments used in NSW, Australia, as this is where my study was conducted.

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[2] Waller et al (n 1) 1; Susi Lund, Alison Richardson and Carl May, 'Barriers to Advance Care Planning at the End of Life: An Explanatory Systematic Review of Implementation Studies' (2015) 10(2) *PLOS ONE* e0116629:1-15, 3.

[3] Lund, Richardson and May (n 2) 3.

[4] Craig Sinclair, 'Now Is the Time for Advance Care Planning with Patients', *InSight+* (Blog Post, 21 March 2022) <https://insightplus.mja.com.au/2022/10/now-is-the-time-for-advance-care-planning-with-patients/>; Advance Care Planning Australia and Austin Health, *Advance Care Planning: Getting Started Guide* (Guidelines, 2020) 1 <https://palliativecarensw.org.au/wp-content/uploads/2022/03/getting-started-guide-2020.pdf>; 'The Case for Prioritising Advance Care Planning in COVID-19 Response', *Advance Care Planning Australia* (Web Page, 12 August 2020) <https://www.advancecareplanning.org.au/about-us/news/the-case-for-prioritising-advance-care-planning-in-covid-19-response>; Frances Batchelor et al, 'Facilitators and Barriers to Advance Care Planning Implementation in Australian Aged Care Settings: A Systematic Review and Thematic Analysis' (2019) 38(3) *Australasian Journal on Ageing* 173, 176; Kimberly Buck et al, *Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services* (Report, Advance Care Planning Australia and Austin Health, October 2019) 8 <https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3668752> ('*Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services*').

A Will, the most commonly recognised and completed APP instrument, is made to dispose of property and assets following death. An Enduring Power of Attorney is authorised to make decisions relating to a person's property or financial matters during a period of incapacity, while an Enduring Guardian has the power to make decisions regarding health and personal matters if an individual is not able to make and communicate these choices for themselves. Finally, a person may make an Advance Care Directive to legally set out their wishes, values and preferences relating to future medical treatment and personal matters, which may include their intentions for end of life care. These terms and instruments will be discussed in more detail in the following chapter.

APP emphasises the importance of all aspects of planning, and encourages a holistic perspective of how legal and health professionals can work together to better assist their clients or patients who wish to plan ahead. Similarly, it allows individuals to critically think about how they would like to plan for the rest of their life, as opposed to perceiving APP as only for the end of life.

1.2.2 Advance Care Planning

Advance Care Planning is concerned with an individual's wishes, values and preferences associated with future health care only, therefore it is a far narrower process than APP. It prepares for a time when a person may be either too ill to speak for themselves or unable to communicate their decisions due to a decline in, or loss of, capacity.[5] Advance Care Planning may involve a series of acts, including thinking about preferences for future care, discussing these wishes with important parties including family and health professionals,[6] and potentially

[5] Maria T Carney et al, 'Impact of a Community Health Conversation upon Advance Care Planning Attitudes and Preparation Intentions' (2021) 42(1) *Gerontology & Geriatrics Education* 82, 82; Karen M Detering et al, 'Prevalence of Advance Care Planning Documentation and Self-Reported Uptake in Older Australians with a Cancer Diagnosis' (2021) 12(2) *Journal of Geriatric Oncology* 274, 274 ('Prevalence of Advance Care Planning Documentation and Self-Reported Uptake'); Sonja McIlfatrick et al, '"It's Almost Superstition: If I Don't Think about It, It Won't Happen". Public Knowledge and Attitudes towards Advance Care Planning: A Sequential Mixed Methods Study' (2021) 35(7) *Palliative Medicine* 1356, 1357; Marcus Sellars et al, 'Personal and Interpersonal Factors and their Associations With Advance Care Planning Documentation: A Cross-Sectional Survey of Older Adults in Australia' (2020) 59(6) *Journal of Pain and Symptom Management* 1212, 1212 ('Personal and Interpersonal Factors and their Associations With Advance Care Planning Documentation'); Craig Sinclair et al, 'Advance Care Planning in Australia during the COVID-19 Outbreak: Now More Important than Ever' (2020) 50(8) *Internal Medicine Journal* 918, 919;) Ian A Scott et al, 'Difficult but Necessary Conversations — The Case for Advance Care Planning' (2013) 199(10) *The Medical Journal of Australia* 662, 662.

[6] Sudore et al (n 1) 825–826. See also Karen M Detering et al, 'Organisational and Advance Care Planning Program Characteristics Associated with Advance Care Directive Completion: A Prospective Multicentre Cross-Sectional Audit among Health and Residential Aged Care Services Caring for Older Australians' (2021) 21 *BMC Health Services Research* 700:1–12, 2 ('Organisational and Advance Care Planning Program Characteristics'); Helena Rodi et al, 'Exploring Advance Care Planning Awareness, Experiences, and Preferences of People with

taking the step of formally recording these intentions.[7] It has been described as empowering[8] and an important exercise in self-determination,[9] as it represents 'a means of extending the autonomy of patients to stages in life where they have become incompetent'.[10] There is a need for honest and ongoing communication between the person who is making their wishes known and those around them, whether they be family, friends or professionals.[11] Sabatino describes this as a change from the traditional 'legal transactional approach' to a more flexible

Cancer and Support People: An Australian Online Cross-Sectional Study' (2021) 29(7) *Supportive Care in Cancer* 3677, 3677; Marcus Sellars et al, 'Public Knowledge, Preferences and Experiences about Medical Substitute Decision-Making: A National Cross-Sectional Survey' [2021] *BMJ Supportive & Palliative Care* 1-21, 1; Craig Sinclair et al, 'Association Between Region of Birth and Advance Care Planning Documentation Among Older Australian Migrant Communities: A Multicenter Audit Study' (2021) 76(1) *The Journals of Gerontology: Series B* 109, 117–118; Craig Sinclair et al, 'A Public Health Approach to Promoting Advance Care Planning to Aboriginal People in Regional Communities' (2014) 22(1) *Australian Journal of Rural Health* 23, 25.

[7] Adam D Schickedanz et al, 'A Clinical Framework for Improving the Advance Care Planning Process: Start with Patients' Self-Identified Barriers' (2009) 57(1) *Journal of the American Geriatrics Society* 31, 31. See also Department of Health, *National Framework for Advance Care Planning Documents* (Report, May 2021) 1, 6 <https://www.health.gov.au/resources/publications/national-framework-for-advance-care-planning-documents?language=en>; Detering et al, 'Organisational and Advance Care Planning Program Characteristics' (n 6) 2.

[8] Helen Close et al, 'Qualitative Investigation of Patient and Carer Experiences of Everyday Legal Needs towards End of Life' (2021) 20 *BMC Palliative Care* 47:1–13, 10; Australian Healthcare Associates, *Exploratory Analysis of Barriers to Palliative Care* (Issues Report on Aboriginal and Torres Strait Islander Peoples, Department of Health, September 2019) 18 <https://www.health.gov.au/resources/publications/exploratory-analysis-of-barriers-to-palliative-care-issues-report-on-aboriginal-and-torres-strait-islander-peoples?language=en>; Batchelor et al (n 4) 176; Sellars et al, 'Perspectives of People with Dementia and Carers on Advance Care Planning and End-of-Life Care' (n 4) 274; Hui Yun Chan, 'Refusing Treatment Prior to Becoming Incapacitated: Supported Decision-Making as an Approach in Advance Directives' (2018) 25(1) *European Journal of Health Law* 24, 33; Nola M Ries et al, 'How Do Lawyers Assist Their Clients with Advance Care Planning? Findings from a Cross-Sectional Survey of Lawyers in Alberta' (2018) 55(3) *Alberta Law Review* 683, 694–695; Australian Law Reform Commission, *Elder Abuse - A National Legal Response* (ALRC Report No 131, June 2017) 69 <https://www.alrc.gov.au/publication/elder-abuse-a-national-legal-response-alrc-report-131/>; Detering et al, 'The Impact of Advance Care Planning on End of Life Care' (n 1) 1.

[9] Department of Health (n 7) 1, 7; Australian Healthcare Associates (n 8) 1; Chan (n 8) 33; Australian Health Ministers' Advisory Council (n 4) 4; Sarah Ellison et al, *The Legal Needs of Older People in NSW* (Report, Law and Justice Foundation of New South Wales, December 2004) 156 <https://lawfoundation.net.au/wp-content/uploads/2023/11/54PJR_The-legal-needs-of-older-people-in-NSW_2004.pdf>.

[10] Brinkman-Stoppelenburg, Rietjens and van der Heide (n 5) 1000. See also Carney et al (n 5) 83; Close et al (n 8) 2; Julie L Masters, Lindsey E Wylie and Sarah B Hubner, 'End-of-Life Planning: Normalizing the Process' (2022) 34(4) *Journal of Aging & Social Policy* 641, 641–642; Jane B Baron, 'Fixed Intentions: Wills, Living Wills, and End-of-Life Decision Making' (2020) 87(2) *Tennessee Law Review* 375, 409–410; Nadia Moore et al, 'Doctors' Perspectives on Adhering to Advance Care Directives When Making Medical Decisions for Patients: An Australian Interview Study' (2019) 9 *BMJ Open* e032638:1-11, 1–2; Meredith Blake, Olivia Nicole Doray and Craig Sinclair, 'Advance Care Planning for People with Dementia in Western Australia: An Examination of the Fit Between the Law and Practice' (2018) 25(2) *Psychiatry, Psychology and Law* 197, 210; Sophie Trarieux-Signol et al, 'Advance Directives from Haematology Departments: The Patient's Freedom of Choice and Communication with Families. A Qualitative Analysis of 35 Written Documents' (2018) 17 *BMC Palliative Care* 10:1-12, 2.

[11] Sinclair (n 4); Carney et al (n 5) 82; Detering et al, 'Prevalence of Advance Care Planning Documentation and Self-Reported Uptake' (n 5) 274; Sellars et al, 'Personal and Interpersonal Factors and their Associations With Advance Care Planning Documentation' (n 5) 1212; Buck et al, 'Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services' (n 4) 14; Sellars et al, 'Perspectives of People with Dementia and Carers on Advance Care Planning and End-of-Life Care' (n 4) 284–285; Lum, Sudore and Bekelman (n 5) 396; Brinkman-Stoppelenburg, Rietjens and van der Heide (n 5) 1000.

'communications approach',[12] where a 'greater emphasis is placed on the process, not the form'.[13] This highlights the requirement for any form of advance planning, whether it be Advance Care Planning or the broader legal process of APP, to be viewed as an ongoing process of reflecting on wishes and preferences, communicating with key people, and making relevant legal documents that continue to take account of changing personal circumstances and values.

1.3 Gaps in the Legal Conceptualisation of Advance Personal Planning

While the literature on Advance Care Planning is established,[14] researchers have only recently begun to examine the legal processes of APP more broadly.[15] APP allows people to plan ahead to prevent unwanted medical, financial and legal consequences from arising in future, if they are no longer able to speak for themselves due to either a periodic loss of capacity or death.[16] To be effective, instruments must meet legal requirements, provide actionable instructions, be

[12] Charles P Sabatino, 'The Evolution of Health Care Advance Planning Law and Policy' (2010) 88(2) *The Milbank Quarterly* 211, 218.
[13] Ibid 227. See also Australian Health Ministers' Advisory Council (n 4) 6.
[14] Juliet Jacobsen, Rachelle Bernacki and Joanna Paladino, 'Shifting to Serious Illness Communication' (2022) 327(4) *JAMA* 321; Gloria T Anderson, 'Let's Talk About ACP Pilot Study: A Culturally-Responsive Approach to Advance Care Planning Education in African-American Communities' (2021) 17(4) *Journal of Social Work in End-of-Life & Palliative Care* 267; Kimberly Buck et al, 'Advance Care Directive Prevalence among Older Australians and Associations with Person-Level Predictors and Quality Indicators' (2021) 24(4) *Health Expectations* 1312 ('Advance Care Directive Prevalence among Older Australians'); Sinclair et al, 'Association Between Region of Birth and Advance Care Planning Documentation' (n 6); Laura Panozzo et al, 'Communication of Advance Care Planning Decisions: A Retrospective Cohort Study of Documents in General Practice' (2020) 19 *BMC Palliative Care* 108:1–7; Kimberly Buck et al, 'Concordance Between Self-Reported Completion of Advance Care Planning Documentation and Availability of Documentation in Australian Health and Residential Aged Care Services' (2019) 58(2) *Journal of Pain and Symptom Management* 264 ('Concordance Between Self-Reported Completion of Advance Care Planning Documentation and Availability of Documentation'); Moore et al (n 10); Marcus Sellars et al, 'Costs and Outcomes of Advance Care Planning and End-of-Life Care for Older Adults with End-Stage Kidney Disease: A Person-Centred Decision Analysis' (2019) 14(5) *PLOS ONE* e0217787:1-11; Blake, Doray and Sinclair (n 10); Weathers et al (n 5); Karen A Horridge, 'Advance Care Planning: Practicalities, Legalities, Complexities and Controversies' (2015) 100(4) *Archives of Disease in Childhood* 380; Tim Luckett et al, 'Advance Care Planning in 21st Century Australia: A Systematic Review and Appraisal of Online Advance Care Directive Templates against National Framework Criteria' (2015) 39(5) *Australian Health Review* 552; Brinkman-Stoppelenburg, Rietjens and van der Heide (n 5); Russell (n 5); Scott et al (n 5); Sabatino (n 12).
[15] Waller et al (n 1).
[16] Jacobsen, Bernacki and Paladino (n 14) 322; Grace W Orsatti, 'Attorneys as Healthcare Advocates: The Argument for Attorney-Prepared Advance Healthcare Directives' (2022) 50(1) *Journal of Law, Medicine & Ethics* 157, 157; Jamie Bryant et al, 'Inadequate Completion of Advance Care Directives by Individuals with Dementia: National Audit of Health and Aged Care Facilities' (2022) 12 *BMJ Supportive & Palliative Care* e319; Canadian Hospice Palliative Care Association, *Advance Care Planning in Canada: A Pan-Canadian Framework* (Report, January 2020) 7 <https://www.advancecareplanning.ca/wp-content/uploads/2020/06/ACP-Framework-EN-Updated.pdf>; Cancer Council NSW, *Getting Your Affairs in Order: Information for People Affected by Cancer* (Legal and Financial Fact Sheet) 3 <www.cancercouncil.com.au/wp-content/uploads/2022/03/Getting-your-affairs-in-order-NSW.pdf>.

regularly updated and available when decisions are made.[17] This is where an understanding of Advance Care Planning helps enrich the exploration of APP, as:

> Preferences about end-of-life property distribution, like preferences about end-of-life health care, may be affected by new information, changed circumstances, or altered wishes. Rather than pushing testators to foresee the unforeseeable and come to painfully final decisions fixed in documentary form, perhaps we might learn from end-of-life health care decision-making to conceptualize end-of-life property decision-making as fluid.[18]

The current literature does not account for, nor critically examine, the experiences of lawyers within the context of advance planning or acknowledge the important role they play.[19] One of the only studies to obtain the perspectives of lawyers in the context of Advance Care Planning was conducted by Ries et al in Alberta, Canada.[20] While this study provides invaluable insights regarding the role of lawyers in Advance Care Planning processes, there is little additional research that explicitly explores the perspectives of lawyers regarding their role in the broader context of APP, especially in the Australian context. As a result, understanding of these professional experiences is limited, particularly with assisting older adults to engage with APP processes. This is a critical gap in the literature.

[17] Advance Care Planning Australia, 'The Importance of Storing Your Patients' Advance Care Planning Documents in My Health Record', *Advance Care Planning Australia* (online, 21 March 2022) <https://www.advancecareplanning.org.au/about-us/news/the-importance-of-storing-your-patients-advance-care-planning-documents-in-my-health-record>; Royal Australian College of General Practitioners, *Advance Care Planning and My Health Record: Information for GPs* (Report, 2021) <https://www.racgp.org.au/FSDEDEV/media/documents/Clinical%20Resources/My%20health%20record/ACP-MHR-Information-for-GPs.pdf>; Royal Australian College of General Practitioners, *Planning and Recording My Future Healthcare Wishes: Advance Care Planning and My Health Record* (Report, 2021) <https://www.racgp.org.au/FSDEDEV/media/documents/Clinical%20Resources/My%20health%20record/ACP-MHR-Information-for-patients.pdf>; Advance Care Planning Australia and Austin Health (n 4) 6; Panozzo et al (n 14) 1; Buck et al, 'Concordance Between Self-Reported Completion of Advance Care Planning Documentation and Availability of Documentation' (n 14); Ina Carola Otte et al, 'The Utility of Standardized Advance Directives: The General Practitioners' Perspective' (2016) 19(2) *Medicine, Health Care and Philosophy* 199, 203; Lum, Sudore and Bekelman (n 5); Kelly J Purser and Tuly Rosenfeld, 'Evaluation of Legal Capacity by Doctors and Lawyers: The Need for Collaborative Assessment' (2014) 201(8) *The Medical Journal of Australia* 483.

[18] Baron (n 10) 380.

[19] Ariane Plaisance et al, 'How Engaged in Legal Planning for Incapacity and Death Are Canadians? A Mixed-Methods Survey' (2023) 18(3) *Healthcare Policy = Politiques De Sante* 47; Ries et al (n 8).

[20] Ries et al (n 8).

Further, while previous studies have provided some knowledge of rates of prevalence of health-related instruments,[21] and the quality of Advance Care Planning processes,[22] there is a lack of data considering the experiences and perspectives of older adults living in rural and regional contexts. My research sought to provide new data by exploring the experiences of older adults living in regional and rural NSW, Australia. While existing studies have examined the perspectives of healthcare professionals[23] and older people[24] relating to Advance Care Planning prevalence, processes and quality, the perspective of lawyers has largely been excluded. Further, available data do not combine the perspectives of professionals and community-dwelling older adults to create a holistic and multifaceted understanding of APP from engagement through to future use of completed instruments. My research therefore provides a comprehensive and integrative examination of the perspectives of older adults, lawyers and professional key informants with experience in the fields of law, health and ageing.

The existing literature also continues to separate the experiences of health professionals[25] and lawyers.[26] Adopting this siloed approach reinforces the separation between the professions. However, both legal and health practitioners should have familiarity with, and knowledge of, the full suite of available APP instruments and appointments relevant to their professional role

[21] Buck et al, 'Advance Care Directive Prevalence among Older Australians' (n 14); Sellars et al, 'Personal and Interpersonal Factors and their Associations With Advance Care Planning Documentation' (n 5); Buck et al, 'Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services' (n 4); Siobhan Calafiore, 'Advance Care Directives Frequently Written by Someone Other than the Patient', *Australian Doctor Group* (online, 27 December 2019) <https://www.ausdoc.com.au/news/advance-care-directives-frequently-written-someone-other-patient/>; Jeong et al (n 5); Michael R Greenberg, Marc Weiner and Gwendolyn B Greenberg, 'Risk-Reducing Legal Documents: Controlling Personal Health and Financial Resources' (2009) 29(11) *Risk Analysis* 1578.

[22] Jacobsen, Bernacki and Paladino (n 14); Orsatti (n 16); R Sean Morrison, 'Advance Directives/Care Planning: Clear, Simple, and Wrong' (2020) 23(7) *Journal of Palliative Medicine* 878; Batchelor et al (n 4); Yapp et al (n 5); Rhee, Zwar and Kemp (n 5).

[23] Carney et al (n 5); Suet Ying Ng and Eliza Lai-Yi Wong, 'The Role Complexities in Advance Care Planning for End-of-Life Care—Nursing Students' Perception of the Nursing Profession' (2021) 18(12) *International Journal of Environmental Research and Public Health* 6574:1–13; Craig Sinclair et al, 'Professionals' Views and Experiences in Supporting Decision-Making Involvement for People Living with Dementia' (2021) 20(1) *Dementia* 84 ('Professionals' Views and Experiences in Supporting Decision-Making Involvement'); Batchelor et al (n 4); Dixon and Knapp (n 5); Zhou et al (n 5).

[24] Catherine L Auriemma et al, 'How Traditional Advance Directives Undermine Advance Care Planning: If You Have It in Writing, You Do Not Have to Worry About It' (2022) 182(6) *JAMA Internal Medicine* 682; Detering et al, 'Organisational and Advance Care Planning Program Characteristics' (n 6); Sarah Nouri et al, 'Evaluation of Neighborhood Socioeconomic Characteristics and Advance Care Planning Among Older Adults' (2020) 3(12) *JAMA Network Open* e2029063:1-12; Sellars et al, 'Personal and Interpersonal Factors and their Associations With Advance Care Planning Documentation' (n 5); Buck et al, 'Concordance Between Self-Reported Completion of Advance Care Planning Documentation and Availability of Documentation' (n 14); Musa et al (n 5).

[25] Carney et al (n 5); Ng and Wong (n 23); Sinclair et al, 'Professionals' Views and Experiences in Supporting Decision-Making Involvement' (n 23).

[26] Ries et al (n 8); E Helmes, VE Lewis and A Allan, 'Australian Lawyers' Views on Competency Issues in Older Adults' (2004) 22(6) *Behavioral Sciences & The Law* 823.

or scope of practice.[27] Familiarity across professions would mean that, in the course of communicating with clients and patients, both lawyers and doctors would be enlivened to any potential legal or personal issues that a person may be experiencing, for example, financial exploitation or pressure from a family member to change their Will. In the case of health professionals, they could have the confidence to assess when it may be suitable to share information with their patient about APP that could help safeguard their patient's interests and preferences or refer them to a lawyer for advice. The combination of knowledge and experience of both lawyers and health professionals through a key informant approach allows a better understanding of similarities and points of distinction across these professions, bridging the siloes between legal and healthcare practices and ultimately providing a more holistic approach to planning processes.[28] While financial planners may also have relevant insights, and data was gathered on whether older people had had contact with financial planners, their views were not sought in this study. Given my focus on the preparation of legal instruments that older people make as part of APP, which may require future interpretation by healthcare professionals, the experience of financial planners was not within this scope. Similarly, lawyers reported the least reported prompt for clients to seek legal advice on APP was a client having had a discussion with a financial planning, banker or advisor.

1.4 Research Questions

My research investigates the experiences and perspectives of older adults living in rural and regional areas of NSW, lawyers and professional key informants with expertise in law, health and ageing with regard to APP. The consideration and combination of these cohorts facilitates an understanding of three main stages of planning ahead. Firstly, initial engagement with APP may arise from lawyers advising older clients of the full range of available legal planning instruments to record their health, financial and personal wishes, or from older people raising future planning with their legal or health advisors. Secondly, the preparation of key legal instruments and lawful appointments is carefully undertaken to ensure any prepared plans meet legal requirements. Finally, the implementation of completed plans overtly respects the legal rights of an older person and avoids legal risks or conflicts.

[27] Orsatti (n 16); Joshua A Rolnick et al, 'Patients' Perspectives on Approaches to Facilitate Completion of Advance Directives' (2019) 36(6) *American Journal of Hospice & Palliative Medicine* 526; Ries et al (n 8); Waller et al (n 1); Russell (n 5).
[28] Orsatti (n 16); Ries et al (n 8).

My research questions, which will be explored in more detail in Chapter 5, are as follows:

1. Are current APP processes clear, transparent and easy to follow from the perspective of older adults living in rural and regional NSW?
2. Are there deficiencies or problems within the current APP processes from the perspective of professional key informants, including lawyers, health professionals and aged care workers?
3. Are there any barriers preventing effective engagement with APP from the perspective of older adults and professional key informants?
4. Are there any barriers affecting the quality of completed APP instruments from the perspective of professional key informants?
5. Are there any barriers relating to the future use or effective implementation of APP instruments from the perspective of professional key informants?
6. Do older adults and professional key informants believe current APP processes can be improved? If so, how?

1.5 ORIGINAL CONTRIBUTIONS TO KNOWLEDGE

The available literature on Advance Care Planning, which has primarily emerged in the last decade,[29] focuses on planning ahead for future medical wishes, and commonly only address end of life considerations. This approach limits understanding of additional financial and legal concerns that may arise at any point in the future. APP therefore requires further investigation, as its broader legal scope takes into account an older person's plans for future financial decisions, personal matters, health management and distribution of property, in addition to wishes relating to end of life care.[30]

While research has sought to understand the knowledge, attitudes and experiences of patients and health professionals regarding Advance Care Planning,[31] the role and views of lawyers and

[29] Detering et al, 'The Impact of Advance Care Planning on End of Life Care' (n 1); Lum, Sudore and Bekelman (n 5); Sabatino (n 12); Scott et al (n 5); Russell (n 5); Brinkman-Stoppelenburg, Rietjens and van der Heide (n 5); Weathers et al (n 5); Horridge (n 14); Luckett et al (n 14); Sellars, Detering and Silvester (n 5); Musa et al (n 5); Lund, Richardson and May (n 2).
[30] Waller et al (n 1).
[31] Russell (n 5); Rhee, Zwar and Kemp (n 5); Robinson et al (n 5); Lum, Sudore and Bekelman (n 5); Horridge (n 14); Lund, Richardson and May (n 2); Merril A Pauls, Peter A Singer and Isser Dubinsky, 'Communicating

older adults with respect to the wider framework of APP have received less attention in the literature.[32] Furthermore, despite their vital role in assisting with the completion of APP instruments, there is currently a lack of empirical evidence available in Australia examining the processes through which lawyers assist older clients in this area. My focus on this area, combined with the incorporation of multiple stakeholder groups at different stages of the APP process, highlights the originality of my research. By expanding knowledge of current perspectives of, and experiences with, APP, I have been able to identify opportunities for improvement and offer recommendations. Drawing on the data gathered via an online survey with lawyers working in regional areas of NSW, and in-depth interviews with older adults living in rural and regional NSW and professional key informants, has allowed me to better understand how APP processes are operating at present, while comparing and contrasting their diverse and similar viewpoints.

My research draws upon themes identified in the existing literature regarding Advance Care Planning while collecting new data on APP processes and barriers. The involvement of older adults in regional areas of NSW is another point of significance, as populations in rural areas often raise additional research considerations,[33] are geographically isolated,[34] have less access to legal and health services,[35] and may experience poorer health[36] and social outcomes.[37] My research therefore expands current knowledge regarding APP and increases awareness of the greater level of legal planning that can be completed by older adults in regional areas to safeguard not only their future medical wishes, but their legal and financial concerns as well.

My research provides a unique contribution to understanding the manner in which APP processes are currently operating, and how they can be improved, for older adults and relevant legal and health professionals. The integration of Preventive Law and Therapeutic

Advance Directives from Long-Term Care Facilities to Emergency Departments' (2001) 21(1) *Journal of Emergency Medicine* 83; Sellars, Detering and Silvester (n 5); Scott et al (n 5).

[32] For studies in which these perspectives have been considered, see Plaisance et al (n 19); Ries et al (n 8).

[33] MR McGrail et al, 'The Planning of Rural Health Research: Rurality and Rural Population Issues' (2005) 5(4) *Rural and Remote Health* 426:1–8.

[34] Lisa Bourke et al, 'Understanding Rural and Remote Health: A Framework for Analysis in Australia' (2012) 18(3) *Health & Place* 496.

[35] Thomas A Arcury et al, 'The Effects of Geography and Spatial Behavior on Health Care Utilization among the Residents of a Rural Region' (2005) 40(1) *Health Services Research* 135.

[36] John Wakerman et al, 'Primary Health Care Delivery Models in Rural and Remote Australia – A Systematic Review' (2008) 8 *BMC Health Services Research* 276:1–10.

[37] Karly B Smith, John S Humphreys and Murray GA Wilson, 'Addressing the Health Disadvantage of Rural Populations: How Does Epidemiological Evidence Inform Rural Health Policies and Research?' (2008) 16(2) *Australian Journal of Rural Health* 56.

Jurisprudence, and application of these theoretical perspectives within the field of Elder Law, is another point of difference. This framework allows for the thematic analysis of results concerned with preventing conflicts, prioritising the wellbeing of individuals, and ultimately upholding an older adult's autonomy and empowerment, guarding against any vulnerability or periods of heightened dependency in the future. Further, it advocates for an ongoing, communicative and collaborative approach to APP, including relevant professionals, the older person and members of their support community, such as family, trusted friends and appointed decision-makers. Through my in-depth interviews with older adults and professional key informants, it has become clear that APP should form part of routine medical and legal practice, with the intention of planning for the rest of life, not the end of life. My recommendations can be used to guide the development and implementation of strategies to enhance professional practices, particularly in the expanding field of Elder Law.

1.6 Structure of the Thesis

Chapter 2 outlines the policy context and legal environment surrounding APP in NSW and includes a detailed examination of the relevant available legal APP instruments, including a Will, an Advance Care Directive, and the appointment of an Enduring Guardian or Enduring Power of Attorney. The significance of decision-making capacity from the perspective of lawyers, along with findings from case law and the legislative framework, are also discussed. This overview of the NSW approach is vital to understanding the environment in which my research took place, offering a clear scaffold for the development of study instruments and subsequent interpretation of results. Potential reforms offered from inquiries and scholarly commentators are also discussed, providing a foundation from which recommendations for improvement can be developed.

Chapter 3 provides a review of relevant literature and findings from existing research, including planning ahead for particular populations. Prevalence and predictive factors, along with the relevance of APP for older adults, are key areas of focus, and results that have informed my own research are outlined. Results from previous studies are considered while relevant gaps are highlighted, including the continued siloing of legal and health perspectives. Significantly, this chapter also identifies deficiencies within existing planning systems, allowing for the recognition of key barriers within current processes. This review provides a detailed

understanding of APP, while distinguishing how my research can fill gaps within the existing literature and offer new insights.

Chapter 4 explores the integration of the theoretical perspectives of Preventive Law and Therapeutic Jurisprudence, termed 'theralaw', and their unique application within the field of Elder Law. The preventive nature of APP, along with the need to prioritise the wellbeing of older adults during legal interactions, are key points of focus. Key concepts, including autonomy, vulnerability and empowerment, are articulated. The identification of an appropriate theoretical lens, and subsequent development of a conceptual framework, was an essential exercise that informed my research design, methodology and analysis of my results.

Chapter 5 details my research context, inquiry worldview and methodology. It makes connections between my research questions and the components of my research, including a survey of lawyers working in regional NSW, and semi-structured in-depth interviews with older adults and professional key informants. This chapter outlines recruitment, sampling techniques, study instruments, data collection and analysis of results for each component. Strengths and limitations of my research are also explored. Establishing a clear and consistent methodology to guide each component of my research was essential to ensuring my results are reliable and able to inform recommendations as a result of my findings.

Chapter 6 presents the findings of my research relating to general views regarding APP and barriers to engagement. Perspectives of older adults, lawyers and professional key informants are included, highlighting points of similarity and difference. Factors including prevalence, advantages and disadvantages of APP for older adults, motivations for planning ahead, and reluctance to engage are explored. Legal professional barriers are also discussed, including whether an older adult has the requisite legal decision-making capacity to engage with APP. The impact of COVID-19 on older people's engagement with APP is also acknowledged. This chapter demonstrates how my research has produced new data regarding attitudes to APP and barriers to engagement, utilising a unique combined cohort approach in the discussion of my findings.

Chapter 7 explores findings relating to factors affecting the quality of prepared APP instruments and challenges associated with their implementation in the future. The inclusion of older adults, lawyers and professional key informants has produced a holistic perspective that represents how these separate groups experience APP, from initial creation of documents

through to responsibility for interpreting completed instruments at a later point in time, and associated challenges. A discussion of high-quality APP is offered, along with examination of levels of confidence in the future use of completed documents. The potential for APP to legally guard against, or provide opportunities for, elder abuse, is considered. Professional strategies to improve the quality of APP are also explored. Building on the previous chapter, this section of my thesis presents new data relating to the final two stages of the APP process, including perceived barriers and professional responses.

Chapter 8 discusses how my findings align with, or diverge from, my chosen theoretical perspective, as well as how they fit within and add to the existing research landscape. The key terms within my conceptual framework, including autonomy, empowerment and vulnerability, are analysed in direct connection with my study findings, offering insights into how these terms are interpreted in the context of my results. The need for increased interprofessional collaboration, along with the benefits of reframing APP as planning for the rest of life, are also explored. This penultimate chapter provides space to fully consider the results of my study in connection with my earlier theoretical explorations, offering an opportunity to make explicit links between my findings and the conceptual framework.

Chapter 9 concludes my thesis by offering recommendations for improvement that are informed by the insights offered from older adults, lawyers and professional key informants in my research. Recommendations are formulated at three levels: micro level recommendations for individuals; meso level recommendations for professions; and macro level recommendations for structural changes. I also reflect on limitations and acknowledge areas for future research. Final conclusions are offered, highlighting my original contribution to the evidence base.

2 THE LEGISLATION AND POLICY CONTEXT OF ADVANCE PERSONAL PLANNING IN NEW SOUTH WALES

2.1 INTRODUCTION

This chapter outlines the legislation and policy surrounding Advance Personal Planning (APP) in New South Wales (NSW), and the context in which APP instruments operate. This background information is essential to understanding the environment in which this study took place, particularly the distinct APP instruments that are central to my research. Further, this understanding of the context and environment provides a scaffold for the arguments advanced in my thesis, such as understanding APP as a holistic, ongoing, communicative process designed to support future decision-making. The four main components of APP are discussed, along with the legislative framework in NSW governing their operation, distinguishing their purposes and scope. Examples from case law are also explored for illustrative purposes, providing insights into the operation of, and points of conflict within, APP processes. The legal concept of decision-making capacity is also addressed, along with the potential for elder abuse within the context of APP.

In Australia, adults can record their wishes concerning their future and legally appoint others to make decisions on their behalf during periods of incapacity with the expectation these instructions will be respected.[1] In NSW, instruments for this purpose include: an Advance Care

[1] Juliet Jacobsen, Rachelle Bernacki and Joanna Paladino, 'Shifting to Serious Illness Communication' (2022) 327(4) *JAMA* 321, 321; Grace W Orsatti, 'Attorneys as Healthcare Advocates: The Argument for Attorney-Prepared Advance Healthcare Directives' (2022) 50(1) *Journal of Law, Medicine & Ethics* 157, 158; Sonja McIlfatrick et al, '"It's Almost Superstition: If I Don't Think about It, It Won't Happen". Public Knowledge and

Directive to express values and instructions with respect to health care;[2] an Enduring Guardian to make health and personal decisions;[3] an Enduring Power of Attorney to make financial decisions;[4] and a Will to distribute assets and property following death.[5] The NSW Government encourages adults to consider using all of these instruments, recommending a holistic approach to APP.[6] These instruments have particular value for adults aged 65 years and older to safeguard their preferences, wishes and future security due to higher levels of chronic and life-limiting illnesses where periods of incapacity are foreseeable. Such factors are even more significant when considering the relevance of APP for older adults living in regional and rural areas. The Australian Institute of Health and Welfare (AIHW) has identified that life expectancy decreases when considering the geographical location where a person resides, with a difference of 12.7 years for males living in remote communities and 10.7 years for females living in remote communities when compared with those who reside in capital cities.[7] There is also a significant disparity in life expectancy between First Nations and non-Indigenous

Attitudes towards Advance Care Planning: A Sequential Mixed Methods Study' (2021) 35(7) *Palliative Medicine* 1356, 1356, 1360; Craig Sinclair et al, 'Association Between Region of Birth and Advance Care Planning Documentation Among Older Australian Migrant Communities: A Multicenter Audit Study' (2021) 76(1) *The Journals of Gerontology: Series B* 109, 117–118 ('Association Between Region of Birth and Advance Care Planning Documentation'); Frances Batchelor et al, 'Facilitators and Barriers to Advance Care Planning Implementation in Australian Aged Care Settings: A Systematic Review and Thematic Analysis' (2019) 38(3) *Australasian Journal on Ageing* 173, 176; Australian Law Reform Commission, *Elder Abuse - A National Legal Response* (ALRC Report No 131, June 2017) 292 <https://www.alrc.gov.au/publication/elder-abuse-a-national-legal-response-alrc-report-131/>; Kelly J Purser and Tuly Rosenfeld, 'Evaluation of Legal Capacity by Doctors and Lawyers: The Need for Collaborative Assessment' (2014) 201(8) *The Medical Journal of Australia* 483; Austin Health, *Respecting Patient Choices: Advance Care Planning with Aboriginals and Torres Strait Islanders* (Report, 2006) 1, 6 <https://www.acrrm.org.au/docs/default-source/all-files/aboriginal_torres_strait_islander_advance_care_planning.pdf?sfvrsn=7d61dcc5_2>; Cancer Council NSW, *Getting Your Affairs in Order: Information for People Affected by Cancer* (Legal and Financial Fact Sheet) 4 <www.cancercouncil.com.au/wp-content/uploads/2022/03/Getting-your-affairs-in-order-NSW.pdf>.

[2] Department of Health, *National Framework for Advance Care Planning Documents* (Report, May 2021) 7 <https://www.health.gov.au/resources/publications/national-framework-for-advance-care-planning-documents?language=en>; NSW Ministry of Health, *Making an Advance Care Directive* (Report, November 2023) <https://www.health.nsw.gov.au/patients/acp/Pages/acd-form-info-book.aspx>.

[3] *Guardianship Act 1987* (NSW);.

[4] *Powers of Attorney Act 2003* (NSW);.

[5] *Succession Act 2006* (NSW).

[6] 'Planning for End of Life', *NSW Government* (Web Page, 17 August 2022) <https://www.nsw.gov.au/family-and-relationships/planning-for-end-of-life>.

[7] Australian Bureau of Statistics, *Life Tables, 2018-2020* (Catalogue No 3302.0.55.001, 4 November 2021) <https://www.abs.gov.au/statistics/people/population/life-expectancy/2018-2020>. See also Australian Institute of Health and Welfare, 'Australian Burden of Disease Study 2022' (n 7) 10.

Australians, which is currently estimated to be 8.6 years lower for First Nations males and 7.8 years for First Nations females when compared with non-Indigenous Australians.[8]

2.2 ENDURING POWER OF ATTORNEY

2.2.1 What is an Enduring Power of Attorney?

An Enduring Power of Attorney has the authority to make decisions regarding financial and legal affairs and the management of property, including executing legal documents on a person's behalf if they are no longer able to make such decisions for themselves.[9] In contrast, a general Power of Attorney only functions while a person has capacity.[10] It is advisable to prepare an Enduring Power of Attorney when engaging in APP as it continues to have effect once capacity has diminished or been lost in relation to decisions affecting financial or legal matters.[11] The Commonwealth Attorney-General's Department recommends an appointed attorney be: willing to enact the other person's wishes, rather than their own; able to understand the role they are undertaking; able to devote sufficient time to the role; able to properly manage money and property; willing to speak up for the other person; and understanding of the other person's culture and community connections.[12]

[8] Australian Institute of Health and Welfare, *Deaths in Australia* (Catalogue No PHE 229, 11 July 2023) <https://www.aihw.gov.au/reports/life-expectancy-deaths/deaths-in-australia/contents/about>; 'Deaths in Australia, Life Expectancy', *Australian Institute of Health and Welfare* (Web Report, 9 June 2022) <https://www.aihw.gov.au/reports/life-expectancy-death/deaths-in-australia/contents/life-expectancy>; Australian Government, *Closing the Gap Report 2020* (Report, 2020) <https://ctgreport.niaa.gov.au/sites/default/files/pdf/closing-the-gap-report-2020.pdf>.

[9] 'Being an Attorney', *Compass: Guiding Action on Elder Abuse* (Web Page, 27 February 2024) <https://www.compass.info/featured-topics/powers-of-attorney/being-an-attorney#protection-against-misuse-of-power/>; Australian Guardianship and Administration Council, *You Decide Who Decides: Making an Enduring Power for Financial Decisions* (Report, Victorian Office of the Public Advocate, October 2019) 8 <https://www.agac.org.au/assets/documents/Other-Publications/You-Decide-Who-Decides.pdf>; NSW Trustee & Guardian, 'Have You Planned Ahead?' (n 5) 2–3; Natalia Wuth, 'Enduring Powers of Attorney: With Limited Remedies - It's Time to Face the Facts' (2013) 7 *Elder Law Review* 1, 5; Sarah Ellison et al, *The Legal Needs of Older People in NSW* (Report, Law and Justice Foundation of New South Wales, December 2004) 306–307 <https://lawfoundation.net.au/wp-content/uploads/2023/11/54PJR_The-legal-needs-of-older-people-in-NSW_2004.pdf>.

[10] Australian Law Reform Commission (n 1) 160–161; NSW Trustee & Guardian, *Plan Ahead for Your Future Legal, Health and Financial Decisions* (Information Brochure and Checklist, 2017) 3 <https://www.swslhd.health.nsw.gov.au/Carers/content/pdf/Planning_Ahead_brochure_.pdf> ('*Plan Ahead for Your Future Legal, Health and Financial Decisions*').

[11] NSW Trustee & Guardian, 'Plan Ahead for Your Future Legal, Health and Financial Decisions' (n 11) 3; Australian Guardianship and Administration Council (n 10) 8.

[12] Attorney-General's Department, *Achieving Greater Consistency in Laws for Financial Enduring Powers of Attorney* (Consultation Paper, September 2023) 19 <https://consultations.ag.gov.au/families-and-marriage/epoa/user_uploads/epoa-consultation-paper.pdf>.

2.2.2 What Legislation Governs the Appointment of an Enduring Power of Attorney?

In NSW, the *Powers of Attorney Act 2003* (NSW) relates to the formal appointment of both a Power of Attorney[13] and Enduring Power of Attorney.[14] The appointment of an Enduring Power of Attorney must be via a written document that has been witnessed[15] and the appointment must be accepted by the person, or persons, to be appointed as attorney.[16] The enduring appointment authorises the attorney to manage the legal and financial affairs of a person immediately or at some other point in time, such as on receipt of medical evidence of lack of capacity.[17] Limitations or conditions on the attorney's actions or power can be specified in the appointment,[18] as well as any benefits the attorney may be able to receive from the appointment.[19] An Enduring Power of Attorney made in others states and territories is recognised in NSW.[20] There is an option to formally register an Enduring Power of Attorney,[21] however, this is not mandatory unless the attorney engages in dealings with land.[22] Similarly, a revocation of an Enduring Power of Attorney may also be registered.[23] An appointment may be reviewed if an 'interested person'[24] makes a formal application to the NSW Civil and Administrative Tribunal or the Supreme Court.[25] If an attorney continues to act following the termination or suspension of their appointment, knowing that their appointment has been suspended or terminated, they may face a penalty of up to five years imprisonment.[26] The *Powers of Attorney Regulation 2016* (NSW) does not include any additional penalties, but Schedule 2 contains the prescribed form for appointments.[27]

[13] *Powers of Attorney Act 2003* (n 4) ss 8-13.
[14] Ibid ss 19-23.
[15] Ibid s 19.
[16] Ibid s 20(1).
[17] Ibid s 21.
[18] *Powers of Attorney Act 2003* (NSW) s 9(2).
[19] Ibid s 12(2).
[20] *Powers of Attorney Act 2003* (n 4) s 25.
[21] Ibid s 51(1).
[22] Ibid s 52.
[23] Ibid s 51(2).
[24] Ibid s 35.
[25] Ibid s 36.
[26] Ibid s 49.
[27] *Powers of Attorney Regulation 2016* (NSW) sch 2.

2.2.3 What Challenges Have Arisen in Case Law Relating to Enduring Power of Attorney Appointments?

The case of *Cohen v Cohen*[28] considered circumstances where a person appointed under an Enduring Power of Attorney had engaged in exploitative behaviour towards an older person. The plaintiff was 92 years old and lived in an aged care facility as a high care resident[29] as she was blind, lived with loss of hearing and was also experiencing mild dementia.[30] Following the death of her husband, the plaintiff appointed her son, the defendant, as her Enduring Power of Attorney under the *Powers of Attorney Act 2003* (NSW). Relying on this appointment, the defendant transferred the plaintiff's home to himself, for the price of $1. The transfer document was signed by the defendant as both transferor and transferee.[31] The NSW Supreme Court found not only did this transfer breach the fiduciary duty owed by the defendant to the plaintiff, it also fulfilled the criteria of an unconscionable dealing. The transfer was clearly not for the benefit of the plaintiff; it disadvantaged her significantly because any ownership of her home was taken from her.[32] Further, there was a relationship of special disadvantage between the parties owing to the plaintiff's age, current residence in an aged care facility and her declining health. The transaction was patently unfair and happened without the approval or knowledge of the plaintiff.[33] While this appointment had apparently been prepared by a solicitor, no limitations or conditions had been specified in the relevant form, despite medical evidence that the plaintiff was living with mild dementia and other life-limiting conditions that may have affected her decision-making capacity.[34] This disconnect between the preparation of the legal instrument, and the significant medical evidence relating to the plaintiff's health, highlights the risks of siloing health and legal professionals in APP processes.[35] For example, if the lawyer who prepared the appointment had sought a medical assessment of capacity, this could have led to the preparation of a stronger instrument that placed conditions on the actions of the attorney or ensured they could not receive a benefit from their role.

[28] *Cohen v Cohen* (n 3).
[29] Ibid [5] (Hallen J).
[30] Ibid [24] (Hallen J).
[31] Ibid [18] (Hallen J).
[32] Ibid [66]-[67] (Hallen J).
[33] Ibid [69] (Hallen J).
[34] Ibid [24]-[25].
[35] Ben P White, Lindy Willmott and Eliana Close, 'Better Regulation of End-Of-Life Care: A Call for A Holistic Approach' (2022) 19 *Journal of Bioethical Inquiry* 683, 687–688; Nola M Ries et al, 'Doctors, Lawyers and Advance Care Planning: Time for Innovation to Work Together to Meet Client Needs' (2016) 12(2) *Healthcare Policy* 12, 13.

The reasoning in Cohen was subsequently considered in *Re Tornya*.[36] with respect to a deceased estate and the actions of the appointed Enduring Power of Attorney. Prior to his death, Mr Tornya had been diagnosed with advanced frontotemporal dementia.[37] Around the time this diagnosis was confirmed, an Enduring Power of Attorney was registered, appointing the defendant, Mr Tornya's wife, in this role and therefore authorising her to deal with transactions involving land.[38] Significantly, the appointment contained a 'benefits clause', which allowed the defendant 'to use the power to confer a benefit on herself'.[39] Over a period of nine years, the defendant relied on her appointment to sell Mr Tornya's assets and engage in other financial transactions that benefited her.[40] Lindsay J, in considering an application for discovery of documents relating to these transactions initiated by Mr Tornya's son, offered the following observations regarding the duty of an appointed attorney:

> The nature and scope of an attorney's obligations, vis a vis the attorney's principal, depend on the arrangement between principal and attorney in the particular case. Prima facie, an attorney owes the obligations of a fiduciary to a principal and, as between principal and attorney, the primary object of a power of attorney is to enable the attorney to act in the management of the principal's affairs. … A power of attorney, with a benefits clause, is not, of itself, as between principal and attorney, a license for the attorney to act otherwise than in the interest of the principal without accountability.[41]

Consequently, Lindsay J concluded, regardless of the inclusion of a benefits clause, 'an enduring attorney who deals with the property of an incapacitated principal in total disregard of the interests of the principal commits a fraud on the power conferred upon him or her and is, accordingly, in breach of his or her fiduciary obligations to the principal'.[42]

[36] *Re Tornya* [2020] NSWSC 1230.
[37] Ibid [56] (Lindsay J).
[38] Ibid [55]-[57] (Lindsay J).
[39] Ibid [50].
[40] Ibid [70]-[73].
[41] Ibid [103] (Lindsay J).
[42] Ibid [161] (Lindsay J).

2.3 ENDURING GUARDIAN

2.3.1 What is an Enduring Guardian?

An Enduring Guardian is permitted to make choices regarding a person's lifestyle, health care and treatment.[43] An appointment of an Enduring Guardian made in another state or territory is recognised in NSW.[44] The NSW Trustee and Guardian[45] has prepared a checklist of considerations when appointing an Enduring Guardian, including that the nomination of the Enduring Guardian should be communicated to others, such as family members or close friends, so that everyone is aware of who holds the authority to make these decisions. Such communication would also help to ensure that the person trusts the person or people they have chosen to appoint, that they have considered the number of Enduring Guardians that should be appointed on their behalf, and that they understand the role and responsibilities they are giving to the appointed person.[46] The checklist also encourages people to seek legal and medical advice prior to finalising the appointment.[47]

An appointed Enduring Guardian or Enduring Power of Attorney should ideally know the person well and seek to advance their preferences and goals. This aims to ensure that the person's wishes are known, respected and communicated so that any treatment received is in accordance with the decision they would have made for themselves, had they been able to do so.

2.3.2 What Legislation Governs the Appointment of an Enduring Guardian?

Part 2 of the *Guardianship Act 1987* (NSW) governs the statutory appointment of Enduring Guardians. Appointments must be of a person aged 18 years or older[48] via a written document[49] that has been signed and witnessed.[50] The person appointed must not provide services in

[43] NSW Trustee & Guardian, *Enduring Guardianship: Planning for Your Future Health and Lifestyle Decisions* (Report, 2019) 2 <https://www.tag.nsw.gov.au/sites/default/files/2023-06/Enduring%20Guardianship%20January%202023_Online.pdf> ('*Enduring Guardianship*'); NSW Trustee & Guardian, 'Have You Planned Ahead?' (n 5) 3; Ellison et al (n 10) 319.
[44] NSW Trustee & Guardian, 'Enduring Guardianship' (n 44) 10; NSW Trustee & Guardian, 'Have You Planned Ahead?' (n 5) 3.
[45] NSW Trustee & Guardian, 'Enduring Guardianship' (n 44).
[46] Ibid 12.
[47] Ibid.
[48] *Guardianship Act 1987* (n 3) ss 6, 6B(1).
[49] Ibid s 6.
[50] Ibid s 6C(1).

exchange for payment or other reward.[51] The existing legislation attempts to uphold the person's autonomy through the statement of several general principles, including that 'the freedom of decision and freedom of action of such persons should be restricted as little as possible'.[52] More than one Enduring Guardian can be appointed,[53] with additional provision made for substitute Enduring Guardians.[54] Their responsibilities extend to a range of health and lifestyle decisions.[55] However, if the person who made the appointment subsequently marries, the Enduring Guardian appointment is automatically revoked.[56] While the Civil and Administrative Tribunal can review an Enduring Guardian appointment[57] and subsequently revoke it where there are concerns for the welfare of the appointor,[58] the Act does not otherwise account for consequences in the event the appointment is misused or the appointed decision-maker has failed to act in accordance with the appointment. Further, no offences are prescribed under the *Guardianship Regulation 2016* (NSW). Schedule 1 of the Regulation contains the prescribed form for appointments.[59]

2.3.3 What Challenges Have Arisen in Case Law Relating to Enduring Guardian Appointments?

In *R v Thompson*, the Supreme Court of NSW was required to consider instructions regarding the refusal of life-sustaining treatment.[60] Two men were facing criminal charges of manslaughter by criminal negligence following the death of their elderly mother.[61] Mrs Thompson was admitted to hospital and died from sepsis 10 days later as a result of infected bed sores.[62] In considering whether the men, who had been appointed by their mother as Enduring Guardians, had fulfilled their duty to provide reasonable care, Fagan J acknowledged Mrs Thompson 'was adamantly opposed to receiving nursing or medical attention, either in her own home or as an inpatient of a nursing home or hospital,' and 'only when she appeared to be seriously unwell and losing coherence did they call an ambulance'.[63] Due to the principles

[51] Ibid s 6B(2).
[52] Ibid s 4(b).
[53] Ibid s 6D.
[54] Ibid s 6DA.
[55] Ibid s 6E(1).
[56] Ibid s 6HA.
[57] Ibid s 6J.
[58] Ibid s 6K.
[59] *Guardianship Regulation 2016* (NSW) sch 1.
[60] *R v Thompson* [2019] NSWSC 1396 ('*R v Thompson*').
[61] Ibid [1] (Fagan J).
[62] Ibid [5] (Fagan J).
[63] Ibid [8] (Fagan J).

established in *Hunter and New England Area Health Service v A by his Tutor T*,[64] Fagan J concluded the case of manslaughter had not been made out against the two men as the precedent was 'relevant to the efficacy of an oral refusal of consent to medical intervention, conveyed by a conscious patient with full legal capacity'.[65] Further, he stated 'Mrs Thompson's refusal of medical intervention was not an ill-considered or momentary whim that a reasonable person in [the son's] position could have disregarded or persuaded his mother to abandon. It was an entrenched and determined set of mind'.[66] The principles of this case highlight the significance of Mrs Thompson's sons respecting and upholding her previously expressed wishes, only intervening when her health significantly declined. Despite the refusal of treatment resulting in her death, the series of events were consistent with Mrs Thompson's preference for no medical intervention, thus ensuring her decisions were autonomous and authentic to her wishes until her death.

The complex interaction between Enduring Guardian appointments, family disputes and visitation in aged care facilities combined in *EB v GB (No 2)*.[67] The plaintiff instigated proceedings in the Supreme Court after she was denied access to visit her father in an aged care facility. Her father, who was living with advanced Alzheimer's disease, appointed his wife, the plaintiff's mother, as his Enduring Guardian in 2016.[68] Significantly, the plaintiff and her brothers were listed as alternate Enduring Guardians in the event their mother died or was unable to act in this role.[69] As part of the Resident Agreement in the aged care facility where the father resided, visitors could be refused entry if they failed to comply with reasonable directions issued by the facility, or care facility rules, such as only visiting during 'reasonable hours'.[70] Matters were further complicated by a separate series of proceedings relating to shares in a family company, which culminated in the NSW Civil and Administrative Tribunal making a management order, at the request of the mother and brothers, that the plaintiff was incapable of managing her own affairs due to mental ill health.[71] The plaintiff alleged she had not seen her father since 2017, despite holding serious concerns regarding his deteriorating health.[72]

[64] *Hunter and New England Area Health Service v A by his Tutor T* (n 3).
[65] *R v Thompson* (n 61) [90] (Fagan J).
[66] Ibid [99] (Fagan J).
[67] *EB v GB (No 2)* [2022] NSWSC 1011.
[68] Ibid [9]-[10] (Robb J).
[69] Ibid [10].
[70] Ibid [16]-[21].
[71] Ibid [23]-[25].
[72] Ibid [36].

The mother, as respondent, alleged she had the power to decide who could visit the father in the aged care facility by virtue of her appointment as Enduring Guardian.[73] Robb J described this perceived 'unilateral and unfettered right to decide who has access to the father' as 'an unproven premise',[74] particularly given there was no evidence available indicating the father did not want to be contacted or visited by his daughter.[75] The judgment noted the following key principles:

> The authority to decide where a person lives does not naturally extend to who has access to that person at the place of residence, or does the right to decide what health care a person should receive extend to deciding when a particular person should be refused access to that person because of some concern that the person may be alarmed or discomfited.[76]

Ultimately, Robb J concluded the decision of whether the plaintiff should be permitted to visit her father was the responsibility of the aged care facility.[77] This case highlights the need to ensure appointed decision-makers are aware of the scope, and limits, of their authority. This knowledge is increasingly important when considering the needs of people as they age, especially if they need to spend time in a care facility. Further, this case draws attention to the importance of ongoing and transparent communication between residents, facility staff and family members. There is a vital need for collaboration between legal and healthcare practitioners to ensure a person's wishes are not only understood but realised in the event an appointed decision-maker is not acting in their best interests.

2.4 Advance Care Directives

2.4.1 What is an Advance Care Directive?

An Advance Care Directive aims to provide a way for appointed decision-makers, health professionals, family members, and friends to interpret and apply a person's wishes and goals

[73] Ibid [46].
[74] Ibid [80].
[75] Ibid [59].
[76] Ibid [102].
[77] Ibid [131].

within their current health context[78] and overcome uncertainty in medical situations.[79] They are intended as a means for people to have some say in their future health care, and represent an expression of a desire 'to live well and die with dignity in accordance with their personal values'.[80] Advance Care Directives carry other potential benefits, including enabling end of

[78] Sinclair (n 2); Helen Close et al, 'Qualitative Investigation of Patient and Carer Experiences of Everyday Legal Needs towards End of Life' (2021) 20 *BMC Palliative Care* 47:1–13, 8; McIlfatrick et al (n 1) 1360; Kimberly Buck et al, *Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services* (Report, Advance Care Planning Australia and Austin Health, October 2019) 14 <https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3668752> ('*Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services*'); Moore et al (n 2) 10; Advance Care Planning Australia, *Factsheet for Individuals: Advance Care Planning and the Law - New South Wales* (Factsheet, Austin Health, October 2018) 1 ('*Factsheet for Individuals: Advance Care Planning and the Law - New South Wales*'); Advance Care Planning Australia, *Factsheet for Healthcare Professionals: What Is Advance Care Planning?* (Factsheet, Austin Health, 2018) 1 ('*Factsheet for Healthcare Professionals: What Is Advance Care Planning?*'); Josie Dixon and Martin Knapp, 'Whose Job? The Staffing of Advance Care Planning Support in Twelve International Healthcare Organizations: A Qualitative Interview Study' (2018) 17(1) *BMC Palliative Care* 78:1–16, 2; NSW Ministry of Health (n 2) 2; Amy Waller et al, 'Increasing Advance Personal Planning: The Need for Action at the Community Level' (2018) 18(1) *BMC Public Health* 606:1–8, 1; Craig Sinclair et al, 'A Public Health Approach to Promoting Advance Care Planning to Aboriginal People in Regional Communities' (2014) 22(1) *Australian Journal of Rural Health* 23, 25 ('A Public Health Approach to Promoting Advance Care Planning to Aboriginal People'); Ellison et al (n 10) 153–154.

[79] Orsatti (n 1) 160; Sinclair (n 2); Department of Health (n 2) 1, 4; Karen M Detering et al, 'Organisational and Advance Care Planning Program Characteristics Associated with Advance Care Directive Completion: A Prospective Multicentre Cross-Sectional Audit among Health and Residential Aged Care Services Caring for Older Australians' (2021) 21 *BMC Health Services Research* 700:1–12, 2 ('Organisational and Advance Care Planning Program Characteristics'); Julien Tran et al, 'Systematic Review and Content Analysis of Australian Health Care Substitute Decision Making Online Resources' (2021) 45(3) *Australian Health Review* 317, 318; Buck et al, 'Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services' (n 79) 14; Ian J Hamilton, 'Advance Care Planning in General Practice: Promoting Patient Autonomy and Shared Decision Making' (2017) 67(656) *British Journal of General Practice* 104, 104; Susi Lund, Alison Richardson and Carl May, 'Barriers to Advance Care Planning at the End of Life: An Explanatory Systematic Review of Implementation Studies' (2015) 10(2) *PLOS ONE* e0116629:1-15, 2; Ben White et al, 'Prevalence and Predictors of Advance Directives in Australia' (2014) 44(10) *Internal Medicine Journal* 975, 975; Ellison et al (n 10) 153–154.

[80] Karen M Detering et al, 'Prevalence and Correlates of Advance Care Directives among Older Australians Accessing Health and Residential Aged Care Services: Multicentre Audit Study' (2019) 9(1) *BMJ Open* e025255:1-9, 2 ('Prevalence and Correlates of Advance Care Directives among Older Australians'). See also Orsatti (n 1) 158; Julie L Masters, Lindsey E Wylie and Sarah B Hubner, 'End-of-Life Planning: Normalizing the Process' (2022) 34(4) *Journal of Aging & Social Policy* 641, 1; Marcus Sellars et al, 'Public Knowledge, Preferences and Experiences about Medical Substitute Decision-Making: A National Cross-Sectional Survey' [2021] *BMJ Supportive & Palliative Care* (advance):1-21, 8; Emma Spencer and Eswaran Waran, 'Opening the Lines of Communication: Towards Shared Decision Making and Improved End-of-life Care in the Top End' (2020) 213(1) *The Medical Journal of Australia* 10, 10; Sarah Russell, 'Advance Care Planning: Whose Agenda is it Anyway?' (2014) 28(8) *Palliative Medicine* 997, 997; Australian Health Ministers' Advisory Council, *A National Framework for Advance Care Directives* (Report, September 2011) 1 <https://respectingchoices.org/wp-content/uploads/2017/07/a-national-framework-for-advance-care-directives_september-2011.pdf>.

life care that is aligned with the person's wishes,[81] reduced levels of anxiety and stress,[82] higher levels of satisfaction with care received,[83] less chance of receiving health care that is not wanted,[84] and the potential to avoid family conflict.[85] Such benefits therefore apply not only to the person, but also extend to those close to them, especially if they are tasked with making decisions on the person's behalf.[86]

[81] Buck et al, 'Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services' (n 79) 15; Gail Yapp et al, 'Planning for the Rest-of-Life, Not End-of-Life: Reframing Advance Care Planning for People with Dementia' in Gaynor Macdonald and Jane Mears (eds), *Dementia as Social Experience: Valuing Life and Care* (Routledge, 1st ed, 2018) 134, 136; Hamilton (n 80) 104; Nola M Ries, Briony Johnston and Shaun McCarthy, 'Legal Education and the Ageing Population: Building Student Knowledge and Skills through Experiential Learning in Collaboration with Community Organisations' (2016) 37 *Adelaide Law Review* 495, 50; Elizabeth Weathers et al, 'Advance Care Planning: A Systematic Review of Randomised Controlled Trials Conducted with Older Adults' (2016) 91 *Maturitas* 101, 102; Hillary D Lum, Rebecca L Sudore and David B Bekelman, 'Advance Care Planning in the Elderly' (2015) 99(2) *Medical Clinics of North America* 391, 393; Marcus Sellars, Karen M Detering and William Silvester, 'Current Advance Care Planning Practice in the Australian Community: An Online Survey of Home Care Package Case Managers and Service Managers' (2015) 14 *BMC Palliative Care* 15:1–7, 1–2; Royal Australian College of General Practitioners, *Position Statement: Advance Care Planning Should Be Incorporated into Routine General Practice* (Report, September 2012) 1 <https://www.racgp.org.au/FSDEDEV/media/documents/RACGP/Position%20statements/Advance-care-planning-should-be-incorporated-into-routine-general-practice.pdf>; Australian Health Ministers' Advisory Council (n 81) 4; Karen M Detering et al, 'The Impact of Advance Care Planning on End of Life Care in Elderly Patients: Randomised Controlled Trial' (2010) 340 *BMJ* c1345:1-9, 5; Craig Sinclair et al, 'Advance Care Planning in Australia during the COVID-19 Outbreak: Now More Important than Ever' (2020) 50(8) *Internal Medicine Journal* 918, 919 ('Advance Care Planning in Australia during the COVID-19 Outbreak').

[82] Jamie Bryant et al, 'Inadequate Completion of Advance Care Directives by Individuals with Dementia: National Audit of Health and Aged Care Facilities' (2022) 12 *BMJ Supportive & Palliative Care* e319, e319; Maria T Carney et al, 'Impact of a Community Health Conversation upon Advance Care Planning Attitudes and Preparation Intentions' (2021) 42(1) *Gerontology & Geriatrics Education* 82, 83; Batchelor et al (n 1) 173; Buck et al, 'Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services' (n 79) 15; Yapp et al (n 82) 136; Waller et al (n 79) 1; Ries, Johnston and McCarthy (n 82) 501; Lum, Sudore and Bekelman (n 82) 393; Sellars, Detering and Silvester (n 82) 1–2; Arianne Brinkman-Stoppelenburg, Judith AC Rietjens and Agnes van der Heide, 'The Effects of Advance Care Planning on End-of-Life Care: A Systematic Review' (2014) 28(8) *Palliative Medicine* 1000, 1001.

[83] Orsatti (n 1) 157; Batchelor et al (n 1) 173; Joshua A Rolnick et al, 'Patients' Perspectives on Approaches to Facilitate Completion of Advance Directives' (2019) 36(6) *American Journal of Hospice & Palliative Medicine* 526, 526; Advance Care Planning Australia, 'Factsheet for Healthcare Professionals: What Is Advance Care Planning?' (n 79) 1; Hamilton (n 80) 104; Lum, Sudore and Bekelman (n 82) 393; Sellars, Detering and Silvester (n 82) 1–2; Brinkman-Stoppelenburg, Rietjens and van der Heide (n 83) 1001; Royal Australian College of General Practitioners (n 82) 1.

[84] R Sean Morrison, 'Advance Directives/Care Planning: Clear, Simple, and Wrong' (2020) 23(7) *Journal of Palliative Medicine* 878, 878; Batchelor et al (n 1) 173; Buck et al, 'Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services' (n 79) 15; Moore et al (n 2) 9; Waller et al (n 79) 1; Lum, Sudore and Bekelman (n 82) 393; Australian Health Ministers' Advisory Council (n 81) 4.

[85] Orsatti (n 1) 160; Craig Sinclair et al, 'Professionals' Views and Experiences in Supporting Decision-Making Involvement for People Living with Dementia' (2021) 20(1) *Dementia* 84, 91; Tran et al (n 80) 318; Australian Guardianship and Administration Council (n 10) 8; Waller et al (n 79) 1; Yapp et al (n 82) 148; Hamilton (n 80) 104; Lum, Sudore and Bekelman (n 82) 393.

[86] Department of Health (n 2) 1, 4; Detering et al, 'Organisational and Advance Care Planning Program Characteristics' (n 80) 2; Sinclair et al, 'Advance Care Planning in Australia during the COVID-19 Outbreak' (n 82) 919; Buck et al, 'Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services' (n 79) 15; Moore et al (n 2) 1; Advance Care Planning Australia, *Factsheet for Individuals: What Is Advance Care Planning?* (Factsheet, Austin Health, 2018) 1 ('*Factsheet for Individuals: What Is Advance*

The NSW Ministry of Health has included an Advance Care Directive form in their guide *Making an Advance Care Directive*.[87] The form includes identifying details, both for the person and their Enduring Guardian or Person Responsible, an assessment of values in relation to dying, wishes with respect to specific medical treatments including resuscitation and life prolonging treatments, and any specific directions regarding organ, tissue or body donation.[88] A Person Responsible is defined in the *Guardianship Act 1987* (NSW)[89] according to a hierarchy of the following people: the person's guardian, if someone has been appointed in this role; the person's spouse, if their relationship is close and continuing and the spouse is not subject to a guardianship order themselves; a person 'who has care of the person', such as providing domestic services and support, or arranging support to be provided;[90] or a 'close friend or relative of the person', including someone who has a personal relationship and an interest in the person's welfare, but they must not have a financial interest in this connection.[91]

It is recommended that Advance Care Directives remain accessible and are kept in a safe place, with copies distributed to relevant people, including the Enduring Guardian or Person Responsible, family or friends, and health care professionals.[92] Advance Care Directives can be updated as needed to ensure they reflect the current wishes and values of the person.[93] If an

Care Planning?'); Yapp et al (n 82) 136; Rebecca L Sudore et al, 'Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel' (2017) 53(5) *Journal of Pain and Symptom Management* 821, 825; Ina Carola Otte et al, 'The Utility of Standardized Advance Directives: The General Practitioners' Perspective' (2016) 19(2) *Medicine, Health Care and Philosophy* 199, 199–200; Lum, Sudore and Bekelman (n 82) 393; Brinkman-Stoppelenburg, Rietjens and van der Heide (n 83) 1001; Australian Health Ministers' Advisory Council (n 81) 4; Heather Malcomson and Shannon Bisbee, 'Perspectives of Healthy Elders on Advance Care Planning' (2009) 21(1) *Journal of the American Academy of Nurse Practitioners* 18, 22.

[87] NSW Ministry of Health (n 2).

[88] Ibid 12–17.

[89] *Guardianship Act 1987* (n 3) s 33A(4).

[90] Ibid s 3D(1).

[91] Ibid s 3E(1).

[92] Royal Australian College of General Practitioners, *Advance Care Planning and My Health Record: Information for GPs* (Report, 2021) 2 <https://www.racgp.org.au/FSDEDEV/media/documents/Clinical%20Resources/My%20health%20record/ACP-MHR-Information-for-GPs.pdf>; Advance Care Planning Australia and Austin Health (n 2) 6; Bronwyn Hemsley et al, 'An Integrative Review of Stakeholder Views on Advance Care Directives (ACD): Barriers and Facilitators to Initiation, Documentation, Storage, and Implementation' (2019) 102(6) *Patient Education and Counseling* 1067; NSW Trustee & Guardian, 'Enduring Guardianship' (n 44) 10; NSW Ministry of Health (n 2) 5; COTA New South Wales, *Advance Care Planning Fact Sheet* (Factsheet, May 2017) 1; Cancer Council NSW (n 1) 4.

[93] Advance Care Planning Australia and Austin Health (n 2) 6; Advance Care Planning Australia, 'Factsheet for Individuals: Advance Care Planning and the Law - New South Wales' (n 79) 2; Otte et al (n 87) 203; NSW Government, *Making Your Wishes Known* (Information Sheet, 11 March 2019) 2 <https://www.health.nsw.gov.au/patients/acp/Pages/acp-info-sheet.aspx>.

Advance Care Directive is changed or revoked, all copies will need to be replaced with the current version.[94]

2.4.2 Are Advance Care Directives Governed by Legislation?

Advance Care Directives are recognised under common law in NSW, while they are enshrined as statutory instruments in some other states.[95] An Advance Care Directive must be made at a time when the person has decision-making capacity, and must have relevant specificity that can be applied to the present medical situation in order to be valid.[96] In these circumstances, the Advance Care Directive must be followed, even if the stated wishes will result in the person's death.[97]

Advance Care Planning Australia recommends an Advance Care Directive be in writing and signed by the person and a treating health professional to avoid any concerns regarding capacity and to confirm the person understood the nature and effect of the document at the time it was signed.[98] In NSW, an Advance Care Directive does not need to be formally recorded and can be spoken or written,[99] which can help alleviate barriers presented by culture or literacy

[94] Advance Care Planning Australia and Austin Health (n 2) 6; Advance Care Planning Australia, 'Factsheet for Individuals: What Is Advance Care Planning?' (n 87) 2; NSW Government (n 94) 2.

[95] Buck et al, 'Advance Care Directive Prevalence among Older Australians' (n 2) 1323; Department of Health (n 2) 1, 13; Karen M Detering et al, 'Prevalence of Advance Care Planning Documentation and Self-Reported Uptake in Older Australians with a Cancer Diagnosis' (2021) 12(2) *Journal of Geriatric Oncology* 274, 276; Spencer and Waran (n 81); Yapp et al (n 82) 135; Advance Care Planning Australia, *Factsheet for Health Professionals: Advance Care Planning and the Law – New South Wales* (Factsheet, Austin Health, December 2017) 1 ('*Factsheet for Health Professionals: Advance Care Planning and the Law – New South Wales*').

[96] NSW Ministry of Health (n 2) 2; Australian Health Ministers' Advisory Council (n 81) 38; Ellison et al (n 10) 154; Cancer Council NSW (n 1) 4.

[97] NSW Ministry of Health (n 2) 2; NSW Trustee & Guardian, 'Have You Planned Ahead?' (n 5) 4; Advance Care Planning Australia, 'Factsheet for Health Professionals: Advance Care Planning and the Law – New South Wales' (n 96) 1; Australian Health Ministers' Advisory Council (n 81) 38; Cancer Council NSW (n 1) 4; NSW Government (n 94) 2; *Re JS* [2014] NSWSC 302; *Hunter and New England Area Health Service v A by His Tutor T* (n 3).

[98] Advance Care Planning Australia, 'Factsheet for Health Professionals: Advance Care Planning and the Law – New South Wales' (n 96) 1.

[99] Hui Yun Chan, 'Video Advance Directives: A Turning Point for Advance Decision-Making? A Consideration of Their Roles and Implications for Law and Practice' (2020) 41 *Liverpool Law Review* 1, 3, 8; New South Wales Law Reform Commission, *Review of the Guardianship Act 1987* (Report No 145, May 2018) 159 <https://lawreform.nsw.gov.au/completed-projects/recent/guardianship/report-145.html>; Royal Australian College of General Practitioners (n 82) 1; Ellison et al (n 10) 153.

difficulties.[100] An Advance Care Directive made in a different Australian state or territory is also valid in NSW.[101]

2.4.3 What Challenges Have Arisen in Case Law Relating to Advance Care Directives?

Despite the key requirements for validity being relatively straightforward, legal disputes have arisen in NSW where a person's wishes, as expressed in their Advance Care Directive, may result in their death. A seminal case with respect to the recognition of valid Advance Care Directives is *Hunter and New England Area Health Service v A by his Tutor T*.[102] Mr A had prepared an Advance Care Directive that included the refusal of life-sustaining treatment. The Hunter New England Area Health Service sought declarations that they were lawfully able to comply with Mr A's instructions under the Advance Care Directive.[103] McDougall J found that Mr A had made a voluntary decision and was therefore capable of refusing the life-sustaining dialysis. The declarations sought by the Hunter and New England Area Health Service were granted.

This judgment provided very clear parameters that the case should not confuse the ability of a capable adult to refuse certain treatment, as was the case for Mr A, with slippery slope arguments in favour of a right to die or voluntary assisted dying, even where death is the resulting outcome of the refusal of medical treatment.[104] Importantly, the NSW Supreme Court in that case recognised a person's autonomy and the significant opportunity that Advance Care Planning presents, as 'whenever there is a conflict between a capable adult's exercise of the right of self-determination and the State's interest in preserving life, the right of the individual

[100] Sinclair et al, 'Association Between Region of Birth and Advance Care Planning Documentation' (n 1) 116; Laura Panozzo et al, 'Communication of Advance Care Planning Decisions: A Retrospective Cohort Study of Documents in General Practice' (2020) 19 *BMC Palliative Care* 108:1–7, 5; Australian Healthcare Associates, *Exploratory Analysis of Barriers to Palliative Care* (Issues Report on Aboriginal and Torres Strait Islander Peoples, Department of Health, September 2019) 1 <https://www.health.gov.au/resources/publications/exploratory-analysis-of-barriers-to-palliative-care-issues-report-on-aboriginal-and-torres-strait-islander-peoples?language=en>; Laura Vearrier, 'Failure of the Current Advance Care Planning Paradigm: Advocating for a Communications-Based Approach' (2016) 28(4) *HEC Forum* 339, 348–349.

[101] Kimberly Buck et al, 'Concordance Between Self-Reported Completion of Advance Care Planning Documentation and Availability of Documentation in Australian Health and Residential Aged Care Services' (2019) 58(2) *Journal of Pain and Symptom Management* 264, 270; NSW Ministry of Health (n 2) 6; NSW Government (n 94) 2.

[102] *Hunter and New England Area Health Service v A by His Tutor T* (n 3).

[103] Ibid [1]-[2] (McDougall J).

[104] Ibid [4]-[5] (McDougall J).

must prevail'.[105] This case also provides insight regarding appreciation of capacity, which should be viewed on a continuum, 'running from capacity at one end through reduced capacity to lack of capacity at the other. … The capacity required to make a contract to buy a cup of coffee may be present where the capacity to decide to give away one's fortune is not'.[106] As such, the person making an Advance Care Directive must be mindful of the nature of the decision, whether they are able to comprehend and assess information regarding it, and must also communicate their choice to fulfil the definition of decision-making capacity.[107] If an Advance Care Directive has been created at a time when the person had capacity, and it is clear and applies to the current medical circumstances, their wishes must be followed.[108] These principles clearly support the creation of an Advance Care Directive, within the broader context of APP, as a person-centred undertaking.

A similar consideration arose in *Re JS*.[109] The defendant lived with quadriplegia from the age of seven and, as he approached his 28th birthday, he instructed his healthcare providers that he wanted to cease the ventilation that had kept him alive since childhood.[110] He had experienced a serious, progressive decline in his medical situation and prepared a signed document requesting to end treatment.[111] The John Hunter Hospital, which is operated by the Hunter New England Local Health District, sought declarations from the NSW Supreme Court that they were permitted to cease all life sustaining treatment and medical support for the patient, in accordance with the patient's written wishes.[112] The Court held that JS had capacity to make these instructions regarding the cessation of life-sustaining treatment, had received adequate information regarding the treatment and the consequences of its withdrawal, had taken almost 12 months to arrive at his decision, and there was no evidence his request was made as a result of any form of undue influence.[113] As such, the hospital was required to comply with his instructions, and would not face legal repercussions.[114] While no third party decision maker was appointed in this case, it again illustrates the significance of how prepared legal

[105] Ibid [17] (McDougall J).
[106] Ibid [24] (McDougall J).
[107] Ibid [40] (McDougall J).
[108] Ibid.
[109] *Re JS* (n 98).
[110] Ibid [1]-[3], [19]-[20] (Darke J).
[111] Ibid [1]-[3] (Darke J).
[112] Ibid [4] (Darke J).
[113] Ibid [29]-[31] (Darke J).
[114] Ibid [33] (Darke J).

documentation can be relied upon, guiding healthcare professionals to make decisions in accordance with the patient's wishes.

Once again, a person-centred directive was able to be enforced by healthcare practitioners, who were authorised to legally carry out the recorded wishes, including during a future period where JS would lose capacity, without the risk of legal liability. This decision highlighted the significance of involving qualified professionals, such as healthcare practitioners, in advance planning generally and especially in circumstances where it is necessary to provide information regarding a specific treatment option or withdrawal. While a declaration by a court was required in this case to establish the validity of the defendant's wishes, JS had been speaking openly with his family and medical staff regarding his desire to cease treatment for a significant period of time.[115] As a result, the evidence of this ongoing communication between the parties underpinned JS's request to end treatment, ultimately supporting Darke J's decision to provide the declaration.

2.5 WILL

2.5.1 What is a Will?

The creation of a Will can allow for a greater level of autonomy and expression of individual wishes in comparison to other APP instruments.[116] It records explicit directions for the distribution of property and assets following a person's death.[117] A valid Will also avoids the pitfalls of intestacy[118] and may reduce the potential for conflict if the deceased's legacy is left to be distributed according to a statutory hierarchy of spouse, children, parents, siblings and other family members.[119] Documenting these wishes is even more important for First Nations

[115] Ibid [19].

[116] Close et al (n 79) 2; Masters, Wylie and Hubner (n 81) 1–2; Marcus Sellars et al, 'Perspectives of People with Dementia and Carers on Advance Care Planning and End-of-Life Care: A Systematic Review and Thematic Synthesis of Qualitative Studies' (2019) 33(3) *Palliative Medicine* 274, 276; Vines, 'Aboriginal Wills Handbook' (n 5) 3–4; 'Ethics in Advance Care Planning' (n 2); Cancer Council NSW (n 1) 1.

[117] NSW Trustee & Guardian, 'Have You Planned Ahead?' (n 5) 4; Ellison et al (n 10) 335.

[118] Pascoe Pleasence, Nigel J Balmer and Catrina Denvir, 'Why Do I Need a Will Anyway? Assessing the Impact of a Public Legal Education Intervention Embedded in a Longitudinal Survey' (2019) 18(2) *Social Policy and Society* 187; Cheryl Tilse et al, 'Making and Changing Wills: Prevalence, Predictors, and Triggers' (2016) 6(1) *SAGE Open* 1 ('Making and Changing Wills'); Cheryl Tilse et al, *Having the Last Word? Will Making and Contestation in Australia* (ARC Linkage Project Key Findings, The University of Queensland; Victoria University; Australian Centre for Health Law Research, March 2015) <https://eprints.qut.edu.au/215396/> ('*Having the Last Word?*'); Ben White et al, 'Estate Contestation in Australia: An Empirical Study of a Year of Case Law' (2015) 38(3) *UNSW Law Journal* 880; *Succession Act 2006* (n 5) ch 4.

[119] *Succession Act 2006* (NSW) ch 4; Pleasence, Balmer and Denvir (n 119) 188; Tilse et al, 'Having the Last Word?' (n 119); White et al (n 119).

Peoples due to cultural considerations regarding kinship, burial and broader conceptions of 'family' that go beyond traditional legislative understandings.[120] For this reason, the *Succession Act 2006* (NSW) provides for different arrangements if an Indigenous person has died intestate.[121] While the creation of a Will may not completely overcome the difficulties of a person dying intestate, as there is still a possibility the person's Will can be challenged, it is far simpler for the person's wishes to have been recorded ahead of time to ensure it is their voice and their wishes that are preserved. A lack of or minimal property should not be seen as a reason for not preparing a Will.[122] While Wills are included here as an important component of APP, this research is focused on instruments that come into effect while a person is still alive but may be experiencing a period of incapacity. The familiarity people have with the concept of a Will encouraged me to direct further attention to instruments that are less well known, including appointed decision-makers and Advance Care Directives. In turn, this allowed for greater examination of the barriers that arise for older adults when engaging with these particular elements of APP, as well as factors that may affect their quality or prevent their successful implementation in the future.

2.5.2 What Legislation Governs the Operation of a Will?

The *Succession Act 2006* (NSW) governs the creation and execution of Wills. A Will is valid if it is made by an adult testator, in writing, and signed by at least two witnesses[123] who are not beneficiaries under the document.[124] Like the appointment of an Enduring Guardian, a Will is revoked if the testator subsequently marries.[125] In the event a Will is contested, a family provision order may be sought by an 'eligible person'.[126] This definition includes both current

[120] Spencer and Waran (n 81) 10–11; Australian Healthcare Associates (n 101) 18; Sandra Thompson et al, 'Passing on Wisdom: Exploring the End-of-Life Wishes of Aboriginal People from the Midwest of Western Australia' (2019) 19(4) *Rural and Remote Health* 5444:1–9; Eswaran Waran, Sharon Wallace and Jonathan Dodson-Jauncey, 'Failing to Plan Is Planning to Fail: Advance Care Directives and the Aboriginal People of the Top End' (2017) 206(9) *The Medical Journal of Australia* 377; NSW Trustee & Guardian, *Taking Care of Business: Planning Ahead for Aboriginal People in New South Wales* (Information Booklet, 2015) 12–13 <https://www.tag.nsw.gov.au/sites/default/files/2020-10/Taking_Care_of_Business.pdf>; Vines, 'Aboriginal Wills Handbook' (n 5) 9–10; Sinclair et al, 'A Public Health Approach to Promoting Advance Care Planning to Aboriginal People' (n 79) 23–26; Austin Health (n 1) 6–7; 'Discussing Choices – Indigenous Advance Care Plans', *Palliative Care Australia* (Web Page, 2024) <https://palliativecare.org.au/resource/discussing-choices-indigenous-advance-care-planning/>.

[121] *Succession Act 2006* (n 5) ch 4 pt 4.4.

[122] NSW Trustee & Guardian, 'Have You Planned Ahead?' (n 5) 3–4; Vines, 'Aboriginal Wills Handbook' (n 5) 25.

[123] *Succession Act 2006* (n 5) s 6(1).

[124] Ibid s 10.

[125] Ibid s 12.

[126] Ibid s 57.

and former spouses, a de facto partner, children or other dependent persons. However, given the size of estates can be modest, and fees incurred from pursuing such a claim can be significant, the issue of proportionality of legal costs is a key concern. The *Civil Procedure Act 2005* (NSW) and Supreme Court of NSW Equity Practice Notes[127] provide guidance, stating that the 'cost to the parties is proportionate to the importance and complexity of the subject-matter in dispute'.[128] Further, they authorise the capping of costs, especially in cases where the value of the estate does not exceed $500,000.[129] Mandatory mediation was introduced, in part, to reduce costs incurred by parties and provide an alternate path of dispute resolution where litigation could be avoided, particularly in the event of a family dispute regarding the testator's wishes.[130] Despite mediation being prescribed under the legislation, it was only recorded in 30.9% of the files examined by Vines in a detailed examination of family provision claims in NSW in 2011.[131]

2.5.3 What Challenges Have Arisen in Case Law Relating to Wills?

Creating a Will is a complex process and may be open to challenge following a person's death.[132] In a 2015 study, Tilse et al found 86% of 139 contestations in Australia were commenced by members of the testator's immediate family.[133] The highest rate of family provision claims was found in NSW, representing 60% of all cases within Australia.[134] People most likely to challenge a Will were biological children, followed by a spouse or partner, representing 44.3% and 35.6% of cases in NSW respectively.[135] When examining the statistics from a national perspective, 63% of claims were initiated by children of the testator, while 23% were brought by a current or former partner.[136] Family provision claims can be complex[137] and

[127] *Practice Note No. SC EQ 7* 2023.
[128] *Civil Procedure Act 2005* (NSW) s 60.
[129] *Practice Note No. SC EQ 7* (n 128) s 37.
[130] *Succession Act 2006* (n 5) s 98; *Practice Note No. SC EQ 7* (n 128) ss 28-34.
[131] Prue Vines, *Bleak House Revisited? Disproportionality in Family Provision Estate Litigation in New South Wales and Victoria* (Australasian Institute of Judicial Administration, 2011) 23 <https://www.researchgate.net/publication/271769870_Bleak_House_Revisited_Disproportionality_in_Family_Provision_Estate_Litigation_in_New_South_Wales_and_Victoria> ('*Bleak House Revisited?*').
[132] Tilse et al, 'Having the Last Word?' (n 119) 16–18. See also Tilse et al, 'Making and Changing Wills' (n 119); White et al (n 119).
[133] Tilse et al, 'Having the Last Word?' (n 119) 16.
[134] Ibid 18. See also White et al (n 119) 893.
[135] Vines, 'Bleak House Revisited?' (n 132) 25.
[136] Tilse et al, 'Having the Last Word?' (n 119) 16; White et al (n 119) 896.
[137] Tilse et al, 'Having the Last Word?' (n 119).

costly,[138] but have a high rate of success.[139] Legal fees exceeded a quarter of the total estate in 49.7% of cases heard in NSW.[140] These claims also highlight the competing tensions between, on the one hand, upholding testamentary freedom of a person to dispose of their property according to their own beliefs and values, and on the other, courts imposing alternate judgments to ensure any dependents are adequately provided for following the death of the testator.[141]

For example, in *Beech v Squire*,[142] a challenge to a Will made by two adult children under the *Succession Act 2006* (NSW) was dismissed as the NSW Supreme Court was satisfied adequate provision had been made in the distribution of property.[143] Indeed, the court will often privilege the wishes of the testator, as a capable testator is in a far better position to appreciate what is a proper or adequate provision for their beneficiaries in light of their circumstances and the underlying relationship between the parties.[144] A family provision claim by the deceased's son failed in *Larkin v Leech-Larkin*,[145] as the NSW Supreme Court was 'not well-placed to determine the rights and wrongs of the breakdown in the relationship' between the deceased and the plaintiff.[146] As the deceased was closer to her other son, and he had contributed financially to the development of the property, there was a clear reason why he was awarded the whole of the property under the deceased's Will.[147] In the circumstances, Parker J was not satisfied that the deceased had failed to make proper provision for the plaintiff's maintenance, education or advancement as:

> … the law imposes no obligation on parents, during their lifetimes, to provide advancement for their children or to safeguard assets so that such advancement can be provided by will. Nor can the power to make a family provision order under the *Succession Act* be exercised for the purpose of salving wounded feelings or indignation produced by the deceased's behaviour during his or her lifetime.[148]

[138] Vines, 'Bleak House Revisited?' (n 132).
[139] Tilse et al, 'Having the Last Word?' (n 119) 16–18; White et al (n 119) 899.
[140] Vines, 'Bleak House Revisited?' (n 132) 23.
[141] Tilse et al, 'Having the Last Word?' (n 119) 22; White et al (n 119) 906; Vines, 'Bleak House Revisited?' (n 132) 3.
[142] *Beech v Squire* (n 5).
[143] Ibid [6] (Kunc J).
[144] Ibid [96] (Kunc J).
[145] *Larkin v Leech-Larkin* (n 5).
[146] Ibid [80] (Parker J).
[147] Ibid [91] (Parker J).
[148] Ibid [95] (Parker J).

An application for a family provision order was also rejected in *Maynard v Maynard*.[149] Due to the modest size of the deceased's estate, the daughter's claim failed. While the deceased 'recognised that he had testamentary obligations to his wife and daughters … the size of the deceased's estate is plainly insufficient to enable adequate provision to be made in favour of the three claimants, if adequate is given its usual meaning'.[150]

The desire to challenge a Will may increase where there is evidence that the testator created multiple Wills within a short period of time, or where there are concerns regarding their testamentary capacity. This arose in *Drivas v Jakopovic*,[151] where the testator had created three distinct Wills between May and September 2007. The final Will made provision for the testator's son's children in the event he pre-deceased the testator, but did not do the same for her daughter's children, despite this provision appearing in previous versions of the Will.[152] The granddaughter challenged the final Will, claiming the testator lacked testamentary capacity at the time it was made.[153] Despite these concerns, the NSW Supreme Court concluded that the testator met the criteria set out in *Banks v Goodfellow*,[154] as the court was satisfied she was aware that she was making a Will and understood the consequences of her instructions, especially the exclusion of her daughter's children.[155] Ultimately, the Court concluded there was insufficient evidence that the exclusion of the granddaughter was caused by a lack of capacity. There was no unreasonable treatment in this case, despite the unfavourable outcome.[156] A final consideration was offered regarding testamentary capacity:

> The result in the case exposes what might be thought to be a gap in the law. A will is not invalidated even if the testamentary decision was based on a misunderstanding or mistake which the Court is satisfied was clearly wrong. It is only invalidated if the testator's mental state was such that the mistake or misunderstanding could not have been corrected by rational argument. Many mistakes and misunderstandings which arise in family life are ones which could be corrected, but there may never be an opportunity to correct them while the testator is alive and has testamentary capacity.[157]

[149] *Maynard v Maynard* (n 5).
[150] Ibid [178] (Robb J).
[151] *Drivas v Jakopovic* (n 3).
[152] Ibid [1]-[6] (Parker J).
[153] Ibid [9] (Parker J).
[154] *Banks v Goodfellow* (1870) LR 5 QB 549.
[155] *Drivas v Jakopovic* (n 3) [187]-[188] (Parker J).
[156] Ibid [205] (Parker J).
[157] Ibid [206] (Parker J); see also *Hobhouse v Macarthur-Onslow* (n 5).

In contrast, a family provision claim was successful in *Katramados v Hasapis*.[158] This case also involved multiple Wills, some of which were made during the testator's time living in Greece where he owned property. One Will had the effect of revoking a previous Will and leaving the deceased to die intestate.[159] The NSW Supreme Court was satisfied inadequate provision had been made for two of the deceased's children for their proper maintenance, education or advancement,[160] especially as the deceased had told the applicants several times that they would each receive the respective properties in which they lived upon his death.[161]

2.6 RELEVANCE OF CAPACITY

Capacity is an essential concept in the APP process, as the ability to create valid documents and appointments is reliant upon it.[162] Generally, decision-making capacity is concerned with a person's ability to understand the decision they are making, comprehend its significance and consequences, and ultimately communicate this decision to others.[163] With respect to having capacity to appoint decision-makers, or decide on future wishes regarding personal or health care, the NSW Ministry of Health provides the following guidance:

> Generally, when a person has capacity to make a particular decision they can do all of the following: understand and believe the facts involved in making the decision; understand the

[158] *Katramados v Hasapis* (n 5).
[159] Ibid [13] (Robb J).
[160] Ibid [291] (Robb J).
[161] Ibid [304] (Robb J).
[162] Orsatti (n 1) 160; Sinclair (n 2); Department of Health (n 2) 6; Tran et al (n 80) 318; The Law Society of New South Wales, *Elder Abuse of Clients – What Supports can Solicitors Offer?* (Guidelines, September 2020) 2 <https://www.lawsociety.com.au/sites/default/files/2020-09/Guidance%20paper%20-%20Elder%20abuse%20of%20clients%20-%20what%20support%20can%20solicitors%20offer.pdf>; Meredith Blake, Olivia Nicole Doray and Craig Sinclair, 'Advance Care Planning for People with Dementia in Western Australia: An Examination of the Fit Between the Law and Practice' (2018) 25(2) *Psychiatry, Psychology and Law* 197, 211; NSW Trustee & Guardian, 'Have You Planned Ahead?' (n 5) 2; Colleen Cartwright et al, 'Medical Practitioners' Knowledge and Self-Reported Practices of Substitute Decision Making and Implementation of Advance Care Plans' (2014) 44(3) *Internal Medicine Journal* 234, 234; Ellison et al (n 10) 326.
[163] Department of Health (n 2) 4; Australian Guardianship and Administration Council (n 10) 4; Hui Yun Chan, 'Refusing Treatment Prior to Becoming Incapacitated: Supported Decision-Making as an Approach in Advance Directives' (2018) 25(1) *European Journal of Health Law* 24, 14–15; Rodney Lewis, 'Addressing Elder Abuse in Australia: The Case for an Elder Justice Law' (2018) 148 *Precedent* 41, 42; NSW Trustee & Guardian, 'Have You Planned Ahead?' (n 5) 2; Jeffrey P Spike, 'Informed Consent Is the Essence of Capacity Assessment' (2017) 45(1) *The Journal of Law, Medicine & Ethics* 95, 100; NSW Trustee & Guardian, 'Taking Care of Business: Planning Ahead for Aboriginal People in New South Wales' (n 121) 8.

> main choices; weigh up the consequences of the choices; understand how the consequences affect them; make their decision freely and voluntarily; [and] communicate their decision.[164]

While it is presumed that all adults are capable of making their own decisions, capacity is not static.[165] It is fluid and should be considered in light of the particular decision that is being made.[166] It is vital to note that an Advance Care Directive, or decisions by an Enduring Guardian or an Enduring Power of Attorney, are only effective once a person has lost capacity or is experiencing a period of incapacity, and not while they are still able to communicate their own wishes.[167] The only exception is if the Enduring Power of Attorney instrument specifies the attorney can begin to act immediately following their appointment. Even in the event a person's capacity may be declining, their views and values should still be taken into consideration, and they should be supported to make their own decisions for as long as possible.[168]

As people age, their decision-making ability may be affected by declining health.[169] However, a decline in or loss of capacity is not synonymous with ageing.[170] Concerns regarding capacity may arise at any point in a person's life as a result of disability, sickness or injury.[171] However,

[164] NSW Ministry of Health (n 2) 7. See also Australian Health Ministers' Advisory Council (n 81) 13; Cancer Council NSW (n 1) 3; NSW Government (n 94) 1.
[165] Australian Guardianship and Administration Council (n 10) 4; Hamilton (n 80) 104; Royal Australian College of General Practitioners (n 82) 1; LA Frolik, 'Later Life Legal Planning' in Israel Doron (ed), *Theories on Law and Ageing: The Jurisprudence of Elder Law* (Springer, 2009) 11.
[166] Australian Guardianship and Administration Council (n 10) 4; Lise Barry, '"He Was Wearing Street Clothes, Not Pyjamas": Common Mistakes in Lawyers' Assessment of Legal Capacity for Vulnerable Older Clients' (2018) 21(1) *Legal Ethics* 3, 10 ('He Was Wearing Street Clothes, Not Pyjamas'); Waller et al (n 79) 2; Hamilton (n 80) 104; The Law Society of New South Wales, *When a Client's Mental Capacity Is in Doubt: A Practical Guide for Solicitors* (Guidelines, 2016) 5–6 <https://www.lawsociety.com.au/sites/default/files/2018-03/Clients%20mental%20capacity.pdf>; Purser and Rosenfeld (n 1) 484; Australian Health Ministers' Advisory Council (n 81) 13; Laura L Sessums, Hanna Zembrzuska and Jeffrey L Jackson, 'Does This Patient Have Medical Decision-Making Capacity?' (2011) 306(4) *JAMA* 420, 424–425; Ellison et al (n 10) 327–328.
[167] 'Being an Attorney' (n 10); Orsatti (n 1) 160; Tran et al (n 80) 317–318; Advance Care Planning Australia, 'Factsheet for Health Professionals: Advance Care Planning and the Law – New South Wales' (n 96) 1; Australian Law Reform Commission (n 1) 161; Ellison et al (n 10) 326; NSW Government (n 94) 2; *Guardianship Act 1987* (n 3) s 6A.
[168] Attorney-General's Department (n 13) 26; 'Being an Attorney' (n 10); Department of Health (n 2) 13; Tran et al (n 80) 318; NSW Trustee & Guardian, 'Enduring Guardianship' (n 44) 7.
[169] Karen Sullivan and Kelly Purser, 'Developing and Piloting the Consumer Experience of Capacity Assessment Tool (CECAT)' (2022) 29(5) *Psychiatry, Psychology and Law* 752, 752.
[170] Barry, 'He Was Wearing Street Clothes, Not Pyjamas' (n 167) 6–7.
[171] Department of Health (n 2) 6; Masters, Wylie and Hubner (n 81) 642; NSW Trustee & Guardian, 'Enduring Guardianship' (n 44) 2; NSW Trustee & Guardian, 'Taking Care of Business: Planning Ahead for Aboriginal People in New South Wales' (n 121) 8.

disability in and of itself should not be determinative of a lack of decision-making ability.[172] These considerations are especially important as at 30 June 2020, 16% of the Australian population were aged 65 and over,[173] and 50% of these older people lived with some level of disability.[174] As Sullivan and Purser note, 'there is potential for abuse where capacity is erroneously believed to exist (for example, to execute a transfer of property) or is alleged to have been lost (for example, to trigger a substitute decision-maker for financial matters)'.[175] In the context of APP, this thesis focuses on decision-making capacity and explores issues relevant to the ability to make different planning decisions from the perspective of both older adults and professionals.

APP provides an opportunity for an older person to exercise their autonomy by recording their wishes and appointing their own decision-makers prior to a period of incapacity, which may take with it the chance to assert what the person would like to happen to them, or who they trust making those decisions.[176] Appointed decision-makers such as an Enduring Power of Attorney or Enduring Guardian, and documents such as a Will and an Advance Care Directive, can help to overcome future uncertainty regarding an older person's wishes, as they are ideally recorded at a time when the person has capacity. These wishes and preferences are safeguarded for the future and can be understood at a later stage in the event the person is no longer able to speak for themselves.[177] It is this understanding of decision-making capacity that has been applied in this thesis to both health and legal contexts. It is viewed as a multi-step process that

[172] New South Wales Law Reform Commission (n 100) 19; Lise Barry, 'Capacity and Vulnerability: How Lawyers Assess the Legal Capacity of Older Clients' (2017) 25(1) *Journal of Law and Medicine* 267, 281 ('Capacity and Vulnerability').

[173] Australian Institute of Health and Welfare, *Older Australians* (Catalogue No AGE 87, 28 June 2023) 2 <https://www.aihw.gov.au/reports/older-people/older-australians/contents/about>.

[174] Australian Institute of Health and Welfare', *People with Disability in Australia 2022* (Catalogue No DIS 72, 5 July 2022) 22 <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia-2022-in-brief/contents/about-people-with-disability-in-australia-in-brief>.

[175] Sullivan and Purser (n 170) 753.

[176] Close et al (n 79) 2; Sinclair et al, 'Association Between Region of Birth and Advance Care Planning Documentation' (n 1) 117–118; Moore et al (n 2) 1–2; NSW Trustee & Guardian, 'Enduring Guardianship' (n 44) 2; Advance Care Planning Australia, 'Factsheet for Individuals: Advance Care Planning and the Law – New South Wales' (n 79); 'Ethics in Advance Care Planning' (n 2).

[177] 'Being an Attorney' (n 10); Orsatti (n 1) 163–164; Bryant et al (n 83) e326; Department of Health (n 2) 13; Detering et al, 'Organisational and Advance Care Planning Program Characteristics' (n 80) 2; Tran et al (n 80) 318; Billingsley Kaambwa et al, 'Costs and Advance Directives at the End of Life: A Case of the "Coaching Older Adults and Carers to Have Their Preferences Heard (COACH)" Trial' (2015) 15 *BMC Health Services Research* 545:1–12, 2.

involves not only comprehension of the decision being made and its consequences, but also the ability to communicate this decision to others in whatever way a person is able to do so.

2.7 Risk of Elder Abuse Arising from Advance Planning Instruments

Even if a capable adult has engaged in forms of APP, this does not mean that they are necessarily, or completely, protected from manipulation or abuse.[178] According to data collected by the AIHW, up to one in seven older Australians, or between 2% and 14%, are thought to be affected by elder abuse.[179] More recently, Qu estimates 14.8% of older people have experienced elder abuse in the 12 months prior to completing the Survey of Older People in early 2020.[180] As Wuth explains in relation to Enduring Powers of Attorney, the potential for abuse 'stems from the relatively informal, low cost and private nature of the appointment which are considered the practical advantages'.[181] The Council of Attorneys-General defines financial abuse as:

> [T]he misuse or theft of an older person's money or assets. It can include but is not limited to behaviours such as using finances without permission, using a legal document such as an enduring power of attorney for purposes outside what was originally signed for, withholding care for financial gain, or selling or transferring property against a person's wishes.[182]

Given the potential for elder abuse to arise within the context of APP, especially with regard to financial abuse[183] or the misuse of powers that may result in emotional or social abuse through isolation,[184] my research has included an exploration of key informants' views and experiences relating to abuse, risk factors and prevention strategies.

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[178] Australian Institute of Health and Welfare, *Australia's Welfare 2019: Data Insights* (Australia's Welfare Series No 14. Catalogue No AUS 226, 2019) 23 <https://www.aihw.gov.au/reports/australias-welfare/australias-welfare-2019-data-insights/data>; Barry, 'He Was Wearing Street Clothes, Not Pyjamas' (n 167) 22; Barry, 'Capacity and Vulnerability' (n 173); Wuth (n 10) 7–8.

[179] Australian Institute of Health and Welfare, 'Australia's Welfare 2019: Data Insights' (n 179) xx.

[180] Lixia Qu et al, *National Elder Abuse Prevalence Study* (Final Report, Australian Institute of Family Studies, July 2021) 2 <https://aifs.gov.au/research/research-reports/national-elder-abuse-prevalence-study-final-report>.

[181] Wuth (n 10) 7–8. See also Qu et al (n 180) 3; Australian Law Reform Commission (n 1) 206.

[182] Council of Attorneys-General (Australia) and Attorney-General's Department, *National Plan to Respond to the Abuse of Older Australians (Elder Abuse) 2019-2023* (Report, 8 July 2019) 3 <https://www.ag.gov.au/rights-and-protections/publications/national-plan-respond-abuse-older-australians-elder-abuse-2019-2023>. See also Australian Law Reform Commission (n 1) 160–161.

[183] Attorney-General's Department (n 13) 2.

[184] See for example *EB v GB (No 2)* [2022] NSWSC 1011.

2.7.1 Risk Factors for Financial Abuse

Ries cites factors that may increase the vulnerability of an older person to financial exploitation, including 'cognitive impairment, lower numeracy and literacy, physical disability, dependence on others for care, depression and prior life history of trauma or abuse'.[185] Consequently, the risk of a failed civil action seeking a remedy is simply too high for many people to consider seeking a remedy under the current framework.[186] Further, reporting such abuse is made even more difficult as it is contingent upon someone actually recognising the misuse of an Enduring Power of Attorney.[187] Other factors that may contribute to risk of financial elder abuse by an Enduring Power of Attorney include: a lack of knowledge or understanding of what the attorney is expected, and authorised, to do; tensions or conflicts within the family; and a lack of communication or planning with respect to future management of affairs. The difficulty and stress associated with taking on financial management and connected responsibilities, as well as ageist and sexist perceptions regarding who is best placed to act as attorney, may also heighten the risk of abuse. Finally, if adult children hold a belief that they are entitled to their parent's assets, this could result in abusive behaviour that could escalate over time.[188]

2.7.2 Potential Safeguards within APP Frameworks

The *Guardianship Act 1987* (NSW) and *Powers of Attorney Act 2003* (NSW) include safeguards that aim to prevent or reduce the risk of misuses or abuses of power conferred by the appointment of decision-makers. These include formal acceptance by the appointee, a detailed schedule explaining what the attorney is not authorised to do,[189] the requirement that the appointing document be signed in the presence of a listed witness, and optional registration.[190] Such statutory safeguards are especially significant, given remedies for abuses of enduring appointments such as penalties under statute, actions in breach of fiduciary duty and unconscionable conduct at common law,[191] are of very little utility, particularly for older adults due to potential frailty, isolation, and circumstantial or relational vulnerability.[192]

[185] Nola M Ries, 'Enduring Powers of Attorney and Financial Exploitation of Older People: A Conceptual Analysis and Strategies for Prevention' (2022) 34(3) *Journal of Aging & Social Policy* 357, 5.
[186] Wuth (n 10) 14–15.
[187] Ibid 16.
[188] Ries (n 186) 7–11.
[189] *Powers of Attorney Regulation 2016* (n 28) sch 2. See also Ellison et al (n 10) 312–313.
[190] Ellison et al (n 10) 317–318.
[191] Ries (n 186) 4–5; Wuth (n 10) 9–13.
[192] Wuth (n 10) 1.

To overcome the high potential for abuse, the following recommendations have been developed in response to contemporary concerns about Enduring Power of Attorney appointments. Firstly, nationally consistent legislation to regulate Enduring Powers of Attorney,[193] including appointments and actions taken in accordance with that authority, would offer a stronger basis for the prevention of financial abuse.[194] Secondly, the creation of a central registry of Enduring Power of Attorney appointments would allow for greater transparency for organisations regarding who has power to act on behalf of another and protection for the appointee to limit chances for exploitation or abuse.[195] Thirdly, the development of a standardised Enduring Power of Attorney form under national legislation that contains reference to penalties for acting outside the appointment is recommended.[196] Fourthly, mandatory reporting of transactions and financial management matters by Enduring Powers of Attorney would ensure compliance with statutory requirements.[197] Finally, statutory recognition of financial elder abuse as a crime would reflect the seriousness of the behaviour and increase community awareness of the issue.[198] Ries has also compiled a number of strategies that may assist in preventing financial exploitation by Enduring Powers of Attorney.[199] A more stringent process for selecting attorneys, including professional advice,[200] along with a risk assessment of any current or potential abusive relationships in the person's life, are recommended. In addition to evaluating the person's financial decision-making ability,[201] the proposed attorney's capabilities and personal circumstances should also be considered.[202] An understanding of the relationship between the person and any proposed attorneys should also be front of mind, as well as assessing the benefits of appointing more than one Enduring Power of Attorney.[203] An acknowledgement of the impact of social isolation,[204] and the provision of education for both

[193] See also Law Council of Australia, *National Register of Enduring Powers of Attorney* (Report, 8 July 2021) 19–21 <https://lawcouncil.au/resources/submissions/national-register-of-enduring-powers-of-attorney>.
[194] Wuth (n 10) 17.
[195] Ibid 18; Attorney-General's Department, *National Register of Enduring Powers of Attorney* (Public Consultation Paper, April 2021) 4–5 <https://www.ag.gov.au/rights-and-protections/consultations/national-register-enduring-powers-attorney>; Law Council of Australia (n 194) 20–22; Australian Law Reform Commission (n 1) 181–182.
[196] Wuth (n 10) 18.
[197] Ibid 18–19.
[198] Ibid 19. See also Lewis (n 164).
[199] Ries (n 186).
[200] Ibid 11. See also Australian Law Reform Commission (n 1) 282.
[201] Ries (n 186) 11–12.
[202] Ibid 12. See also Australian Law Reform Commission (n 1) 164–165.
[203] Ries (n 186) 12. See also Qu et al (n 181) 3–4, 104.
[204] Ries (n 186) 12–13.

the person and proposed attorneys,[205] should also be considered. Finally, encouragement of increased communication between the parties,[206] greater transparency regarding financial planning,[207] and referrals for financial training for Enduring Powers of Attorney are also noted.[208]

The Australian Guardianship and Administration Council has prepared the *National Standards for Financial Managers* in the more specific context of financial management orders for people living with a disability.[209] However, these measures appear inadequate in the face of growing evidence of elder abuse, with financial abuse being reported as one of the most prevalent forms of abuse affecting older Australians.[210] The Commonwealth Attorney-General is also exploring the benefits of achieving greater consistency in Australian laws regarding the appointment of Enduring Powers of Attorney, and the anticipated reduction in financial elder abuse.[211] One of their proposed strategies is to order an attorney to pay compensation for any loss they have caused, in addition to establishing offences, where they do not already exist, to penalise the dishonest use of an Enduring Power of Attorney appointment.[212]

2.8 Potential for Reform

Potential reforms are underway with respect to Advance Care Directives and enduring appointments that could, should they eventuate, significantly impact the existing APP regime. In my research, I have been proactive in exploring stakeholders' perspectives about these proposed law reforms, including strategies that could improve APP processes and enhance protections for older adults.

The *Guardianship Act 1987* (NSW) was intended to provide protections for persons in need of support to make their own decisions. However, the NSW Law Reform Commission concluded that it has not kept pace with our changing understanding of supported decision-making and

[205] Australian Law Reform Commission (n 1) 290–293.
[206] Ries (n 186) 13.
[207] Ibid.
[208] Ibid 13–14.
[209] Australian Guardianship and Administration Council, *National Standards for Financial Managers* (Report, 2018) <https://www.agac.org.au/assets/documents/Standards/National-Standards-for-Financial-Managers-2018.pdf>.
[210] Qu et al (n 181) 2; The Law Society of New South Wales (n 163) 1; Australian Institute of Health and Welfare, 'Australia's Welfare 2019: Data Insights' (n 179) xx; Ries (n 186) 1; Lewis (n 164) 41; Australian Law Reform Commission (n 1) 160–161; Wuth (n 10) 1; Ellison et al (n 10) 272.
[211] Attorney-General's Department (n 13) 1.
[212] Ibid 30.

international approaches to disability.[213] The NSW Law Reform Commission cites the *Convention on the Rights of Persons with Disabilities*,[214] which conceptualises disability through a social lens, meaning it is 'an evolving concept and that attitudinal and environmental barriers can hinder people with disability from full and effective participation in society on an equal basis with others'.[215] This social model stresses the need to involve the person in decision-making processes as much as possible, instead of decisions being made on their behalf that are thought, or assumed, to result in the best outcome for the person.[216] The NSW Law Reform Commission recommended updated terminology, with 'disability' replaced with a focus on 'decision-making ability'.[217] The 'principle of least restriction' has been reiterated as a top priority by the NSW Law Reform Commission, meaning that a person's ability to make their own decisions should be upheld as much as possible with minimal interference,[218] and the only restrictions that should be imposed on a person's autonomy to make their own decisions are 'to protect them from neglect and abuse'.[219]

While the common law presumption that all adults have decision-making capacity prevails,[220] the NSW Law Reform Commission has recommended the introduction of a statutory presumption that could be rebutted if required.[221] More broadly, the NSW Law Reform Commission recommended the introduction of a new Act, to be known as the *Assisted Decision-Making Act*, which would replace the existing *Guardianship Act 1987* (NSW) and *Powers of Attorney Act 2003* (NSW).[222] The recommended new consolidated legislation would govern all enduring appointments relating to personal, healthcare and financial decisions.[223] Multiple appointments would be replaced by a single 'enduring representation agreement' in which several enduring representatives could be listed.[224] The proposed new legislation would also provide stronger review mechanisms[225] and assurance that a valid Advance Care Directive

[213] New South Wales Law Reform Commission (n 100) xiv.
[214] *Convention on the Rights of Persons with Disabilities,* opened for signature 30 May 2007, 2515 UNTS 3 (entered into force 3 May 2008).
[215] New South Wales Law Reform Commission (n 100) xxi.
[216] Ibid 19. See also Moore et al (n 2) 1–2.
[217] New South Wales Law Reform Commission (n 100) 2.
[218] Ibid xviii.
[219] Australian Institute of Health and Welfare, 'Australia's Welfare 2019: Data Insights' (n 179) 31.
[220] See, eg, Department of Health (n 2) 4.
[221] New South Wales Law Reform Commission (n 100) xxv.
[222] Ibid.
[223] Ibid 25–28.
[224] Ibid 95, 98.
[225] Ibid 109.

would still be followed even if it was contained within an enduring representation agreement that was subsequently revoked.[226] The NSW Law Reform Commission also recommend a further guarantee that marriage would not automatically render an enduring appointment void.[227] Under the current legislative regimes, if a person has made an enduring appointment and subsequently marries, the appointment is automatically revoked.[228] This process seems to fly in the face of the person's autonomy to choose their decision-makers and have these decisions upheld.[229] The unified legislation 'provides an opportunity to enhance and standardise safeguards across all enduring representation arrangements in NSW and protect people from abuse and exploitation'.[230] Further, additional principles for Aboriginal and Torres Strait Islander People have been included to enshrine cultural competence and recognition of the unique circumstances and challenges that may be faced by people in this cohort.[231]

Under the recommended new legislation, appointments made outside of NSW would continue to be recognised.[232] Interestingly, the NSW Law Reform Commission does not recommend the creation of civil or criminal penalties when an appointed representative either 'misuses their power, or fails to act in line with their responsibilities'.[233] As Advance Care Directives are currently common law creations in NSW, the NSW Law Reform Commission has recommended their explicit inclusion in the new legislation, as this 'will make it easier for health professionals to refer to the law, minimise confusion around their validity and, therefore, encourage people to use them'.[234] Finally, the creation of a new independent statutory role, the Public Advocate, is recommended.[235] Despite the perceived benefits of these amendments to the existing decision-making legislation, as at March 2024, the *Guardianship Act 1987* (NSW) and *Powers of Attorney Act 2003* (NSW) remain in force without any of the suggested amendments, and the proposed *Assisted Decision-Making Act* is yet to be realised.

At a federal level, there are also reform developments surrounding Advance Care Directives and Advance Care Planning. The *National Framework for Advance Care Directives*[236] ('the

[226] Ibid 115.
[227] Ibid.
[228] Ibid 121–122.
[229] Ibid.
[230] Ibid 96.
[231] Australian Institute of Health and Welfare, 'Australia's Welfare 2019: Data Insights' (n 179) 47, 64, 127.
[232] New South Wales Law Reform Commission (n 100) 281.
[233] Ibid 151.
[234] Ibid 160.
[235] Ibid 206–207.
[236] Australian Health Ministers' Advisory Council (n 81).

Framework') was endorsed by the Australian Health Ministers' Advisory Council in 2011.[237] It was originally created due to the significant variability in approaches between Australian states and territories.[238] The Framework was always clearly labelled as an aspirational construct, but it provides a thoughtful basis from which future policy decisions can be made.[239] Interestingly, the Framework did not recommend the creation of a national register of Advance Care Directives, citing that such registers are expensive, time-consuming and unlikely to return results given the low uptake of Advance Care Directives.[240]

While a free, compulsory register may have some benefit, there has been no evidence that such a measure actually safeguards people against abuse or neglect from appointed decision-makers.[241] The Framework has since been reviewed,[242] culminating in the *National Framework for Advance Care Planning Documents* ('the National Framework').[243] A key theme of the updated National Framework is the need to normalise forms of planning ahead, as well as recognising 'that illness, death and dying are normal parts of life'.[244] The promotion of an ethical approach to Advance Care Planning and prioritising best-practice approaches to planning ahead is intended to improve consistency across jurisdictions and encourage 'mutual recognition of quality Advance Care Directives' that uphold 'the recognition of an individual's documented values, beliefs and preferences, ensuring they can be acted upon anywhere in Australia'.[245] The updates to the National Framework could facilitate further reform, including the development of a national online register for matters relating to enduring appointments[246] and compulsory registration of appointments.[247] The Council of Attorneys-General have also continued to support the introduction of a mandatory national register of Enduring Power of

[237] Ibid. See also Office of the Public Advocate, *Australian Guardianship and Administration Council Elder Abuse National Projects: Enduring Powers of Attorney (Financial)* (Options Paper, Australian Guardianship and Administration Council, December 2018) 24–25 <https://www.agac.org.au/assets/documents/Other-Publications/Elder-Abuse-National-Projects-EPOA-financial.pdf>.
[238] Australian Health Ministers' Advisory Council (n 81) 1.
[239] Ibid.
[240] Ibid 35.
[241] Ibid.
[242] 'What we're Doing about Palliative Care', *Department of Health & Aged Care* (Web Page, 27 March 2019) <https://www.health.gov.au/health-topics/palliative-care/about-palliative-care/what-were-doing-about-palliative-care>.
[243] Department of Health (n 2).
[244] Ibid 6.
[245] Ibid 7.
[246] Attorney-General's Department (n 196) 4–5; Law Council of Australia (n 194) 21–22; John Chesterman and Lois Bedson, *Decision Time: Activating the Rights of Adults with Cognitive Disability* (Report, Office of the Public Advocate, 15 February 2021) 9 <https://apo.org.au/node/314188>.
[247] Australian Law Reform Commission (n 1) 181; Chesterman and Bedson (n 247) 9.

Attorney instruments.[248] However, the Law Council of Australia has raised a number of concerns regarding the implementation of such a register.[249] They note several risks including: significant differences in appointment forms across jurisdictions; lack of a nationally endorsed, standardised method of appointment; and the existence of multiple forms for appointment in some jurisdictions. Similarly, levels of compliance with prescribed forms are not the same across jurisdictions and compulsory registration has not prevented elder abuse in states where it is currently required. Laws regarding the validity of appointments may also be different to legislation regarding the function of appointments, while there is an absence of legislation that recognises the revocation of enduring appointments across jurisdictions. Finally, the lack of uniform restrictions across all jurisdictions is highlighted.[250] In light of these concerns, the Law Council of Australia has recommended the implementation of nationally consistent legislation, as opposed to a national register.[251] Additional safeguards and remedies could also be implemented, including compensation in instances where the appointed representative does not comply with their obligations.[252]

On the point of legislation, the creation of a new Elder Justice Law, which is designed to protect vulnerable older adults from various forms of abuse, has been advocated by Lewis.[253] The new law would govern offences including elder abuse via undue influence, a breach of fiduciary duty, unlawful restraint, battery, assault and neglect, as well as aggravated forms of these behaviours.[254] If these offences are made out, sentencing options would be 'as wide as possible to fit the circumstances',[255] and may provide for recovery of property, the return of money that was taken without authority, and the completion of intervention programs by offenders.[256] Mandatory conferences would also be required between the victim and the offender,[257] promoting open communication, encouraging cooperation, and even working to preserve family connections in the event the perpetrator had a close relationship with the victim.[258]

[248] Council of Attorneys-General, *Summary of Decisions* (Communique, 29 November 2019) 2–3.
[249] Law Council of Australia (n 194).
[250] Ibid 21–22.
[251] Ibid 19.
[252] Council of Attorneys-General (n 249) 3. See also John Chesterman and Lois Bedson, *Submission to the Australian Law Reform Commission in Response to the Elder Abuse Discussion Paper 83* (Submission, Office of the Public Advocate, 2017) 22, 11.
[253] Lewis (n 164).
[254] Ibid 45.
[255] Ibid.
[256] Ibid 44–45.
[257] Ibid 45.
[258] Ibid 44.

Through my research, I have been able to explore some of these proposals for reform, including shifting the focus to planning for the rest of life, not the end of life, the benefits of consolidating enduring appointments, and the need to implement stronger protections against elder abuse. I was able to discuss these recommendations with professional key informants, understand the benefits of the suggested interventions, and better comprehend the disadvantages and risks associated with the various reform models.

2.9 CONCLUSION

While there are overall positives within the current framework, such as people having statutory rights to engage in forms of advance legal planning, the applicable legislation is dated and still reliant on substituted rather than supported decision-making. Further, there is a lack of statutory support for Advance Care Directives. Calls for reform have emerged, yet they are not a priority for current governments. Illustrative case examples highlight the potential for conflict or disputes in practice when APP instruments are misused or interpreted incorrectly. Providing this foundational overview of the NSW context and environment that governs APP allows for a deeper understanding of why planning ahead using available legal instruments is a significant process for older adults. The benefits of safeguarding wishes for the future, preparing for potential periods of incapacity and providing guidance for appointed decision-makers are clear. Additionally, careful consideration must be given to the potential for elder abuse to arise from appointments, with particular concerns regarding financial exploitation.

These elements highlight the need to involve qualified professionals in APP processes, including lawyers and healthcare practitioners. Consequently, my research is valuable in understanding more about APP from the perspective of both older people and professional key informants, including lawyers who play a vital role in engaging older people in planning ahead and preparing APP instruments. Such professional involvement may ensure older adults are aware of all available APP instruments, their distinct purposes, and how they can be prepared to ensure their best chance of successful implementation in the future. Further, this context allows for critical assessment of existing studies and findings from interventions relating to Advance Care Planning and consideration of how my research can address gaps in the current data, providing insights regarding the broader, interdisciplinary process of APP.

3 LITERATURE REVIEW

3.1 INTRODUCTION

This chapter provides an overview of the literature on Advance Care Planning and Advance Personal Planning (APP), highlighting previous findings and exploring gaps that my research addresses. In the process of conducting my research, understanding the current evidence base enabled me to recognise where further analysis was required and frame my research around those issues. In addition to understanding the contribution of other researchers to the field of Advance Care Planning, and how their conclusions may extrapolate to, or differ from, the broader concept of APP, this chapter also identifies deficiencies within existing planning processes. A thorough understanding of the barriers that can arise for individuals, professionals and within society at large provided an essential foundation upon which I have analysed my results and addressed opportunities for improvement.

Most of the existing research examines Advance Care Planning, rather than more comprehensive approaches to APP. Current research appears to remain divided between forms of legal and health planning and fails to address APP as a holistic and ongoing process. Further, as very little literature is available regarding the broader process of APP, as opposed to only advance planning for healthcare or end of life care, there is a lack of empirical evidence available that explores how professionals are assisting older adults to engage with the full range of available APP mechanisms that can help to prevent legal, health, financial and personal conflicts arising in future. Similarly, following extensive literature searches, there appear to be no extant studies involving professional key informants and older adults in a single project, analysing data for points of convergence and divergence in experiences. Finally, while quantitative studies have investigated uptake, fewer qualitative studies have explored the

perspectives and experiences of older people and key professional informants regarding their experiences with the broader process of APP and the available legal instruments.

Through my research, I have produced new data regarding: professionals' experiences regarding APP; their views on the advantages and disadvantages of APP for older people; how capacity concerns can be addressed; their general views on current processes; identifiable barriers, benefits and risks of APP; and potential areas for improvement. Further, I interviewed older adults to learn more about: aspects of APP they may have completed, including any discussion with their support network; the review and storage of instruments; their confidence in their chosen appointed decision-makers; aspects of APP they may not have completed, including factors that have stopped them engaging with APP; whether the preparation of instruments would increase their level of confidence that their wishes will be followed in future; and their views on the benefits and risks of APP. These data provide new insight into not only the effectiveness of current processes and the occurrence of existing deficiencies, but also the quality of prepared instruments and opportunities for improvement. My research has also allowed me to explore some of the critiques of advance planning from the international literature within the local context of New South Wales (NSW), Australia, with a particular focus on experiences in rural and regional areas.

3.2 Planning Ahead for Particular Populations

While research on the wider notion of APP is scarce, there is considerable research on the narrower frame of Advance Care Planning processes with particular population groups. Key cohorts include: older people;[1] health care professionals, particularly those working with

[1] Kimberly Buck et al, 'Advance Care Directive Prevalence among Older Australians and Associations with Person-Level Predictors and Quality Indicators' (2021) 24(4) *Health Expectations* 1312 ('Advance Care Directive Prevalence among Older Australians'); Karen M Detering et al, 'Organisational and Advance Care Planning Program Characteristics Associated with Advance Care Directive Completion: A Prospective Multicentre Cross-Sectional Audit among Health and Residential Aged Care Services Caring for Older Australians' (2021) 21 *BMC Health Services Research* 700:1–12 ('Organisational and Advance Care Planning Program Characteristics'); Sarah Nouri et al, 'Evaluation of Neighborhood Socioeconomic Characteristics and Advance Care Planning Among Older Adults' (2020) 3(12) *JAMA Network Open* e2029063:1-12; Marcus Sellars et al, 'Personal and Interpersonal Factors and their Associations with Advance Care Planning Documentation: A Cross-Sectional Survey of Older Adults in Australia' (2020) 59(6) *Journal of Pain and Symptom Management* 1212 ('Personal and Interpersonal Factors and their Associations with Advance Care Planning Documentation'); Kimberly Buck et al, 'Concordance Between Self-Reported Completion of Advance Care Planning Documentation and Availability of Documentation in Australian Health and Residential Aged Care Services' (2019) 58(2) *Journal of Pain and Symptom Management* 264 ('Concordance Between Self-Reported Completion of Advance Care Planning Documentation and Availability of Documentation'); Irfana Musa et al, 'A Survey of Older Peoples' Attitudes towards Advance Care Planning' (2015) 44(3) *Age and Ageing* 371.

patients who have chronic and/or terminal illnesses;[2] patients;[3] healthy elders;[4] people with dementia and their families;[5] older Australians accessing health and residential aged care services;[6] staff of international healthcare organisations;[7] and lawyers.[8] These studies provide a useful foundation by delineating relevant factors that require consideration, such as: prevalence and predictors of completing documents;[9] the importance of an individual's

[2] Maria T Carney et al, 'Impact of a Community Health Conversation upon Advance Care Planning Attitudes and Preparation Intentions' (2021) 42(1) *Gerontology & Geriatrics Education* 82; Suet Ying Ng and Eliza Lai-Yi Wong, 'The Role Complexities in Advance Care Planning for End-of-Life Care—Nursing Students' Perception of the Nursing Profession' (2021) 18(12) *International Journal of Environmental Research and Public Health* 6574:1–13; Craig Sinclair et al, 'Professionals' Views and Experiences in Supporting Decision-Making Involvement for People Living with Dementia' (2021) 20(1) *Dementia* 84 ('Professionals' Views and Experiences in Supporting Decision-Making Involvement'); Frances Batchelor et al, 'Facilitators and Barriers to Advance Care Planning Implementation in Australian Aged Care Settings: A Systematic Review and Thematic Analysis' (2019) 38(3) *Australasian Journal on Ageing* 173; Guiyun Zhou et al, 'Knowledge, Attitudes, and Practice Behaviors of Oncology Advanced Practice Nurses Regarding Advanced Care Planning for Patients with Cancer' (2010) 37(6) *College of Nursing Faculty Papers & Presentations* 400.

[3] Detering et al, 'Prevalence of Advance Care Planning Documentation and Self-Reported Uptake' (n 1); Helena Rodi et al, 'Exploring Advance Care Planning Awareness, Experiences, and Preferences of People with Cancer and Support People: An Australian Online Cross-Sectional Study' (2021) 29(7) *Supportive Care in Cancer* 3677; Joshua A Rolnick et al, 'Patients' Perspectives on Approaches to Facilitate Completion of Advance Directives' (2019) 36(6) *American Journal of Hospice & Palliative Medicine* 526.

[4] Heather Malcomson and Shannon Bisbee, 'Perspectives of Healthy Elders on Advance Care Planning' (2009) 21(1) *Journal of the American Academy of Nurse Practitioners* 18.

[5] Jamie Bryant et al, 'Inadequate Completion of Advance Care Directives by Individuals with Dementia: National Audit of Health and Aged Care Facilities' (2022) 12 *BMJ Supportive & Palliative Care* e319 ('Inadequate Completion of Advance Care Directives by Individuals with Dementia'); Jamie Bryant et al, 'Advance Care Planning Participation by People with Dementia: A Cross-Sectional Survey and Medical Record Audit' (2022) 12 *BMJ Supportive & Palliative Care* e464 ('Advance Care Planning Participation by People with Dementia'); Sinclair et al, 'Professionals' Views and Experiences in Supporting Decision-Making Involvement' (n 2); Marcus Sellars et al, 'Perspectives of People with Dementia and Carers on Advance Care Planning and End-of-Life Care: A Systematic Review and Thematic Synthesis of Qualitative Studies' (2019) 33(3) *Palliative Medicine* 274 ('Perspectives of People with Dementia and Carers on Advance Care Planning and End-of-Life Care'); Meredith Blake, Olivia Nicole Doray and Craig Sinclair, 'Advance Care Planning for People with Dementia in Western Australia: An Examination of the Fit Between the Law and Practice' (2018) 25(2) *Psychiatry, Psychology and Law* 197; Claire Dickinson et al, 'Planning for Tomorrow Whilst Living for Today: The Views of People with Dementia and Their Families on Advance Care Planning' (2013) 25(12) *International Psychogeriatrics* 2011.

[6] Detering et al, 'Organisational and Advance Care Planning Program Characteristics' (n 1); Karen M Detering et al, 'Prevalence and Correlates of Advance Care Directives among Older Australians Accessing Health and Residential Aged Care Services: Multicentre Audit Study' (2019) 9(1) *BMJ Open* e025255:1-9 ('Prevalence and Correlates of Advance Care Directives among Older Australians').

[7] Josie Dixon and Martin Knapp, 'Whose Job? The Staffing of Advance Care Planning Support in Twelve International Healthcare Organizations: A Qualitative Interview Study' (2018) 17(1) *BMC Palliative Care* 78:1–16.

[8] Nola M Ries et al, 'How Do Lawyers Assist Their Clients with Advance Care Planning? Findings from a Cross-Sectional Survey of Lawyers in Alberta' (2018) 55(3) *Alberta Law Review* 683.

[9] Buck et al, 'Advance Care Directive Prevalence among Older Australians' (n 1); Sonja McIlfatrick et al, '"It's Almost Superstition: If I Don't Think about It, It Won't Happen". Public Knowledge and Attitudes towards Advance Care Planning: A Sequential Mixed Methods Study' (2021) 35(7) *Palliative Medicine* 1356; Rodi et al (n 3); Batchelor et al (n 2); Patricia D Biondo et al, 'How to Increase Public Participation in Advance Care Planning: Findings from a World Café to Elicit Community Group Perspectives' (2019) 19(1) *BMC Public Health* 679; Detering et al, 'Prevalence of Advance Care Planning Documentation and Self-Reported Uptake' (n 1); Musa et al (n 1).

circumstances;[10] identified barriers;[11] the benefits of a standardised Advance Care Planning process;[12] and the significance of interprofessional collaboration.[13] Research involving older adults has mainly involved participants who are living with terminal illness, living with dementia, undergoing treatment for cancer, admitted to hospital, or residing in aged care facilities rather than those still living in the community. Yet, according to the Australian Health Ministers' Advisory Council, 60% of people who are considering preparing an Advance Care Directive are in good health, 30% are living with a chronic illness, and only 10% are nearing the end of life.[14] These statistics indicate that Advance Care Directives are not only relevant for those who have been diagnosed with a terminal or life-limiting illness, and that people in good health are receptive to making them.[15] Further, studies examining older people and their engagement with Advance Care Planning have only recently begun to consider the unique experiences for older adults residing in regional or rural areas.[16] The collection of new data relating to this specific cohort is a clear point of distinction of my research.

[10] Detering et al, 'Prevalence of Advance Care Planning Documentation and Self-Reported Uptake' (n 1); Julie L Masters, Lindsey E Wylie and Sarah B Hubner, 'End-of-Life Planning: Normalizing the Process' (2022) 34(4) *Journal of Aging & Social Policy* 641; Rodi et al (n 3); Sellars et al, 'Personal and Interpersonal Factors and their Associations with Advance Care Planning Documentation' (n 1); Sarah Russell, 'Advance Care Planning: Whose Agenda is it Anyway?' (2014) 28(8) *Palliative Medicine* 997.

[11] Helen Close et al, 'Qualitative Investigation of Patient and Carer Experiences of Everyday Legal Needs towards End of Life' (2021) 20 *BMC Palliative Care* 47:1–13; Julien Tran et al, 'Systematic Review and Content Analysis of Australian Health Care Substitute Decision Making Online Resources' (2021) 45(3) *Australian Health Review* 317; Australian Healthcare Associates, *Exploratory Analysis of Barriers to Palliative Care* (Issues Report on Aboriginal and Torres Strait Islander Peoples, Department of Health, September 2019) 31 <https://www.health.gov.au/resources/publications/exploratory-analysis-of-barriers-to-palliative-care-issues-report-on-aboriginal-and-torres-strait-islander-peoples?language=en>; Batchelor et al (n 2); Nadia Moore et al, 'Doctors' Perspectives on Adhering to Advance Care Directives When Making Medical Decisions for Patients: An Australian Interview Study' (2019) 9 *BMJ Open* e032638:1-11; Dixon and Knapp (n 7); Dickinson et al (n 5); Zhou et al (n 2).

[12] Detering et al, 'Organisational and Advance Care Planning Program Characteristics' (n 1); Batchelor et al (n 2); Detering et al, 'Prevalence and Correlates of Advance Care Directives among Older Australians' (n 6).

[13] Grace W Orsatti, 'Attorneys as Healthcare Advocates: The Argument for Attorney-Prepared Advance Healthcare Directives' (2022) 50(1) *Journal of Law, Medicine & Ethics* 157, 164; Rolnick et al (n 3); Ries et al (n 8) 695.

[14] Australian Health Ministers' Advisory Council, *A National Framework for Advance Care Directives* (Report, September 2011) 7 <https://respectingchoices.org/wp-content/uploads/2017/07/a-national-framework-for-advance-care-directives_september-2011.pdf>.

[15] McIlfatrick et al (n 9) 1360; Stephanie B Johnson et al, 'Patient Autonomy and Advance Care Planning: A Qualitative Study of Oncologist and Palliative Care Physicians' Perspectives' (2018) 26(2) *Supportive Care in Cancer* 565, 566.

[16] For example, see Emilie Cameron et al, 'Advance Personal Planning Knowledge, Attitudes, and Participation amongst Community-Dwelling Older People Living in Regional New South Wales: A Cross-Sectional Survey' (2024) 19(8) *PLoS ONE* e0309152.

3.3 Prevalence and Predictive Factors in Australia

Most Australian studies focus on the prevalence of planning instruments, rather than the actual experiences and perceptions of older people and key informant professionals. These studies reveal varied rates of uptake. Most recently, Cameron et al conducted a descriptive cross-sectional survey of community-dwelling older adults living in regional areas of NSW.[17] Of the 216 respondents, 90% reported having completed a Will, 67% had appointed an Enduring Power of Attorney, 54% had appointed an Enduring Guardian, and 32% had made an Advance Care Directive.[18] Only 9.3% had engaged with all APP activities.[19] Older age, positive attitudes towards APP, and having private health insurance were significant predictive factors.[20] However, this study also demonstrates that participants had concerningly low levels of knowledge of APP, with only 2.8% accurately responding to all six statements regarding the correct purpose and use of various APP instruments.[21] This study is part of a broader Australian Research Council (ARC) Discovery Project Grant that supported my candidature and in which my PhD was embedded.[22] Therefore, the results are highly relevant to my research because they concern the specific cohort that I am focused on, being adults aged 65 years and over who are living in regional NSW.

Tilse et al examined the prevalence and predictive factors of Will making in Australia.[23] They found that almost 60% of adults have a Will, and 54% of those who don't intend to prepare one.[24] When focusing on people aged 70 and over, 93% were found to have a Will, and they did not report that property or wealth was a determining factor in creating it.[25] For 82%, the decision to make a Will was self-directed, while age, having children, and acquisition of property were all significant predictive factors.[26] Of those who had made a Will, only 46% had ever amended it.[27] While the most recognised reason for creating a Will is the distribution of

[17] Ibid.
[18] Ibid.
[19] Ibid.
[20] Ibid.
[21] Ibid.
[22] 'Taking Action: Increasing Advance Personal Planning by Community-Dwelling Older Adults' (DP190100861).
[23] Cheryl Tilse et al, *Having the Last Word? Will Making and Contestation in Australia* (ARC Linkage Project Key Findings, The University of Queensland; Victoria University; Australian Centre for Health Law Research, March 2015) <https://eprints.qut.edu.au/215396/> ('*Having the Last Word?*').
[24] Ibid 8.
[25] Ibid.
[26] Ibid.
[27] Ibid 9.

property following death, the nature of a Will as a family planning document is often overlooked.[28] These additional purposes can extend to nominating executors, considering guardians for children, and detailing arrangements following death.[29] Tilse et al, also found that 30% of those surveyed had appointed an Enduring Power of Attorney and only 14% had prepared an Advance Care Directive.[30]

White et al found similar results in a nationwide survey of 2,405 participants aged 18 and over.[31] They found the strongest predictive factor associated with preparing an Advance Care Directive was completion of other APP instruments.[32] Relationship status also had some influence; single respondents were more likely than married participants to have prepared an Advance Care Directive, while married respondents were more likely to have prepared a Will.[33] In relation to my research, both the Tilse et al and White et al studies provided a basis for including all APP instruments in my study, expanding the focus beyond planning for future healthcare alone. Further, they provide insight into relevant interpersonal factors that may influence a person to complete some form of advance planning, and highlight the need to consider all aspects of their wellbeing.

More recently, Detering et al conducted a national prevalence study of Advance Care Directives in several settings, including residential aged care facilities, general practice surgeries and hospitals.[34] They conducted a health record audit for individuals aged 65 and over who were admitted to, or attended, a relevant study site.[35] While this study is highly relevant to my research, given it relates to adults aged 65 and over, it only considers the prevalence of healthcare planning, rather than APP more broadly. Considering the logistics involved in a national study, and the disparate forms of Advance Care Directives across Australian states and territories, the authors examined: common law or non-statutory Advance Care Directives that record an individual's values, goals, preferences and instructions for future care;[36] statutory Advance Care Directives that formally appoint a substitute decision-maker;[37] statutory

[28] Ibid.
[29] Ibid.
[30] Ibid 9–10.
[31] Ben White et al, 'Prevalence and Predictors of Advance Directives in Australia' (2014) 44(10) *Internal Medicine Journal* 975, 976.
[32] Ibid 978.
[33] Ibid.
[34] Detering et al, 'Prevalence and Correlates of Advance Care Directives among Older Australians' (n 6) 2.
[35] Ibid.
[36] Ibid.
[37] Ibid.

Advance Care Directives that explicitly record preferences for care and specific treatment instructions;[38] and other Advance Care Planning documents, extending to any other form of Advance Care Planning not fulfilling the criteria of an Advance Care Directive.[39] Among the 2,285 participants, 29.8% had at least one of the forms of Advance Care Directives included in the study, with 20.9% of these being non-statutory Advance Care Directives.[40] Only 10.9% of respondents had appointed a substitute decision-maker under statute,[41] and only 2.7% had made a statutory Advance Care Directive regarding their preferences for care.[42] Of those participants who had prepared an Advance Care Directive, 47.7% resided in aged care facilities, 15.7% were admitted to hospital, and 3.2% were visiting General Practitioners in the community.[43] In relation to my research, the findings of this study encouraged me to give further consideration to the quality of the prepared instruments and planning processes, including their legal status, whether the person making the document understood when and how it would begin to operate, and whether they had actually spoken about their wishes with people in their support community. All these factors are key to assessing the quality of prepared planning instruments to ensure they can be effectively used in future.

In another study conducted by the same research team, Buck et al analysed data from the 2018 Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services Study.[44] This national project included a survey and audit of health records to gain deeper insight into the 'prevalence, characteristics and accessibility of statutory and non-statutory advance care directives for older people at the point of care in Australian health and residential aged care services'.[45] Importantly, 54% of the participant sites were located in regional (39%) and rural or remote (15%) areas.[46] Of the 100 sites selected, 58 were residential

[38] Ibid. See also Kimberly Buck et al, *Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services* (Report, Advance Care Planning Australia and Austin Health, October 2019) 14–15 <https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3668752> ('*Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services*').
[39] Detering et al, 'Prevalence and Correlates of Advance Care Directives among Older Australians' (n 6) 2.
[40] Ibid 4.
[41] Ibid.
[42] Ibid.
[43] Ibid.
[44] Buck et al, 'Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services' (n 38). See also Siobhan Calafiore, 'Advance Care Directives Frequently Written by Someone Other than the Patient', *Australian Doctor Group* (online, 27 December 2019) <https://www.ausdoc.com.au/news/advance-care-directives-frequently-written-someone-other-patient/>.
[45] Buck et al, 'Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services' (n 38) 8.
[46] Ibid 25.

aged care facilities, 27 were hospitals and 15 were general practice surgeries.[47] A total of 4,187 health records were audited for people aged 65 years and older who attended or resided at a participating site.[48] They found 46.5% of the total records had some form of Advance Care Planning documentation, while 25.3% had created an Advance Care Directive,[49] which is only slightly lower than Detering et al's finding of 29.8%.[50] The inclusion and analysis of regional areas was significant for my purposes, and prompted me to consider factors that may influence older adults living in rural or regional areas with respect to their willingness or ability to engage with APP. However, the limitation of this study to health-based and residential aged care sites highlighted the need to gather data focused on the needs and preferences of older adults living in the community.

3.3.1 Predictive Factors

Existing research has sought to identify the types of people who are most likely to have completed various APP documents. For example, Buck et al found those most likely to have prepared an Advance Care Directive 'were older, female, widowed, born in Australia and/or spoke English'.[51] In their survey of Australian participants accessing health and aged care services, Sellars et al found that the strongest predictive factor for completing some form of Advance Care Planning documentation was having discussed the process with someone else.[52] People living with dementia were no more likely to have an Advance Care Directive than individuals diagnosed with other medical conditions (31.6%). However, only 17% of people living with dementia had appointed a substitute decision-maker.[53]

3.3.2 Quality of APP Documents

A small number of studies have addressed issues regarding the quality of completed documents.[54] Among these studies, quality has been reported as mixed, with only 26.5% of

[47] Ibid 8.
[48] Ibid.
[49] Buck et al, 'Advance Care Directive Prevalence among Older Australians' (n 1) 1312.
[50] Detering et al, 'Prevalence and Correlates of Advance Care Directives among Older Australians' (n 6) 4.
[51] Buck et al, 'Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services' (n 38) 31.
[52] Sellars et al, 'Personal and Interpersonal Factors and their Associations with Advance Care Planning Documentation' (n 1) 1212.
[53] Buck et al, 'Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services' (n 38) 32.
[54] Buck et al, 'Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services' (n 38); Mark I Friedewald and Peter A Cleasby, 'Advance Care Directive Documentation: Issues for Clinicians in New South Wales' (2018) 42(1) *Australian Health Review: A Publication of the Australian*

Advance Care Directives including full details for the person, being their 'full name, date of birth, address, the signature of the person, document date and the signature of a witness'.[55] Friedewald and Cleasby discovered that only 50% of the reviewed Advance Care Directives were valid, with prepared documents varying significantly in length, ranging from two to 18 pages.[56] Over half of the documents included in Buck et al's study were more than three years old.[57] Alarmingly, 18.1% of the total completed Advance Care Directives were invalid, as they had been prepared by another person on behalf of the individual who was not a competent person at the time the document was completed.[58] This figure increased to 30.4% when limited only to those prepared by people in residential aged care facilities.[59] Only 25% of the total invalid Advance Care Directives actually acknowledged discussion had occurred between the individual on whose behalf the Advance Care Directive had been made and the person preparing the document.[60]

3.3.3 Involvement of Professionals

With respect to the involvement of professionals, Rolnick et al[61] found that of the 11 patients aged 70 years and over who were interviewed regarding their experience of creating an Advance Care Directive, six had prepared the document in consultation with a lawyer as it was often incorporated as part of the estate planning process.[62] Even the four participants who completed their Advance Care Directive through a medical clinic had not sought the involvement of health professionals when documenting their wishes.[63] Participants reported that they appreciated lawyers' knowledge of, and attention to, legal requirements, which gave them a sense of assurance that their wishes would be followed in future.[64] Understandably, they did not believe lawyers were equipped to answer health-related questions.[65] Despite the fact that health professionals were not involved in the preparation of any of the Advance Care

Hospital Association 89; Friedemann Nauck et al, 'To what Extent are the Wishes of a Signatory Reflected in their Advance Directive: A Qualitative Analysis' (2014) 15 *BMC Medical Ethics* 1.

[55] Buck et al, 'Advance Care Directive Prevalence among Older Australians' (n 1) 1320.

[56] Friedewald and Cleasby (n 54).

[57] Buck et al, 'Advance Care Directive Prevalence among Older Australians' (n 1) 1318.

[58] Buck et al, 'Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services' (n 38) 39.

[59] Ibid.

[60] Ibid.

[61] Rolnick et al (n 3).

[62] Ibid 528.

[63] Ibid 529.

[64] Ibid.

[65] Ibid.

Directives in Rolnick et al's study, almost all participants said a medical professional's input would have been useful in terms of their knowledge of the patient's health record and a relationship of trust between the parties.[66] However, participants were worried that medical professionals may not follow their indicated preferences if they, in their professional judgement, believed alternative treatment should be administered.[67] These results demonstrate there is not only a clear need but a desire for lawyers and health professionals to be involved in APP with older clients across both legal and health contexts. Involving both health and legal professionals in the preparation of relevant instruments may increase the validity and applicability of APP documents in future circumstances, especially if an older person is living with a particular illness or is facing an anticipated disease trajectory.

3.4 International Research

There is an extant body of international research that examines Advance Care Planning. In 2009, Greenberg et al surveyed 900 adults in the United States to determine prevalence of APP instruments from a risk-reduction perspective.[68] The study included participants aged 25 and over, with no differentiation for those aged 65 and over,[69] which is a limiting factor of this study. Greenberg et al hypothesised four factors would influence the completion of APP: (1) possession of wealth and/or property; (2) a triggering event; (3) personal experience with other forms of risk-reducing behaviour; and (4) a history of self-protection, such as regular check-ups.[70] They found 46% of participants had prepared a Will, 32% had appointed the equivalent of an Enduring Power of Attorney, and 30% had recorded the equivalent of an Advance Care Directive.[71] However, 42% had none of the documents, and only 9% had all three as well as a living trust.[72] Approximately half of the participants who reported making a Will had never reviewed it.[73] This demonstrates that while there is a certain level of engagement with APP, there are very few individuals who are actually aware of, and complete, all of the instruments and appointments that are available. There were a range of predictive factors for appointing an

[66] Ibid 530.
[67] Ibid.
[68] Michael R Greenberg, Marc Weiner and Gwendolyn B Greenberg, 'Risk-Reducing Legal Documents: Controlling Personal Health and Financial Resources' (2009) 29(11) *Risk Analysis* 1578.
[69] Ibid 1578.
[70] Ibid 1579–1580.
[71] Ibid 1578.
[72] Ibid 1581–1582.
[73] Ibid. See also Jane B Baron, 'Fixed Intentions: Wills, Living Wills, and End-of-Life Decision Making' (2020) 87(2) *Tennessee Law Review* 375, 405; Tilse et al, 'Having the Last Word?' (n 23) 20.

Enduring Power of Attorney, including life-threatening experiences, ageing, prompting from others, and self-protection actions. Wealth was not a significant indicator.[74] Similarly, age, having children and enduring life-threatening experiences were strong factors in favour of preparing an Advance Care Directive, but wealth was not significant.[75]

Also in the United States, in 2008 Johnson et al surveyed 205 adults aged 65 and over who were living in the community and highlighted the significance of culture and race with respect to Advance Care Planning and end of life care.[76] When compared with Caucasian cohorts, African Americans were less likely to have prepared an Advance Care Directive and had less positive attitudes towards hospice care.[77] There was a general reluctance across all cohorts to talk about dying, a greater preference for life-prolonging treatment, and a higher emphasis on faith or religious and spiritual values.[78] These results largely mirror the findings from Australian research discussed below, demonstrating a consistency of findings within the available literature with respect to Advance Care Planning for culturally and linguistically diverse older adults.

Musa et al researched public attitudes towards Advance Care Planning among community-dwelling adults aged 65 and over in the United Kingdom.[79] Alarmingly, only 4.6% of the 1,823 participants reported having been given an opportunity to discuss Advance Care Planning.[80] Of the 84 participants who had had this opportunity, 70% subsequently completed a formal Advance Care Planning document.[81] Only 12% had approached someone to discuss their Advance Care Planning preferences, and most frequently reported doing this with friends or family (73%). Only 18% had raised their future care wishes with their General Practitioner.[82] However, 74% felt comforted by the thought that Advance Care Planning would provide

[74] Greenberg, Weiner and Greenberg (n 68) 1583–1584.
[75] Ibid 1582.
[76] Kimberly S Johnson, Maragatha Kuchibhatla and James A Tulsky, 'What Explains Racial Differences in the use of Advance Directives and Attitudes toward Hospice Care?' (2008) 56(10) *Journal of the American Geriatrics Society* 1953. See also Gloria T Anderson, 'Let's Talk about ACP Pilot Study: A Culturally-Responsive Approach to Advance Care Planning Education in African-American Communities' (2021) 17(4) *Journal of Social Work in End-of-Life & Palliative Care* 267; Laura Vearrier, 'Failure of the Current Advance Care Planning Paradigm: Advocating for a Communications-Based Approach' (2016) 28(4) *HEC Forum* 339, 347.
[77] Johnson, Kuchibhatla and Tulsky (n 76) 1956.
[78] Ibid. See also Anderson (n 76) 267–268.
[79] Musa et al (n 1).
[80] Ibid 374.
[81] Ibid.
[82] Ibid.

guidance to their family and health professionals at a later date,[83] while 44% indicated they would leave any decisions to others in the event they could no longer speak for themselves.[84] Overall, 85% trusted their family to make such decisions, and 61% trusted their doctor to do so.[85] An overwhelming majority of respondents preferred to discuss their Advance Care Planning wishes informally, rather than completing a formal record.[86] This reiterates the communicative nature of Advance Care Planning, and APP, and the need to ensure the steps of contemplation and discussion are explicitly encouraged throughout the process. However, these results did not state whether the preference for an informal discussion accounted for a possible lack of knowledge regarding what a formal document can include, for example, how it can be a statement of the person's values and what quality of life means to them, as opposed to a record of end of life treatment preferences.

Nauck et al sought to discover the extent to which a person's wishes are actually reflected in Advance Care Directives in Germany.[87] Participants were aged 55 to 70 years and divided into three groups: healthy adults; those living with chronic illness; and those receiving palliative care.[88] A quarter of the 53 participants reported changing their Advance Care Directive at least once, and people were more likely to seek legal advice than speak with their doctor,[89] similar to the findings of Rolnick et al in their Australian study.[90] Further, 36 participants did not inform their doctor that they had prepared an Advance Care Directive.[91] There was a clear tendency for Advance Care Directives to utilise an online template that was not altered or individualised by a legal professional, which subsequently increased the potential for inconsistencies within the document.[92] However, this lack of personalisation is not necessarily cause for concern, as the Advance Care Directive may never actually be relevant with respect to the medical care they receive, and an appointed decision-maker or proxy could help alleviate any confusion.[93] It should be noted this study is specific to the process of preparing Advance

[83] Ibid.
[84] Ibid.
[85] Ibid.
[86] Ibid.
[87] Nauck et al (n 54).
[88] Ibid 2.
[89] Ibid 3.
[90] Rolnick et al (n 3). See also Musa et al (n 1) 374; Adam D Schickedanz et al, 'A Clinical Framework for Improving the Advance Care Planning Process: Start with Patients' Self-Identified Barriers' (2009) 57(1) *Journal of the American Geriatrics Society* 31, 35.
[91] Nauck et al (n 54) 3. See also Vearrier (n 76) 348.
[92] Nauck et al (n 54) 7.
[93] Ibid 9.

Care Directives in Germany and does not completely align with the position in NSW, but does appear to mirror some of the earlier results regarding a lack of involvement by health professionals in the Advance Care Planning process.

Nauck et al's study was subsequently cited in Otte et al's investigation of the utility of standardised advance directives from the perspective of General Practitioners.[94] The national study of Swiss doctors included qualitative interviews with 23 participants.[95] While General Practitioners are considered best-placed to engage in Advance Care Planning discussions where they have ongoing relationships with patients, this factor can also work against effective communication if they are concerned about the emotional impact such a topic may have on their patient.[96] In these circumstances, templates have high utility to introduce the concept of planning ahead.[97] Despite the various options available for formally recording a patient's wishes, some respondents made it clear 'that it is not the form, but the conversation itself that matters to them. Under this approach, the final document (which they think is too hypothetical anyway) seems to lose some of its importance, while the focus clearly lies on the verbal anamneses of patient's values'.[98] The difficulty of very broad instructions was highlighted by General Practitioners, as patients did not provide sufficient detail that could be effectively relied upon when making treatment decisions.[99] However, the results of the study indicated that patients often recorded their wishes in an Advance Care Directive at home and did not seek the input of their General Practitioner. Consequently, this 'can lead to various difficulties and inaccuracies that can compromise the quality of an [Advance Care Directive]'.[100] In relation to my research, these results highlighted the need to consider several cohorts, including legal and health professionals as well as older adults, when collecting and analysing data on APP. Including these various perspectives has allowed my research to provide a more holistic perspective of the process of APP, rates of prevalence, perceived quality of instruments and

[94] Ina Carola Otte et al, 'The Utility of Standardized Advance Directives: The General Practitioners' Perspective' (2016) 19(2) *Medicine, Health Care and Philosophy* 199.
[95] Ibid 200.
[96] Ibid 201. See also Vearrier (n 76) 350; Richard L Kaplan, 'Elder Law as Proactive Planning and Informed Empowerment during Extended Life' (2010) 40(1) *Stetson Law Review* 15, 21.
[97] Otte et al (n 94) 201, 203.
[98] Ibid 203.
[99] Ibid 204.
[100] Ibid.

difficulties associated with implementing the prepared documents, with my results being informed by both professional expertise and personal experiences.

3.5 What is the Relevance of APP for Older Adults?

The specific circumstances of older adults can give rise to particular or additional needs when compared with other population groups.[101] Certain lifecycle factors that may affect people as they age must be considered, such as the physical and mental effects of the ageing process, social perceptions or expectations of ageing populations, retirement or exclusion from the workforce, changing financial circumstances, changing family circumstances, continuing or increased family or carer responsibilities, increased health concerns, changing accommodation, ageism and discussion of end of life.[102] These factors, while common ageing-related concerns, indicate the need for older adults to consider how they would like to live the rest of their life, taking into account their health, when they might retire, their financial needs and social connections.

As such, APP has particular significance for older Australians. Many older adults, defined as those aged 65 years and over,[103] are at risk of periodic, temporary or permanent loss of

[101] Buck et al, 'Advance Care Directive Prevalence among Older Australians' (n 1); Close et al (n 11); Detering et al, 'Prevalence of Advance Care Planning Documentation and Self-Reported Uptake' (n 1); Detering et al, 'Organisational and Advance Care Planning Program Characteristics' (n 1); Craig Sinclair et al, 'Association Between Region of Birth and Advance Care Planning Documentation Among Older Australian Migrant Communities: A Multicenter Audit Study' (2021) 76(1) *The Journals of Gerontology: Series B* 109 ('Association Between Region of Birth and Advance Care Planning Documentation'); Nouri et al (n 1); Sellars et al, 'Personal and Interpersonal Factors and their Associations with Advance Care Planning Documentation' (n 1); Buck et al, 'Concordance Between Self-Reported Completion of Advance Care Planning Documentation and Availability of Documentation' (n 1); Karen Detering et al, 'Feasibility and Acceptability of Advance Care Planning in Elderly Italian and Greek Speaking Patients as Compared to English-Speaking Patients: An Australian Cross-Sectional Study' (2015) 5(8) *BMJ Open* e008800:1-7 ('Feasibility and Acceptability of Advance Care Planning in Elderly Italian and Greek Speaking Patients'); Hillary D Lum, Rebecca L Sudore and David B Bekelman, 'Advance Care Planning in the Elderly' (2015) 99(2) *Medical Clinics of North America* 391.

[102] Sarah Ellison et al, *The Legal Needs of Older People in NSW* (Report, Law and Justice Foundation of New South Wales, December 2004) 2–3 <https://lawfoundation.net.au/wp-content/uploads/2023/11/54PJR_The-legal-needs-of-older-people-in-NSW_2004.pdf>. See also Buck et al, 'Advance Care Directive Prevalence among Older Australians' (n 1); Close et al (n 11); Detering et al, 'Prevalence of Advance Care Planning Documentation and Self-Reported Uptake' (n 1); Carmelle Peisah et al, 'IPA and WPA-SOAP Joint Statement on the Rights of Older Persons with Mental Health Conditions and Psychosocial Disabilities' (2022) 34(11) *International Psychogeriatrics* 943; Nouri et al (n 1); Detering et al, 'Feasibility and Acceptability of Advance Care Planning in Elderly Italian and Greek Speaking Patients' (n 101).

[103] Australian Institute of Health and Welfare, *Australia's Welfare 2019: Data Insights* (Australia's Welfare Series No 14. Catalogue No AUS 226, 2019) 48 <https://www.aihw.gov.au/reports/australias-welfare/australias-welfare-2019-data-insights/data>.

capacity,[104] as cognitive ageing and conditions such as dementia are more prevalent.[105] However, capacity issues are not always identified or managed appropriately.[106] This subsequently heightens the risk that, in the absence of APP, decisions will be made in future that do not align with the wishes or values of the older person.[107] The consequences may be severe, as older adults in these circumstances 'are more likely to experience loss of control, unwanted medical interventions and poorer quality of life as they deal with deteriorating health and reduced independence, and be vulnerable to financial exploitation'.[108]

Older people may also encounter difficulties in appointing a suitable decision-maker due to strained family relationships, lack of trusted friends[109] or social isolation.[110] Discussions regarding Advance Care Planning can be very difficult to maintain if the person is seeing multiple health professionals for a variety of conditions, which can lead to fragmented quality of care and oversight.[111] The limited data that are currently available suggests that APP does

[104] See, eg, Karen Sullivan and Kelly Purser, 'Developing and Piloting the Consumer Experience of Capacity Assessment Tool (CECAT)' (2022) 29(5) *Psychiatry, Psychology and Law* 752, 752–753.

[105] Lum, Sudore and Bekelman (n 101) 399. See also Bryant et al, 'Advance Care Planning Participation by People with Dementia' (n 5); Sinclair et al, 'Professionals' Views and Experiences in Supporting Decision-Making Involvement' (n 2); Sellars et al, 'Perspectives of People with Dementia and Carers on Advance Care Planning and End-of-Life Care' (n 5); Blake, Doray and Sinclair (n 5); Billingsley Kaambwa et al, 'Costs and Advance Directives at the End of Life: A Case of the "Coaching Older Adults and Carers to Have Their Preferences Heard (COACH)" Trial' (2015) 15 *BMC Health Services Research* 545:1–12.

[106] Sinclair et al, 'Professionals' Views and Experiences in Supporting Decision-Making Involvement' (n 2) 85; Kelly Purser and Karen Sullivan, 'Capacity Assessment and Estate Planning - The Therapeutic Importance of the Individual' (2019) 64 *International Journal of Law and Psychiatry* 88, 88–89; Paul A Gardiner et al, 'Financial Capacity in Older Adults: A Growing Concern for Clinicians' (2015) 202(2) *The Medical Journal of Australia* 82, 84–85; Kelly J Purser and Tuly Rosenfeld, 'Evaluation of Legal Capacity by Doctors and Lawyers: The Need for Collaborative Assessment' (2014) 201(8) *The Medical Journal of Australia* 483, 483; Laura L Sessums, Hanna Zembrzuska and Jeffrey L Jackson, 'Does This Patient Have Medical Decision-Making Capacity?' (2011) 306(4) *JAMA* 420; E Helmes, VE Lewis and A Allan, 'Australian Lawyers' Views on Competency Issues in Older Adults' (2004) 22(6) *Behavioral Sciences & The Law* 823, 824.

[107] Nola M Ries, Briony Johnston and Shaun McCarthy, 'Legal Education and the Ageing Population: Building Student Knowledge and Skills through Experiential Learning in Collaboration with Community Organisations' (2016) 37 *Adelaide Law Review* 495, 497.

[108] Ibid. See also R Sean Morrison, Diane E Meier and Robert M Arnold, 'What's Wrong with Advance Care Planning?' (2021) 326(16) *JAMA* 1575, 1575; Moore et al (n 11) 9; Rodney Lewis, 'Addressing Elder Abuse in Australia: The Case for an Elder Justice Law' (2018) 148 *Precedent* 41, 42.

[109] Morrison, Meier and Arnold (n 108) 1576; Sinclair et al, 'Professionals' Views and Experiences in Supporting Decision-Making Involvement' (n 2) 91; The Law Society of New South Wales, *Elder Abuse of Clients – What Supports Can Solicitors Offer?* (Guidelines, September 2020) 1; Australian Law Reform Commission (n 103) 161; Lum, Sudore and Bekelman (n 101) 399; Craig Sinclair et al, 'A Public Health Approach to Promoting Advance Care Planning to Aboriginal People in Regional Communities' (2014) 22(1) *Australian Journal of Rural Health* 23, 25 ('A Public Health Approach to Promoting Advance Care Planning to Aboriginal People').

[110] Nouri et al (n 1) 7; The Law Society of New South Wales (n 109) 1; Lewis (n 108) 42; Lum, Sudore and Bekelman (n 101) 399.

[111] Hui Yun Chan, 'Video Advance Directives: A Turning Point for Advance Decision-Making? A Consideration of their Roles and Implications for Law and Practice' (2020) 41 *Liverpool Law Review* 1, 8; Lum, Sudore and Bekelman (n 101) 399; Kritika Samsi and Jill Manthorpe, '"I Live for Today": A Qualitative Study Investigating Older People's Attitudes to Advance Planning' (2011) 19(1) *Health & Social Care in the Community* 52, 57.

not occur in a systematic way, with low and variable uptake among older adults.[112] Despite high rates of preparation, Wills are often out of date and do not reflect current assets, intentions or family circumstances, increasing the likelihood of disputes.[113] While these are clear barriers for older adults who are wishing to engage in APP, they also highlight the need for high quality planning to help guard against future uncertainties relating to health, legal and financial circumstances involving the older person.

Similarly, there are what Ellison et al[114] describe as 'cohort effects' that 'distinguish the present group of older people from the cohorts born before and after them'.[115] These cohort effects include having lower levels of education and potentially lower rates of literacy; different employment trajectories that have been far more stable than for future cohorts, given the constantly changing workforce; higher retirement age with less superannuation and better opportunities to receive a government pension; more likely to own their own homes; lower divorce rates; more likely to have had children who have left home and were independent earlier; and potential technological challenges.[116] Additional factors that can increase disadvantage for older adults include ethnicity,[117] changing family circumstances, place of

[112] Anderson (n 76) 270; Carney et al (n 2) 83; Detering et al, 'Organisational and Advance Care Planning Program Characteristics' (n 1) 1–2; McIlfatrick et al (n 9) 1356; Rodi et al (n 3) 3678; Australian Healthcare Associates (n 11) 18; Ries, Johnston and McCarthy (n 107) 500; Detering et al, 'Feasibility and Acceptability of Advance Care Planning in Elderly Italian and Greek Speaking Patients' (n 101) 4; Marcus Sellars, Karen M Detering and William Silvester, 'Current Advance Care Planning Practice in the Australian Community: An Online Survey of Home Care Package Case Managers and Service Managers' (2015) 14 *BMC Palliative Care* 15:1–7; Joel J Rhee, Nicholas A Zwar and Lynn A Kemp, 'Uptake and Implementation of Advance Care Planning in Australia: Findings of Key Informant Interviews' (2012) 36(1) *Australian Health Review* 98, 99 ('Uptake and Implementation of Advance Care Planning in Australia').

[113] Tilse et al, 'Having the Last Word?' (n 23). See also Ben White et al, 'Estate Contestation in Australia: An Empirical Study of a Year of Case Law' (2015) 38(3) *UNSW Law Journal* 880; Ellison et al (n 102).

[114] Ellison et al (n 102). See also Sellars et al, 'Personal and Interpersonal Factors and their Associations with Advance Care Planning Documentation' (n 1) 1214–1215.

[115] Ellison et al (n 102) 3.

[116] Ibid 3–4. See also Pascoe Pleasence, Nigel J Balmer and Catrina Denvir, 'Legal Information and Advice in the Information Age' in *How People Understand and Interact with the Law* (The Legal Education Foundation, 2015) 133, 155.

[117] Anderson (n 76); Sinclair et al, 'Association Between Region of Birth and Advance Care Planning Documentation' (n 101); Emma Spencer and Eswaran Waran, 'Opening the Lines of Communication: Towards Shared Decision Making and Improved End-of-life Care in the Top End' (2020) 213(1) *The Medical Journal of Australia* 10; Australian Healthcare Associates (n 11); NSW Health, *NSW Plan for Healthy Culturally and Linguistically Diverse Communities: 2019-2023* (Policy Directive No PD2019_018, May 2019) <https://www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2019_018.pdf>; Sandra Thompson et al, 'Passing on Wisdom: Exploring the End-of-Life Wishes of Aboriginal People from the Midwest of Western Australia' (2019) 19(4) *Rural and Remote Health* 5444:1–9; Amanda Pereira-Salgado, Patrick Mader and Leanne M Boyd, 'Advance Care Planning, Culture and Religion: An Environmental Scan of Australian-Based Online Resources' (2018) 42(2) *Australian Health Review* 152; Eswaran Waran, Sharon Wallace and Jonathan Dodson-Jauncey, 'Failing to Plan Is Planning to Fail: Advance Care Directives and the Aboriginal People of the Top End' (2017) 206(9) *The Medical Journal of Australia* 377; Detering et al, 'Feasibility and Acceptability of Advance Care Planning in Elderly Italian and Greek Speaking Patients' (n 101); Sinclair et al, 'A Public Health Approach

residence including regional areas, income, accommodation and health concerns.[118] Higher levels of dependency and increased isolation, especially for older adults from culturally and linguistically diverse backgrounds,[119] may also negatively impact older adults,[120] which can give rise to circumstantial or contextual vulnerability.[121] Older adults may also have higher expectations of the law's ability to solve problems they are experiencing,[122] and if these expectations are not met, there may be a feeling of disempowerment.[123] These factors highlighted the need for research to pay attention to the various aspects of an older adult's life that may impact their willingness or ability to engage with APP. Factors such as place of residence, limited social connections, lack of trusted family members and difficulty accessing local services were all key points of focus in my interviews with older people.

3.5.1 Older Adults in Regional Areas

Where older adults choose to live has significance not only for their ability to access services,[124] but also behavioural factors,[125] such as education levels, use of health services and an older

to Promoting Advance Care Planning to Aboriginal People' (n 109); Johnson, Kuchibhatla and Tulsky (n 76); Austin Health, *Respecting Patient Choices: Advance Care Planning with Aboriginals and Torres Strait Islanders* (Report, 2006) <https://www.acrrm.org.au/docs/default-source/all-files/aboriginal_torres_strait_islander_advance_care_planning.pdf?sfvrsn=7d61dcc5_2>.

[118] Ellison et al (n 102) 5–11. See also Buck et al, 'Advance Care Directive Prevalence among Older Australians' (n 1); Rodi et al (n 3); Sellars et al, 'Personal and Interpersonal Factors and their Associations with Advance Care Planning Documentation' (n 1); Karen M Detering et al, 'Prospective Multicentre Cross-Sectional Audit among Older Australians Accessing Health and Residential Aged Care Services: Protocol for a National Advance Care Directive Prevalence Study' (2019) 9(10) *BMJ Open* e031691:1-10.

[119] D Visala Rao, Jeni Warburton and Helen Bartlett, 'Health and Social Needs of Older Australians from Culturally and Linguistically Diverse Backgrounds: Issues and Implications' (2006) 25(4) *Australasian Journal on Ageing* 174, 177. See also Sinclair et al, 'Association Between Region of Birth and Advance Care Planning Documentation' (n 101) 111; NSW Health (n 117) 5; Pereira-Salgado, Mader and Boyd (n 117) 160; Detering et al, 'Feasibility and Acceptability of Advance Care Planning in Elderly Italian and Greek Speaking Patients' (n 101); Sarah Jeong et al, '"Planning Ahead" among Community-Dwelling Older People from Culturally and Linguistically Diverse Background: A Cross-Sectional Survey' (2015) 24 *Journal of Clinical Nursing* 244.

[120] Lum, Sudore and Bekelman (n 101) 399; Ellison et al (n 102).

[121] Australian Association of Gerontology and Older Persons Advocacy Network, *Submission on Australian Guardianship and Administration Council National Elder Abuse Project: Best Practice Resource on Enduring Appointments* (Submission, 6 August 2019) 2. See also NSW Health (n 117) 5, 11; Lise Barry, 'Capacity and Vulnerability: How Lawyers Assess the Legal Capacity of Older Clients' (2017) 25(1) *Journal of Law and Medicine* 267, 270; MI Hall, 'Equity Theory: Responding to the Material Exploitation of the Vulnerable but Capable' in Israel Doron (ed), *Theories on Law and Ageing: The Jurisprudence of Elder Law* (Springer, 2009) 107.

[122] Ellison et al (n 102) 32–33.

[123] Ibid 36.

[124] Karly B Smith, John S Humphreys and Murray GA Wilson, 'Addressing the Health Disadvantage of Rural Populations: How does Epidemiological Evidence Inform Rural Health Policies and Research?' (2008) 16(2) *Australian Journal of Rural Health* 56, 57; Rao, Warburton and Bartlett (n 119) 175.

[125] Smith, Humphreys and Wilson (n 124) 57; Thomas A Arcury et al, 'The Effects of Geography and Spatial Behavior on Health Care Utilization among the Residents of a Rural Region' (2005) 40(1) *Health Services Research* 135, 135.

person's lifestyle.[126] Geographic location, combined with these behavioural factors, may result in a lack of social support and fewer opportunities for interactions with trusted people, including legal and health professionals.[127] Longer distances to travel and fewer transportation options also contribute to difficulties accessing health care.[128] Rates of health disadvantage are higher in rural areas, which contribute to increased hospitalisation, a greater range of risk factors and less access to health services.[129] This also leads to extended consequences, such as unmet health needs and limited to no continuity of care for the individuals involved.[130] Physical factors, including decreased mobility, contribute to an inability or difficulty in accessing support services.[131] Lack of financial resources, higher rates of unemployment, lower levels of education and language difficulties for residents from culturally and linguistically diverse backgrounds are all relevant influences on their completion of APP instruments.[132] There may be a preference among individuals from culturally and linguistically diverse backgrounds to care for relatives at home, rather than accessing aged care services.[133] Similarly, individuals from culturally and linguistically diverse communities have been found to exhibit lower rates of person-completed APP and prefer involvement of family or loved ones in the planning process.[134]

While the needs and preferences of culturally and linguistically diverse communities are not a specific focus of my research, some relevant studies deserve mention. Jeong et al surveyed 171 adults aged 65 years and over who came from culturally and linguistically diverse backgrounds to learn more about their experiences with Advance Care Planning.[135] Results indicated 37.5% of individuals from Anglo Celtic backgrounds had appointed an Enduring Guardian, while only 15.5% from Mediterranean, 24.1% from Eastern European and 13.3% from Asia Pacific

[126] Smith, Humphreys and Wilson (n 124) 60.
[127] Nouri et al (n 1) 7; Rao, Warburton and Bartlett (n 119) 176.
[128] Smith, Humphreys and Wilson (n 124) 57; Arcury et al (n 125) 136.
[129] John Wakerman et al, 'Primary Health Care Delivery Models in Rural and Remote Australia – A Systematic Review' (2008) 8 *BMC Health Services Research* 276:1–10, 2.
[130] Close et al (n 11) 2; Wakerman et al (n 129) 2.
[131] Arcury et al (n 125) 137.
[132] Sinclair et al, 'Association Between Region of Birth and Advance Care Planning Documentation' (n 101) 111; Australian Healthcare Associates (n 11) 1; NSW Health (n 117) 5; Vearrier (n 76) 347; Detering et al, 'Feasibility and Acceptability of Advance Care Planning in Elderly Italian and Greek Speaking Patients' (n 101) 4; Smith, Humphreys and Wilson (n 124) 59; Rao, Warburton and Bartlett (n 119) 175.
[133] Spencer and Waran (n 117) 11; Thompson et al (n 117) 5; Waran, Wallace and Dodson-Jauncey (n 117) 377; Sinclair et al, 'A Public Health Approach to Promoting Advance Care Planning to Aboriginal People' (n 109) 23, 25; Austin Health (n 117) 6; Rao, Warburton and Bartlett (n 119) 177.
[134] Sinclair et al, 'Association Between Region of Birth and Advance Care Planning Documentation' (n 101).
[135] Jeong et al (n 119) 244.

backgrounds had done so.[136] While Will making was more prevalent for all groups, there were still differences in usage, with 83.9% of Anglo Celtic, 77.5% of Mediterranean, 72.4% of Eastern European and 53.3% of Asia Pacific backgrounds reporting they had completed this form of planning.[137] Advance Care Directives were far less common among all respondents, with only 14% of Anglo Celtic, under 3% of Mediterranean, only one Eastern European participant and no one from Asia Pacific backgrounds indicating they had one.[138] Levels of knowledge were also low among respondents, with 75.9% indicating they had never heard of Advance Care Directives, 79.6% reported they did not know about Advance Care Planning, and only 44.4% were familiar with Enduring Guardian appointments.[139] Of those who were aware of Advance Care Directives and Advance Care Planning generally, the most common sources of this information were, in the following order: doctors, family, media, friends and nurses.[140] These respondents also indicated the main challenges to completing an Advance Care Directive or engaging in Advance Care Planning were: having sufficient time; feeling it was difficult to talk about it with family; they were not sure what it was; they didn't know what to do; they weren't sure who to talk to; or the instruments were too hard to understand.[141] Similarly, Sinclair et al's muti-centre audit study found individuals who were born in Australia were more likely to have completed their own Advance Care Directive,[142] exhibiting a level of individuality that was often out of reach for people belonging to culturally and linguistically diverse communities, where decision-making is more often community- or family-based.[143]

These studies enhance the understanding of prevalence rates and predictive factors for the different types of advance planning instruments, revealing disparate usage. The focus tends to be either on Will making or Advance Care Planning, with a lack of consideration of APP as a whole. Similarly, population groups included in existing studies have either been extremely broad, such as adults aged 18 years or older, or very narrow, such as patients living with specific health conditions. This reveals a gap relating to what is known about APP for adults aged 65 years and over living in the community, as well as older adults who are living in regional areas.

[136] Ibid 249.
[137] Ibid.
[138] Ibid.
[139] Ibid.
[140] Ibid 249–250.
[141] Ibid 250.
[142] Sinclair et al, 'Association Between Region of Birth and Advance Care Planning Documentation' (n 101) 114–115.
[143] Ibid 117–118.

My research addresses these gaps and provides new insights, predictive factors and attitudes towards APP from the perspective of older adults living in regional areas of NSW as well as professional key informants.

3.6 Older Adults' Perspectives of APP Processes

Several Australian and international studies have explored older people's perceptions and experiences of the APP process. Malcomson and Bisbee interviewed healthy older adults aged between 60 and 94 to learn more about their views of Advance Care Planning.[144] They found that while participants were enthusiastic about discussing their wishes for their final years, they did not want to make those around them uncomfortable by raising the topic.[145] This meant that while older adults felt well prepared for their death, they were not necessarily well prepared for the process of dying.[146] Further, many older adults believed that those close to them were aware of their preferences, even if they had not been formally recorded.[147] Continuity of care with a regular doctor was preferred, as it carried the added benefit of trust that the health professional would know and respect their Advance Care Planning preferences.[148] Malcomson and Bisbee is one of the few publications that acknowledges the role of lawyers in the broad Advance Care Planning process, rather than simply approaching the research from a health perspective, with respondents noting that their lawyer was often the first person to raise Advance Care Planning with them.[149] The results also support the previous assertions that informal communication is a vital component of both Advance Care Planning and APP, and represents an important step in the overall planning process.[150] Accordingly, I made sure to include communication-based questions in my research instruments, asking whether older adults had talked about their wishes with their support community, and whether professionals routinely encouraged this type of communication when meeting with their older patients and clients.

[144] Malcomson and Bisbee (n 4).
[145] Ibid 20.
[146] Ibid 19, 21.
[147] Ibid 19.
[148] Ibid.
[149] Ibid 21. See also Ries et al (n 8).
[150] Cameron et al (n 16).

The experiences, preferences and knowledge of Advance Care Planning among cancer patients has recently been studied by Detering et al[151] and Rodi et al.[152] Detering et al combined a multi-centre audit of available health records with a self-report survey of adults aged 65 years and over who were living with cancer to compare rates of purported Advance Care Directive completion with the actual presence of Advance Care Planning documents in medical records.[153] While 58% of respondents to the survey believed they had completed some form of Advance Care Planning documentation, only 30% of the audited records actually contained an Advance Care Directive.[154] These rates of concordance were considered only fair, yet 72% of participants had engaged in conversations with someone close to them about their preferences for future care.[155] Through a national survey of people with cancer and their support people, Rodi et al found just under half of the respondents were aware of Advance Care Planning before participating in the study, while 65% had talked about their preferences with another person.[156] However, only 33% had taken the step of formally documenting their preferences.[157] These findings mirror previous discussion, supporting the recommendation that Advance Care Planning be introduced as early as possible and form part of the ongoing treatment journey for individuals, especially people who are living with a chronic or terminal illness, so they are given ample opportunities to discuss and refine their preferences for future treatment and decision-making processes.

A significant proportion of the literature examining older people's views of APP has focused specifically on Advance Care Planning for people living with dementia.[158] Yapp et al conducted semi-structured telephone interviews with 82 participants.[159] Their results echo best practice advice that Advance Care Planning should commence as early as possible following a diagnosis of dementia, and that further support may be needed to allow the person to meaningfully participate in decision-making for as long as they are able.[160] A broader focus should also be adopted, taking into account not only end of life considerations but also how the person would

[151] Detering et al, 'Prevalence of Advance Care Planning Documentation and Self-Reported Uptake' (n 1).
[152] Rodi et al (n 3).
[153] Detering et al, 'Prevalence of Advance Care Planning Documentation and Self-Reported Uptake' (n 1) 274.
[154] Ibid 276.
[155] Ibid 276–277.
[156] Rodi et al (n 3) 3677.
[157] Ibid 3686.
[158] Gail Yapp et al, 'Planning for the Rest-of-Life, Not End-of-Life: Reframing Advance Care Planning for People with Dementia' in Gaynor Macdonald and Jane Mears (eds), *Dementia as Social Experience: Valuing Life and Care* (Routledge, 1st ed, 2018) 134.
[159] Ibid 138.
[160] Ibid 138–139.

like to continue living following their diagnosis.[161] Yapp et al's conceptualisation of autonomy, which goes beyond an individualistic approach to one that promotes values-based discussion and acknowledges the significance of family relationships,[162] will be discussed further in the following chapter. This conceptualisation not only relieves some of the emotional burden carried by family members, but is also more likely to be acceptable to a wider variety of communities, including those from culturally and linguistically diverse backgrounds.[163] This process also allows for increased and longer involvement of the person living with dementia in decision-making processes, and can potentially reduce conflict for those who are called upon to make decisions on behalf of the person.[164] Overall, Yapp et al recommend a more personal Advance Care Planning process to increase engagement for people living with dementia and those who are close to them.[165] The shift in focus from end of life care to personal values is a notable distinction.[166] A focus on prioritising the individual, their values and their involvement is also emphasised by the Australian Guardianship and Administration Council in their best practice guidelines for tribunals when making decisions for people who lack decision-making capacity.[167]

3.7 Professional Perspectives

Ries et al have conducted one of the few studies that examines the views of lawyers, and their practices, in relation to assisting clients with Advance Care Planning.[168] In this Canadian study, predictive factors for lawyers discussing Advance Care Planning with clients include the client engaging in other forms of APP, experiencing poorer health in general or having received a serious diagnosis, caring for someone whose health is declining or acting as a substitute decision-maker, or having been prompted by family, friends or media campaigns.[169] With

[161] Ibid 140–146.
[162] Ibid 147.
[163] Ibid.
[164] Ibid 148. See also Australian Guardianship and Administration Council, *You Decide Who Decides: Making an Enduring Power for Financial Decisions* (Report, Victorian Office of the Public Advocate, October 2019) 8 <https://www.agac.org.au/assets/documents/Other-Publications/You-Decide-Who-Decides.pdf>, which lists avoidance of family conflict as a key benefit of creating an EPA.
[165] Yapp et al (n 158) 149.
[166] Ibid.
[167] Australian Guardianship and Administration Council, *Maximising the Participation of the Person in Guardianship Proceedings: Guidelines for Australian Tribunals* (Final Report, June 2019) <https://www.agac.org.au/assets/documents/Guidelines/AGAC-Best-Practice-Guidelines-2019-without-annexures.pdf>.
[168] Ries et al (n 8).
[169] Ibid 688–689.

respect to barriers, 73% of respondents indicated that a client's unwillingness to discuss Advance Care Planning was a significant impediment.[170] A majority of participants did not find Advance Care Planning conversations to be difficult from an emotional perspective, and only 20% of respondents stated that time and costs incurred by clients may be a barrier to further engagement.[171] Less than half of the lawyers surveyed indicated they were concerned by a lack of personal knowledge regarding 'medical aspects of Advance Care Planning and health sector policies and practices',[172] while a 'strong majority of respondents expressed confidence in their knowledge of the law relevant to ACP [Advance Care Planning]'.[173] According to these results, lawyers may engage in the communicative aspects of Advance Care Planning with their clients, as an extension of their existing APP discussions. This research explicitly highlights the siloed nature of the medical and legal fields; as Ries et al explain, 'it is not standard practice for lawyers to encourage their clients to discuss their health care wishes with their doctor. Lawyers also do not see liaising with health care providers as part of their professional role'.[174] Ries et al state there is a need to unite best practice approaches and engage in further interprofessional collaboration and training to bridge this gap between the professions, ultimately providing a more holistic approach to Advance Care Planning and, by extension, APP.[175] Their work has led to the development of a public website that promotes APP, and provides planning resources and links to interprofessional education sessions involving legal and health practitioners.[176]

More recently, Orsatti has stressed the significant role lawyers can play in planning processes.[177] In reference to how frequently lawyers prepare Advance Care Planning documents, Orsatti suggests this provides the ideal opportunity for clients to discuss their healthcare preferences and goals for future care with their lawyers.[178] While this level of involvement has been criticised by health professionals due to the lack of medical knowledge possessed by lawyers, Orsatti argues there are several advantages that arise from this approach, including: the ability to provide ongoing support to clients with less time constraints than healthcare professionals; ensuring clients are selecting the best appointed decision-maker to

[170] Ibid 690.
[171] Ibid 691.
[172] Ibid.
[173] Ibid.
[174] Ibid 695. See also Barry (n 121) 282.
[175] Ries et al (n 8) 695.
[176] 'Plan Ahead', *Compassionate Alberta* (Web Page, 2024) <https://compassionatealberta.ca/plan-ahead>.
[177] Orsatti (n 13).
[178] Ibid 157.

support their wishes in future; encouraging communication between the client and people close to them, including family and professionals; creating documents that comply with relevant laws; and providing information for appointed decision-makers to support them in their role.[179] Orsatti stresses the benefits of communication and interprofessional collaboration, recognising the benefits of a combined approach to advance planning:

> Collaboration with medical professionals may help attorneys better understand how to draft meaningful and effective documents. … Medical-legal collaborations and training programs have the capacity to benefit the legal profession and the public by informing attorneys about which advance care planning practices are most helpful to patients and clinicians, thereby improving the efficacy of attorney-facilitated advance care plans. Similarly, through such partnerships, healthcare professionals may gain from the expertise that legal professionals offer.[180]

Recently, Rhee et al completed a national cross-sectional survey of General Practitioners in Australia to assess their attitude regarding the inclusion of Advance Care Planning within the annual 75+ Health Assessment.[181] The 75+ Health Assessment is a Medicare funded appointment, allowing for an in-depth consultation that 'provides a structured way of identifying health issues and conditions that are potentially preventable or amenable to interventions in order to improve health and/or quality of life'.[182] Participants were explicitly asked about the importance of assessing both legal and health planning instruments as part of the 75+ Health Assessment.[183] Of the 185 participants, 60% responded that discussing legal and health issues, including the completion of an Advance Care Directive and appointment of an Enduring Guardian and Enduring Power of Attorney, is 'essential' and should be completed at every health assessment.[184] Interestingly, 82% of respondents believed a nurse or General Practitioner could engage in this discussion during the health assessment, with only 18% asserting these discussions should only be completed by a General Practitioner.[185] This evident support for discussing both legal and health instruments provides a clear opportunity for further

[179] Ibid 158–160.
[180] Ibid 164.
[181] Joel Rhee et al, 'Exploring Patients' Advance Care Planning Needs during the Annual 75+ Health Assessment: Survey of Australian GPs' Views and Current Practice' (2023) 29(6) *Australian Journal of Primary Health* 637.
[182] 'Health Assessment for People Aged 75 Years and Older', *Department of Health and Aged Care* (Web Page, 10 April 2014) <https://www1.health.gov.au/internet/main/publishing.nsf/Content/mbsprimarycare_mbsitem_75andolder>.
[183] Rhee et al (n 181) 638.
[184] Ibid 640.
[185] Ibid.

interprofessional collaboration between lawyers and healthcare professionals, including General Practitioners and nurses. The inclusion of both lawyers and healthcare professionals is a key foundation of my research, addressing this distinct and continuing gap in the available literature. The combination of professionals and the exploration of their perspectives as key informants has been crucial to my understanding of existing APP processes, relevant barriers and understanding opportunities for improvement. It has also informed my development of recommendations that are linked to individual, professional and societal levels, providing a holistic perspective of, and approach to, improving APP.

Blake et al conducted interviews with health professionals involved in the care of people living with dementia. Despite an acknowledgement that the autonomy of the person must be prioritised, Blake et al found that Advance Care Planning is generally conducted in a context of risk minimisation and negotiation towards the 'most agreeable outcome'.[186] This approach allows for a high level of collaboration between the person living with dementia and those who care for them, and seeks to prioritise the therapeutic process for all involved.[187] However, striving for this outcome may also divert attention from the person living with dementia to the concerns of others, undermining the need to prioritise the person's wishes, values and preferences for truly person-centred care.[188] These concepts are directly applicable to the broader process of APP as encompassing a holistic view of the individual, including healthy older adults who are residing in the community. While my research has not focused on dementia, these studies have helped me to identify factors that are universally relevant for older adults, including how their personal circumstances, values and relationships with people in their support community should inform a decision-making process where their voice is prioritised with as little interference as possible.

3.8 Deficiencies in Planning Processes

While it is important to understand current rates of prevalence and attitudes towards advance planning from the existing literature, it is even more significant to recognise deficiencies in current planning systems. In my research, analysing deficiencies highlighted in previous studies relating to Advance Care Planning has allowed for a critical evaluation of these barriers

[186] Blake, Doray and Sinclair (n 5) 210.
[187] Ibid 211.
[188] Ibid.

from the perspective of both older adults and professional key informants. Based on this analysis, I was able to ask my participants how these deficiencies operate and how APP can be improved from the perspective of older adults engaging with APP and key informant professionals working in this area. I have divided the perceived deficiencies into three distinct levels: (1) barriers to engagement; (2) factors affecting the quality of prepared instruments; and (3) barriers to future use. This comprehensive examination of deficiencies aligns with the understanding of APP as a stepped and continuous process, and highlights concerns that both professionals and older adults can be mindful of at every stage of the planning process.

3.8.1 Barriers to Engagement with APP

3.8.1.1 Lack of knowledge and understanding of legal instruments

Lack of knowledge or understanding of the various instruments, their key purposes and how they operate has been documented extensively in the literature on Advance Care Planning,[189] and is also relevant within the broader context of APP. While there is a clear need to improve knowledge and understanding of APP mechanisms through education and other interventions, for both older people and professionals, these factors must also be addressed within the context of other barriers that may prevent individuals from engaging in forms of APP. The barrier presented by lack of knowledge extends not only to those seeking to complete forms of APP,[190]

[189] Sinclair et al, 'Association Between Region of Birth and Advance Care Planning Documentation' (n 101) 111; Baron (n 73) 384–385; Pascoe Pleasence, Nigel J Balmer and Catrina Denvir, 'Why do I need a Will Anyway? Assessing the Impact of a Public Legal Education Intervention Embedded in a Longitudinal Survey' (2019) 18(2) *Social Policy and Society* 187; Rolnick et al (n 3) 526; Sophie Trarieux-Signol et al, 'Advance Directives from Haematology Departments: The Patient's Freedom of Choice and Communication with Families. A Qualitative Analysis of 35 Written Documents' (2018) 17 *BMC Palliative Care* 10:1-12; Amy Waller et al, 'Increasing Advance Personal Planning: The Need for Action at the Community Level' (2018) 18(1) *BMC Public Health* 606:1–8; Ries, Johnston and McCarthy (n 107) 500; Kaambwa et al (n 105); Sellars, Detering and Silvester (n 112); Tilse et al, 'Having the Last Word?' (n 23) 9–10; Nauck et al (n 54); Ian A Scott et al, 'Difficult but Necessary Conversations — The Case for Advance Care Planning' (2013) 199(10) *The Medical Journal of Australia* 662, 663; Rhee, Zwar and Kemp, 'Uptake and Implementation of Advance Care Planning in Australia' (n 112) 99.

[190] Carney et al (n 2); John Chesterman and Lois Bedson, *Decision Time: Activating the Rights of Adults with Cognitive Disability* (Report, Office of the Public Advocate, 15 February 2021) 112 <https://apo.org.au/node/314188>; Marcus Sellars et al, 'Public Knowledge, Preferences and Experiences about Medical Substitute Decision-Making: A National Cross-Sectional Survey' [2021] *BMJ Supportive & Palliative Care* (advance):1-21 ('Public Knowledge, Preferences and Experiences about Medical Substitute Decision-Making'); Laura I van Dyck et al, 'Understanding the Role of Knowledge in Advance Care Planning Engagement' (2021) 62(4) *Journal of Pain and Symptom Management* 778; Nouri et al (n 1) 2; Dickinson et al (n 5) 2014; Miho Matsui, 'Effectiveness of End-of-Life Education among Community-Dwelling Older Adults.' (2010) 17(3) *Nursing Ethics* 363, 364; Boaz Kahana et al, 'The Personal and Social Context of Planning for End-of-Life Care' (2004) 52(7) *Journal of the American Geriatrics Society* 1163, 1163.

but also healthcare professionals[191] and even lawyers.[192] The need to provide further education and training for medical professionals has been highlighted in recent intervention studies. For example, Liang et al developed a program of educational materials and communication training for senior medical staff with the aim of improving the uptake of Advance Care Planning within a geriatric clinic in Western Australia.[193] The intervention included departmental meetings, the provision of official Department of Health documentation relating to Advance Care Planning, a communication skills workshop, and the inclusion of a specific section prompting 'Advance Care Plan' discussions in the departmental clinic letter template.[194] These steps led to a 13% improvement in discussions between healthcare professionals and older people relating to Advance Care Planning, and a 23% increase in discussions regarding Advance Care Directives.[195] Improving knowledge across both professional and personal levels is essential to overcoming the lack of knowledge regarding the range of APP instruments available, and it is encouraging to know that successful interventions are being pursued for this purpose.

3.8.1.2 Personal factors that prevent engagement

Aside from lack of knowledge, several access and personal barriers may also impact planning. Butterworth cites ten factors that may stop people from wanting to plan ahead: (1) patient and provider reluctance to initiate planning conversations; (2) lack of time to properly engage in planning conversations; (3) assumptions regarding the types of treatment that may be wanted; (4) denial of the dying process or procrastination regarding appropriate treatment; (5) patient and families' unrealistic expectations regarding lifesaving treatments; (6) waiting for a crisis to occur before planning in detail; (7) discomfort with planning for palliative care; (8) a lack of

[191] Sarah Donnelly et al, 'Assisted Decision-Making and Interprofessional Collaboration in the Care of Older People: A Qualitative Study Exploring Perceptions of Barriers and Facilitators in the Acute Hospital Setting' (2021) 35(6) *Journal of Interprofessional Care* 852, 853; Ng and Wong (n 2); Sinclair et al, 'Professionals' Views and Experiences in Supporting Decision-Making Involvement' (n 2); Nouri et al (n 1) 2; C Haining, L Nolte and KM Detering, *Australian Advance Care Planning Laws: Can We Improve Consistency?* (Report, Advance Care Planning Australia, Austin Health, 2019) 73–74; Vivian Masukwedza et al, 'Use of Advance Care Directives for Individuals with Dementia Living in Residential Accommodation: A Descriptive Survey' (2019) 26(3) *Collegian* 348, 351; Moore et al (n 11); Sellars, Detering and Silvester (n 112); Colleen Cartwright et al, 'Medical Practitioners' Knowledge and Self-Reported Practices of Substitute Decision Making and Implementation of Advance Care Plans' (2014) 44(3) *Internal Medicine Journal* 234, 238; Zhou et al (n 2); Kahana et al (n 190) 1167.

[192] Orsatti (n 13); Daren Heyland, 'How can we get Lawyers to Change the Way they do Advance Medical Care Planning with Their Clients? A Physician's Reflections', *Slaw* (Blog Post, 25 September 2019) <http://www.slaw.ca/2019/09/25/how-can-we-get-lawyers-to-change-the-way-they-do-advance-medical-care-planning-with-their-clients-a-physicians-reflections/>; Ries et al (n 8).

[193] Qi'En Liang, Derek Eng and Joel Tate, 'Improving Uptake of Advance Care Planning through Education and Training in a Public Hospital Geriatric Clinic' (2023) 42(3) *Australasian Journal on Ageing* 577.

[194] Ibid 579.

[195] Ibid 580.

advance planning documents; (9) barriers relating to an individual's culture or their access to the health system; and (10) ultimately a readiness to engage in the planning process.[196] Individuals may believe that APP is simply not relevant for them.[197] A reluctance to prepare written documents,[198] and the quality of the relationship that individuals have with professionals, especially in the field of healthcare, are also notable factors.[199] Social or personal barriers to planning can include 'the patient's relationships with the health care professional and health care system'[200] or legal professionals, and previous experiences, if any, with the legal system, as well as 'emotions such as anger, anxiety or fear' about potential poor health, spending time in hospital and dying.[201] Finally, an older person may not feel equipped to name decision-makers, such as an Enduring Guardian or Enduring Power of Attorney, as there may be a lack of trusted individuals in their life whom they would feel comfortable appointing.[202] These factors, including access to services, geographical isolation and a lack of trusted people to appoint as decision-makers, were key focus areas in my interviews with older people.

[196] Ann M Butterworth, 'Reality Check: 10 Barriers to Advance Planning' (2003) 28(5) *The Nurse Practitioner* 42. See also Yapp et al (n 158) 135–136; Susi Lund, Alison Richardson and Carl May, 'Barriers to Advance Care Planning at the End of Life: An Explanatory Systematic Review of Implementation Studies' (2015) 10(2) *PLOS ONE* e0116629:1-15, 9; Dickinson et al (n 5) 2014; Scott et al (n 189) 663; Tim Sharp et al, 'Do the Elderly Have a Voice? Advance Care Planning Discussions with Frail and Older Individuals: A Systematic Literature Review and Narrative Synthesis' (2013) 63(615) *British Journal of General Practice* e657, e660; Samsi and Manthorpe (n 111) 55–56.

[197] Lum, Sudore and Bekelman (n 101) 398; Scott et al (n 189) 663; Rhee, Zwar and Kemp, 'Uptake and Implementation of Advance Care Planning in Australia' (n 112) 100; Schickedanz et al (n 90) 35.

[198] Masters, Wylie and Hubner (n 10) 652; McIlfatrick et al (n 9) 1360; Batchelor et al (n 2) 176; Moore et al (n 11) 9; Yapp et al (n 158) 135–136; Rebecca L Sudore et al, 'Engagement in Multiple Steps of the Advance Care Planning Process: A Descriptive Study of Diverse Older Adults' (2008) 56(6) *Journal of the American Geriatrics Society* 1006, 1011; Sellars et al, 'Perspectives of People with Dementia and Carers on Advance Care Planning and End-of-Life Care' (n 5) 284–285.

[199] Orsatti (n 13) 158; Chan (n 111) 8; Ries et al (n 8) 695; Waller et al (n 189) 7; Lum, Sudore and Bekelman (n 101) 399; Karen M Detering et al, 'The Impact of Advance Care Planning on End of Life Care in Elderly Patients: Randomised Controlled Trial' (2010) 340 *BMJ* c1345:1-9, 1; Malcomson and Bisbee (n 4) 22; Muriel R Gillick, 'A Broader Role for Advance Medical Planning' (1995) 123(8) *Annals of Internal Medicine* 621, 623.

[200] Masters, Wylie and Hubner (n 10) 643.

[201] Ibid. See also R Sean Morrison, 'Advance Directives/Care Planning: Clear, Simple, and Wrong' (2020) 23(7) *Journal of Palliative Medicine* 878, 878; Sellars et al, 'Perspectives of People with Dementia and Carers on Advance Care Planning and End-of-Life Care' (n 5) 276; Otte et al (n 94) 200–201; Scott et al (n 189) 663; Vearrier (n 76) 350; Susan E Hickman, 'Improving Communication Near the End of Life' (2002) 46(2) *American Behavioral Scientist* 252, 254; Kaplan (n 96) 21.

[202] Close et al (n 11) 2; Morrison, Meier and Arnold (n 108) 1576; Sinclair et al, 'Professionals' Views and Experiences in Supporting Decision-Making Involvement' (n 2) 91; Lum, Sudore and Bekelman (n 101) 399; Sinclair et al, 'A Public Health Approach to Promoting Advance Care Planning to Aboriginal People' (n 109) 25.

3.8.1.3 Associating advance planning only with the end of life

Advance Care Planning for future healthcare and medical treatment is often situated within the context of end of life care,[203] and the treatment goals and preferences someone has in mind for their final days or hours. This limited perspective contributes to the reluctance of many people to discuss planning.[204] People have also expressed fears that discussing planning may result in withholding or withdrawing of treatment.[205] This hesitation to discuss forms of advance planning extends to professionals, with the siloed nature of the medical and legal professions continuing to underpin this barrier.[206] Dixon and Knapp note that 'time constraints; lack of knowledge, skills and confidence; and concerns related to professional autonomy and patient care'[207] were persistent barriers for physicians to engage in planning conversations with their patients, even if their organisation supported Advance Care Planning. These concerns were shared by nurse practitioners[208] and social workers.[209] These barriers persist despite patients' expectation that members of their care team will initiate planning conversations. As a result, discussions about future planning 'are uncommon and rarely documented'.[210] This is a real concern, given the increase in the number of individuals living with chronic illnesses[211] and the rise of neurocognitive conditions such as dementia.[212] These trends support

[203] Pleasence, Balmer and Denvir (n 189) 189; Yapp et al (n 158) 135–136; Rhee, Zwar and Kemp, 'Uptake and Implementation of Advance Care Planning in Australia' (n 112) 100; Ellison et al (n 102).

[204] Buck et al, 'Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services' (n 38) 8; Kathryn Almack et al, 'After You: Conversations between Patients and Healthcare Professionals in Planning for End of Life Care' (2012) 11 *BMC Palliative Care* 15:1–10; Deborah P Waldrop and Mary Ann Meeker, 'Communication and Advanced Care Planning in Palliative and End-of-Life Care' (2012) 60(6) *Nursing Outlook* 365, 367; Matsui (n 190) 364; Joseph A Carrese et al, 'Planning for Death but Not Serious Future Illness: Qualitative Study of Housebound Elderly Patients' (2002) 325(7356) *BMJ* 125, 126; Hickman (n 201) 253.

[205] McIlfatrick et al (n 9) 1360; Batchelor et al (n 2) 176; Ke et al (n 204) 399; Musa et al (n 1) 374; Lum, Sudore and Bekelman (n 101) 398.

[206] Dixon and Knapp (n 7) 8. See also Ries et al (n 8) 695.

[207] Dixon and Knapp (n 7) 8. See also Ng and Wong (n 2) 6.

[208] Dixon and Knapp (n 7) 9.

[209] Ibid 10.

[210] Almack et al (n 204) 1.

[211] Carney et al (n 2); Department of Health, *National Framework for Advance Care Planning Documents* (Report, May 2021) 6 <https://www.health.gov.au/resources/publications/national-framework-for-advance-care-planning-documents?language=en>; Ng and Wong (n 2); Tran et al (n 11) 318; Jenni Burt et al, 'Care Plans and Care Planning in Long-Term Conditions: A Conceptual Model' (2014) 15(4) *Primary Health Care Research & Development* 342, 342; Jenny Newbould et al, 'Experiences of Care Planning in England: Interviews with Patients with Long Term Conditions' (2012) 13 *BMC Family Practice* 71:1–9, 1; Zhou et al (n 2); Susan E Hickman et al, 'Hope for the Future: Achieving the Original Intent of Advance Directives' (2005) 35(6) *The Hastings Center Report* S26, S30; Carrese et al (n 204) 125.

[212] Bryant et al, 'Inadequate Completion of Advance Care Directives by Individuals with Dementia' (n 5); Bryant et al, 'Advance Care Planning Participation by People with Dementia' (n 5); Sinclair et al, 'Professionals' Views and Experiences in Supporting Decision-Making Involvement' (n 2); Masukwedza et al (n 191) 348; Royal Commission into Aged Care Quality and Safety, *Advance Care Planning in Australia* (Background Paper 5, Commonwealth of Australia, 2019) 4–5

recommendations that planning should occur earlier, and at a time when an individual is well and able to fully consider their wishes and preferences for care and treatment, and their personal decisions.[213]

While planning for the very end of life is important and should not be discouraged, it is not sufficient on its own. As Carrese et al discovered in their qualitative study of chronically ill adults aged 75 years and over:

> Our patients were least likely to envision and help to plan for a period of chronic serious illness when death is not certain. It is precisely in this interval that the most difficult decisions often arise. … In the interval when death is near and certain and these decisions are becoming simpler, our patients were somewhat more willing to help to decide in advance. In their view advance directives apply to this more hopeless situation. Our patients do plan for the certain future. They know that one day they will be dead, and arrangements have been made for that day.[214]

This sentiment is echoed by Heyland, who states '[t]his discrimination between serious illness and terminal care is not trivial. Planning for a certain death is not the same as planning for an uncertain outcome associated with serious illness'.[215] Engaging in Advance Care Planning and only considering values and preferences for medical care at the end of life fails to take full advantage of the broader preventive benefits of the full range of APP,[216] including financial planning.[217] Similarly, considerations of an individual's wellbeing,[218] and the many factors it involves, should not be confined to end of life discussions. As Yapp et al argue, in the context

<https://agedcare.royalcommission.gov.au/publications/Documents/background-paper-5.pdf>.

[213] Rodi et al (n 3) 3677; Baron (n 73) 386–387; Biondo et al (n 9) 682; Moore et al (n 11) 10; Yapp et al (n 158) 136; Judith AC Rietjens et al, 'Definition and Recommendations for Advance Care Planning: An International Consensus Supported by the European Association for Palliative Care' (2017) 18(9) *The Lancet. Oncology* e543; Cognitive Decline Partnership Centre, *Clinical Practice Guidelines and Principles of Care for People with Dementia* (Report, NHMRC Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People, February 2016) <https://cdpc.sydney.edu.au/wp-content/uploads/2019/06/CDPC-Dementia-Guidelines_WEB.pdf>; Kimberly J Johnson et al, 'Social Work should be more Proactive in Addressing the Need to Plan for End of Life' (2016) 41(4) *Health & Social Work* 271, 272.

[214] Carrese et al (n 204) 127. See also Ke et al (n 204) 400.

[215] Heyland (n 192). See also Juliet Jacobsen, Rachelle Bernacki and Joanna Paladino, 'Shifting to Serious Illness Communication' (2022) 327(4) *JAMA* 321.

[216] Louis M Brown, 'The Law Office – A Preventive Law Laboratory' (1956) 104(7) *University of Pennsylvania Law Review* 940; Dennis P Stolle et al, 'Integrating Preventive Law and Therapeutic Jurisprudence: A Law and Psychology Based Approach to Lawyering' (1997) 34 *California Western Law Review* 15; Bruce J Winick, 'The Expanding Scope of Preventive Law Therapeutic Jurisprudence Symposium' (2002) 3 *Florida Coastal Law Journal* 189.

[217] Ries, Johnston and McCarthy (n 107) 497; Dickinson et al (n 5) 2014.

[218] Mark Glover, 'A Therapeutic Jurisprudential Framework of Estate Planning' (2011) 35 *Seattle University Law Review* 427; MB Kapp, 'A Therapeutic Approach' in Israel Doron (ed), *Theories on Law and Ageing: The Jurisprudence of Elder Law* (Springer, 2009) 31.

of people living with dementia, individuals face a range of lifestyle decisions throughout their disease trajectory that are far removed from the end of life.[219] These may include 'decisions about pets and visitors, retirement from driving, location of care and living arrangements as well as decisions about medications or medical interventions'.[220] Notably, for individuals living in regional or rural areas, Yapp et al found their participants often preferred to 'remain close to family or community, even if this limits what care is available'.[221] By framing Advance Care Planning as only relevant for end of life decisions, it fails to take into account periods of vulnerability or heightened dependency that a person may experience during various points in their life span,[222] as distinct from dependency that may arise only at the end of life.

On this note, it is easy to adopt the presumption that incapacity only occurs once for an individual at the end of life, rather than understanding that incapacity can strike for a short period of time and may recur frequently or infrequently during a person's life.[223] While planning for the end of life allows an individual to have power and control over their final days, months or years, we can expand a person's ability to participate in the management of their own affairs for a longer period of time. This participation, incorporating notions of power and control,[224] empowers an individual to effectively and proactively ensure their wishes, preferences and goals are able to be followed in future. Further, it recognises a person's competency and autonomy, upholding not only their right of control, but also their ability to make self-directed choices that are authentic to their true wishes.[225] The desire to live authentically is not only relevant for decisions relating to the end of life, but all decisions made by older people throughout their lives.[226] The narrow view of Advance Care Planning as planning only for the end of life also fails to acknowledge the key role others may play in the

[219] Yapp et al (n 158).
[220] Ibid 144.
[221] Ibid.
[222] Martha Albertson Fineman, 'The Vulnerable Subject: Anchoring Equality in the Human Condition' (2008) 20(1) *Yale Journal of Law and Feminism* 1.
[223] Close et al (n 11) 2; Sinclair et al, 'Association Between Region of Birth and Advance Care Planning Documentation' (n 101) 117–118; Moore et al (n 11) 1–2; Purser and Sullivan (n 106); Purser and Rosenfeld (n 106).
[224] Zoë Oxaal and Sally Baden, *Gender and Empowerment: Definitions, Approaches and Implications for Policy* (BRIDGE Report No 40, Institute of Development Studies, January 1997) <https://archive.ids.ac.uk/bridge/bridge-publications/reports/document/A23334.html>; Marilee Karl, 'Obstacles and Opportunities' in *Women and Empowerment: Participation and Decision-Making* (Zed Books Ltd, 1995).
[225] Kathryn Abrams, 'From Autonomy to Agency: Feminist Perspectives on Self-Direction' (1999) 40 *William and Mary Law Review* 805; Joel Feinberg, 'Autonomy' in John Christman (ed), *The Inner Citadel: Essays on Individual Autonomy* (Oxford University Press, 1989) 27.
[226] Yapp et al (n 158); Sandra Timmermann, 'Planning for the Rest of Your Life: A New Perspective' (2001) 55(2) *Journal of Financial Service Professionals* 28.

care of, and advocacy for, older adults over an extended period, and often throughout a significant portion of their lives, not merely at the very end. There is a need to explicitly acknowledge this relational autonomy, where it exists, for individuals.[227]

Prevalence or rate of uptake is not an effective measure of successful engagement with APP instruments.[228] As Samsi and Manthorpe found, '[f]inancial plans and funeral arrangements were most commonly drawn up with an absence of health and social care plans, which participants tended to postpone considering'.[229] White et al also highlight the different nature of financial and health planning:

> [W]ills and financial EPA [Enduring Power of Attorney] … do not require the same engagement with one's mortality and possible ill health. … Further, AD [Advance Directives] are often conceptualised as documents only to make specific future health decisions (particularly refusals of treatment). This can limit their perceived utility as being relevant only to those who are older or are already unwell.[230]

Such health-related plans, according to Sutton et al, could be considered 'an unwanted burden and a form of "responsibilization" rather than "empowerment"',[231] where older adults feel pressured or obliged to make these plans in the absence of meaningful participation within a collaborative and communicative process with relevant professionals.

These concerns reflect the lack of understanding and guidance regarding instruments and appointments, as they may be merely understood as a burden on others, rather than a collaborative undertaking to ensure a person's wishes can be followed at any point in their future. Further, the willingness of older people to undertake financial forms of planning, such as appointing an Enduring Power of Attorney, may also point to the trust that individuals place in the health system to step in and act for them at a point where they are unwell, without needing

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[227] Tamryn F Gray et al, 'The Decision Partner in Healthcare Decision-Making: A Concept Analysis' (2019) 92 *International Journal of Nursing Studies* 79.

[228] Kerstin Knight, '50 Years of Advance Care Planning: What do we Call Success?' (2021) 39(1) *Monash Bioethics Review* 28, 37–38; Amy Waller et al, 'Are Older and Seriously Ill Inpatients Planning Ahead for Future Medical Care?' (2019) 19 *BMC Geriatrics* 212:1–8, 5; Joel J Rhee, Nicholas A Zwar and Lynn A Kemp, 'Why are Advance Care Planning Decisions not Implemented? Insights from Interviews with Australian General Practitioners' (2013) 16(10) *Journal of Palliative Medicine* 1197, 1197 ('Why are Advance Care Planning Decisions not Implemented?').

[229] Samsi and Manthorpe (n 111) 52. See also Masters, Wylie and Hubner (n 10) 654–655; Dickinson et al (n 5) 2014.

[230] White et al (n 31) 978.

[231] Elizabeth Sutton, Helen Eborall and Graham Martin, 'Patient Involvement in Patient Safety: Current Experiences, Insights from the Wider Literature, Promising Opportunities?' (2015) 17(1) *Public Management Review* 72, 77–78. See also Waldrop and Meeker (n 204) 367.

to depend on the advocacy of others. Expanding older adults' understanding of Advance Care Planning and financial planning, beyond the end of life to considering how individuals want to continue living for the rest of their life, may overcome the perception that forms of health planning are only relevant for individuals who are unwell or nearing the end of life.[232] Framing APP as planning for the rest of life is a key theme in my research.

3.8.2 Factors that Affect the Quality of Prepared APP Instruments

3.8.2.1 Lack of knowledge of when instruments operate

Older adults' lack of knowledge about the full range of APP mechanisms,[233] and the need for better education on how and when they operate,[234] are once again notable with respect to assessing the quality of prepared instruments. As van Dyck states, '[w]hile knowledge is empowering, it is also not enough for engagement'.[235] For example, it is vital to ensure people are aware that in NSW, an Enduring Power of Attorney appointment can operate immediately and continues to be effective even if a person is experiencing a period of incapacity.[236] However, with respect to healthcare decisions, an Enduring Guardian appointment only commences once an individual cannot make their own decisions.[237]

3.8.2.2 Instruments are not tailored to an individual's circumstances

In the event APP instruments have been completed, there may be doubts with respect to their quality.[238] There is a legitimate concern that the creation of APP documents could merely become 'a tick box exercise, rather than being tailored to individual patient needs'.[239] This is

[232] Masters, Wylie and Hubner (n 10) 642; Batchelor et al (n 2) 176; Buck et al, 'Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services' (n 38) 8; Moore et al (n 11) 9; Yapp et al (n 158) 138–139.

[233] Knight (n 228); van Dyck et al (n 190) 786; Masters, Wylie and Hubner (n 10) 643; Waller et al (n 228) 3–4; Houben et al (n 204) 477–478; Dickinson et al (n 5) 2014; Samsi and Manthorpe (n 111) 58; Ellison et al (n 102) 307.

[234] Chesterman and Bedson (n 190) 112; Knight (n 228); van Dyck et al (n 190); Waller et al (n 228) 5–6; Sellars, Detering and Silvester (n 112); Cartwright et al (n 191) 238; Purser and Rosenfeld (n 106); Samsi and Manthorpe (n 111) 58; Matsui (n 190) 364.

[235] van Dyck et al (n 190).

[236] Chesterman and Bedson (n 190) 104.

[237] Ibid.

[238] Buck et al, 'Advance Care Directive Prevalence among Older Australians' (n 1); Otte et al (n 94) 204; Tim Luckett et al, 'Advance Care Planning in 21st Century Australia: A Systematic Review and Appraisal of Online Advance Care Directive Templates against National Framework Criteria' (2015) 39(5) *Australian Health Review* 552; Donald R Sullivan and Christopher G Slatore, 'Advance Care Planning: Does it Benefit Surrogate Decision Makers in the Intensive Care Unit?' (2015) 12(10) *Annals of the American Thoracic Society* 1432, 1433; Scott et al (n 189) 662.

[239] Louise Robinson et al, 'A Qualitative Study: Professionals' Experiences of Advance Care Planning in Dementia and Palliative Care, "A Good Idea in Theory but …"' (2013) 27(5) *Palliative Medicine* 401, 403. See also Buck et al, 'Advance Care Directive Prevalence among Older Australians' (n 1) 1312; Buck et al, 'Prevalence

especially true in circumstances where an individual has simply used a pro forma document that has not adequately considered and accounted for their individual circumstances and preferences.[240] Buck et al studied Advance Care Planning documents in their research to assess the prevalence and quality of Advance Care Directives among older Australians.[241] They concluded:

> Low ACP [Advance Care Planning] documentation prevalence and a lack of accessible, person-completed and quality ACDs [Advance Care Directives] represent an important ACP implementation issue. Low prevalence is complicated by poor document quality and a higher prevalence of documents being completed by someone other than the person.[242]

When documents have been created by a proxy, such as a family member or appointed decision-maker, this can undermine the autonomy and wellbeing of the individual who is subject to the document.[243] However, when prepared thoughtfully and as part of a communicative and collaborative relationship, these documents can be an important demonstration of an older adult's autonomy.[244] These concerns regarding uptake and quality can be expanded more broadly to APP documents and appointments in general. Even if an individual has made a document, if it has not been reviewed or updated, it is unlikely to reflect their current wishes.[245] In my interviews, I took into account when individuals had made relevant APP documents, as well as whether they had been updated or reviewed over time. Similarly, participants were asked whether they had discussed their wishes with their support community to ensure these wishes, in the context of their specific circumstances, could be fulfilled in future.

of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services' (n 38) 8–9; Calafiore (n 44); Moore et al (n 11) 8; Russell (n 10) 998.

[240] Moore et al (n 11) 8; Otte et al (n 94); Luckett et al (n 238); Pascoe Pleasence, Nigel J Balmer and Catrina Denvir, *How People Understand and Interact with the Law* (The Legal Education Foundation, 2015) ii; Robinson et al (n 239) 403; Russell (n 10) 998.

[241] Buck et al, 'Advance Care Directive Prevalence among Older Australians' (n 1).

[242] Ibid 1312. See also Jürgen in der Schmitten et al, 'Advance Care Planning by Proxy in German Nursing Homes: Descriptive Analysis and Policy Implications' (2021) 69(8) *Journal of the American Geriatrics Society* 2122, 2123–2124.

[243] Schmitten et al (n 242) 2125.

[244] Ibid 2128.

[245] Orsatti (n 13) 157; Buck et al, 'Advance Care Directive Prevalence among Older Australians' (n 1) 1318; Sarah Hooper, Charles P Sabatino and Rebecca L Sudore, 'Improving Medical-Legal Advance Care Planning' (2020) 60(2) *Journal of Pain and Symptom Management* 487, 490; Baron (n 73) 406; Buck et al, 'Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services' (n 38) 35; Tilse et al, 'Having the Last Word?' (n 23) 20; Greenberg, Weiner and Greenberg (n 68) 1578.

3.8.2.3 Poor execution of documents

Carter et al list several factors that increase the validity of Advance Care Directives, which can be understood as factors that could improve the overall execution process and quality of APP documents and appointments more broadly.[246] These include ensuring written documents are created; capacity is confirmed at the time documents are made; documents are witnessed; documents are reviewed regularly; current conditions have been considered; and appropriate wording has been used.[247] However, several studies indicate that Advance Care Directives are not properly executed. As noted previously, Buck et al found only 73% of the prepared documents in their study 'included full name, signature, document date and witnessing'.[248] Therefore, whether a document has been completed is not an accurate indicator that high-quality planning has been undertaken. As such, my research has focused not only on prevalence but the quality of prepared instruments, from the perspective of both older adults and professional key informants.

3.8.3 Barriers to the Appropriate Use of Completed Instruments in Future

3.8.3.1 Uncertainty regarding the role of appointed decision-makers

The lack of guidance for appointed decision-makers and the need for more understanding regarding their roles is significant.[249] This barrier has been linked with 'a dearth of such research on supported decision-making'.[250] While substitute decision-making has been the focus of some of the existing literature,[251] research on the rise of supported decision-making in relation to older people who live with conditions that affect their capacity is only now emerging.[252] This highlights an ethical dilemma, beyond the scope of this thesis, regarding

[246] Rachel Z Carter et al, 'Advance Care Planning in Australia: What does the Law Say?' (2016) 40(4) *Australian Health Review* 405.
[247] Ibid 412. See also Haining, Nolte and Detering (n 191) 25–31.
[248] Buck et al, 'Advance Care Directive Prevalence among Older Australians' (n 1) 1312. See also Sarah Jeong et al, 'Prevalence of Advance Care Planning Practices among People with Chronic Diseases in Hospital and Community Settings: A Retrospective Medical Record Audit' (2021) 21(1) *BMC Health Services Research* 303, 303; Knight (n 228) 34.
[249] Orsatti (n 13) 158–160; Chesterman and Bedson (n 190) 114–115; Knight (n 228) 41–42; Sellars et al, 'Public Knowledge, Preferences and Experiences about Medical Substitute Decision-Making' (n 190) 1; David Wendler, 'A Call for a Patient Preference Predictor' (2021) 49(6) *Critical Care Medicine* 877, 877; Yapp et al (n 158) 149; Sullivan and Slatore (n 238) 1432; '7 Things to Know When Making Medical Decisions for Others', *Advance Care Planning Australia* (Web Page, 19 September 2023) <https://www.advancecareplanning.org.au/about-us/news/7-things-to-know-when-making-medical-decisions-for-others>.
[250] Chesterman and Bedson (n 190) 24.
[251] Department of Health (n 211) 1; Knight (n 228); Barry (n 121); Jeong et al (n 119); Cartwright et al (n 191); Ellison et al (n 102).
[252] Theresa S Wied et al, 'Supported Decision-Making in Persons With Dementia: Development of an Enhanced Consent Procedure for Lumbar Puncture' (2021) 12 *Frontiers in Psychiatry* 780276:1–7; Office of the Public Advocate, *Supported Decision-Making in Victoria: A Guide for Families and Carers* (Guidelines, October 2020)

circumstances where a person expresses certain views prior to a diagnosis of dementia, and differing views following their diagnosis, adding another element of uncertainty for appointed decision-makers. Lower rates of completion of Advance Care Directives may indicate some older people find it difficult to imagine themselves losing capacity in future and, as such, do not want to record their wishes until such time as it is necessary. Similarly, healthcare professionals may also feel uncomfortable following Advance Care Directives in such circumstances, fearing any instructions do not reflect the person's current preferences. Interestingly, the even lower rates of appointment of a decision-maker means that no specific person has been identified to ensure any future care aligns with the person's wishes. These are certainly significant points that should be examined in other projects.

Knowledge of when an appointed decision-maker's role commences, the scope of their duties, the range of authorised actions that have been informed by conversations with the older person and whether they are truly acting according to the person's wishes are all key considerations. If a person has appointed decision-makers, such as an Enduring Guardian or Enduring Power of Attorney, they may not have considered the extent of the decision-maker's role or any limitations they would like to put on the appointee's power. Further, they may not have actually discussed their wishes regarding their healthcare or finances in any detail with the decision-maker.[253] These factors highlight the need to ensure APP documents and appointments, if prepared, are of high quality and are reviewed regularly to ensure they are accurate.[254] The development of a standardised national form for enduring appointments has been recommended as a potential strategy for overcoming these barriers.[255] In my research, I

<https://www.publicadvocate.vic.gov.au/joomlatools-files/docman-files/general/Supported_Decision_Making_in_Victoria.pdf>; Craig Sinclair et al, '"A Real Bucket of Worms": Views of People Living with Dementia and Family Members on Supported Decision-Making' (2019) 16(4) *Journal of Bioethical Inquiry* 587; Hui Yun Chan, 'Refusing Treatment Prior to Becoming Incapacitated: Supported Decision-Making as an Approach in Advance Directives' (2018) 25(1) *European Journal of Health Law* 24.

[253] Sellars et al, 'Personal and Interpersonal Factors and their Associations with Advance Care Planning Documentation' (n 1) 1212; Haining, Nolte and Detering (n 191) 37–38; Moore et al (n 11); Nola M Ries, 'Enduring Powers of Attorney and Financial Exploitation of Older People: A Conceptual Analysis and Strategies for Prevention' (2022) 34(3) *Journal of Aging & Social Policy* 357, 369; Otte et al (n 94) 204.

[254] Orsatti (n 13) 157; Buck et al, 'Advance Care Directive Prevalence among Older Australians' (n 1) 1313; Baron (n 73) 377; Buck et al, 'Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services' (n 38) 35; Greenberg, Weiner and Greenberg (n 68) 1578.

[255] New South Wales Law Reform Commission, *Review of the Guardianship Act 1987* (Report No 145, May 2018) 25–28, 96 <https://lawreform.nsw.gov.au/completed-projects/recent/guardianship/report-145.html>; Natalia Wuth, 'Enduring Powers of Attorney: With Limited Remedies – It's Time to Face the Facts' (2013) 7 *Elder Law Review* 1, 18.

explicitly explored this recommendation with professional key informants to better understand the advantages, and any risks, of such a development.

3.8.3.2 Lack of support for appointed decision-makers

In addition to lack of knowledge about the role of appointed decision-makers, there is also limited support available for people who find themselves in this position.[256] Further, there is a prevalent assumption that an individual's family members or care team will automatically know their preferences for future care, even if they have not been discussed, which is inaccurate.[257] This lack of support may prevent individuals from successfully enacting the wishes of their family member, friend or loved one.[258] Online resources are available to help guide healthcare substitute decision-makers,[259] yet further attention and education needs to be provided regarding the scope of the role, duties of appointed decision-makers, rights held by decision-makers and supports that are available to assist them in their functions.[260] The usability of existing resources could also be improved.[261] Lühnen et al recently piloted an education program for appointed decision-makers who are supporting people living with dementia.[262] According to their results, decision-makers felt more confident to carry out their role following the training. However, they still often felt disempowered within medical systems and 'did not feel well enough prepared for healthcare decisions'.[263] This, in turn, may undermine the decision-maker's ability to effectively follow or execute a person's wishes in future. If APP is framed as solely preparing for the end of life, and members of an individual's family or support community are excluded from any decision-making,[264] ensuring any future

[256] Sellars et al, 'Public Knowledge, Preferences and Experiences about Medical Substitute Decision-Making' (n 190) 9. See also Cheryl Tilse et al, 'Community Knowledge of Law on End-of-Life Decision-Making: An Australian Telephone Survey' (2019) 27(2) *Journal of Law and Medicine* 399 ('Community Knowledge of Law on End-of-Life Decision-Making').
[257] Wendler (n 249) 878; Waller et al (n 228) 5; Ke et al (n 204) 395; Samsi and Manthorpe (n 111) 56.
[258] Tilse et al, 'Community Knowledge of Law on End-of-Life Decision-Making' (n 256).
[259] Tran et al (n 11).
[260] Ibid 321. See also '7 Things to Know When Making Medical Decisions for Others' (n 249).
[261] Tran et al (n 11) 321–324.
[262] Julia Lühnen, Ingrid Mühlhauser and Tanja Richter, 'Informed Decision-Making with and for People with Dementia: Developing and Pilot Testing an Education Program for Legal Representatives (PRODECIDE)' (2019) 18(6) *Dementia* 2303.
[263] Ibid 2314.
[264] Sellars et al, 'Personal and Interpersonal Factors and their Associations with Advance Care Planning Documentation' (n 1) 1212; Ries (n 253) 370; Yapp et al (n 158) 138–139; Ryan, Amen and McKeown (n 204) 386; Malcomson and Bisbee (n 4) 19–21.

choices made by a decision-maker accurately represent the wishes of the person on whose behalf they have been appointed can be incredibly difficult.[265]

3.8.3.3 Potential abuse of prepared instruments

In the event documents have been prepared, there are concerns that they can be used to manipulate the older person who made them and lead to forms of abuse.[266] While there is plenty of literature on the prevalence and operation of Advance Care Planning and Advance Care Directives, there has been comparatively little investigation of Enduring Powers of Attorney, particularly instances where they have been abused. However, documented instances of financial exploitation and elder abuse through the appointment of Enduring Powers of Attorney are increasing.[267] According to Ellison et al, abuse of Enduring Powers of Attorney is more common than other APP instruments because: a person may not have the inclination or ability to monitor the actions of the person they have appointed as their financial decision-maker; the high rates of family members or relatives being named in this role; the common occurrence of breaches of trust rather than a legally actionable behaviour; and the generally limited understanding of authorised actions and permitted duties.[268] Other deficiencies that may contribute to a risk of financial elder abuse include family conflict, insufficient communication or planning for future financial management, and an inherent societal belief that adult children are entitled to receive their parent's assets.[269]

[265] Orsatti (n 13) 157; Buck et al, 'Advance Care Directive Prevalence among Older Australians' (n 1) 1323; Baron (n 73) 377; Buck et al, 'Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services' (n 38); Hickman et al (n 211) S29–S30; Hickman (n 201) 258.

[266] Lixia Qu et al, *National Elder Abuse Prevalence Study* (Final Report, Australian Institute of Family Studies, July 2021) 2 <https://aifs.gov.au/research/research-reports/national-elder-abuse-prevalence-study-final-report>; Ries (n 253) 357; Australian Guardianship and Administration Council (n 164) 9, 25; Lewis (n 108) 41; Office of the Public Advocate, *Australian Guardianship and Administration Council Elder Abuse National Projects: Enduring Powers of Attorney (Financial)* (Options Paper, Australian Guardianship and Administration Council, December 2018) 17 <https://www.agac.org.au/assets/documents/Other-Publications/Elder-Abuse-National-Projects-EPOA-financial.pdf>; Wuth (n 255) 1; Ellison et al (n 102) 272, 310–312.

[267] Australian Institute of Health and Welfare (n 103) xx; Council of Attorneys-General (Australia) and Attorney-General's Department, *National Plan to Respond to the Abuse of Older Australians (Elder Abuse) 2019-2023* (Report, 8 July 2019) 3 <https://www.ag.gov.au/rights-and-protections/publications/national-plan-respond-abuse-older-australians-elder-abuse-2019-2023>; Ries (n 253) 361; Lewis (n 108) 41; Wuth (n 255) 9–13.

[268] Ellison et al (n 102) 310–312.

[269] Ries (n 253) 363–367.

3.8.3.4 Completed instruments are stored inconsistently and not accessible

Inconsistent storage practices undermine the efficacy of Advance Care Planning and APP,[270] affecting the future use of prepared instruments.[271] Accessibility of key documents increases the likelihood that recorded wishes are easy to locate, able to be reviewed and updated as required, and consequently reflect the current intentions of the person who made the document.[272] Ideally, prepared instruments should be shared with family, appointed decision-makers and healthcare providers, as well as being included in any medical records an individual may have at separate facilities.[273] In the National Framework for Advance Care Planning Documents, the Department of Health recommends that Advance Care Planning instruments be as accessible as possible and 'should be stored in a way that makes their existence known'.[274] This means an individual should 'communicate with their substitute decision-maker, family, carers and/or health practitioners that they have completed an advance care planning document and provide copies'.[275]

[270] Australian Digital Health Agency, *National Guidelines: Using My Health Record to Store and Access Advance Care Planning and Goals of Care Documents* (Guidelines, March 2021) <https://www.digitalhealth.gov.au/healthcare-providers/advance-care-planning>; Department of Health (n 211) 13; Laura Panozzo et al, 'Communication of Advance Care Planning Decisions: A Retrospective Cohort Study of Documents in General Practice' (2020) 19 *BMC Palliative Care* 108:1–7, 1; Buck et al, 'Concordance Between Self-Reported Completion of Advance Care Planning Documentation and Availability of Documentation' (n 1); Haining, Nolte and Detering (n 191) 69; Royal Commission into Aged Care Quality and Safety (n 212) 6; Otte et al (n 94) 203; Charles P Sabatino, 'Advance Care Planning Tools That Educate, Engage, and Empower' (2014) 24(3) *Public Policy & Aging Report* 107, 110.

[271] Buck et al, 'Advance Care Directive Prevalence among Older Australians' (n 1) 1315; Detering et al, 'Prevalence of Advance Care Planning Documentation and Self-Reported Uptake' (n 1) 274; Morrison (n 201) 878; Baron (n 73) 385–386; Batchelor et al (n 2) 176; Rolnick et al (n 3) 526; Lund, Richardson and May (n 196) 12; Rhee, Zwar and Kemp, 'Uptake and Implementation of Advance Care Planning in Australia' (n 112) 100; Charles P Sabatino, 'The Evolution of Health Care Advance Planning Law and Policy' (2010) 88(2) *The Milbank Quarterly* 211, 221–224.

[272] Orsatti (n 13) 157; Buck et al, 'Advance Care Directive Prevalence among Older Australians' (n 1) 1318; Baron (n 73) 377; Buck et al, 'Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services' (n 38) 35; Haining, Nolte and Detering (n 191) 69–70; Luckett et al (n 238) 554; Rhee, Zwar and Kemp, 'Why are Advance Care Planning Decisions not Implemented?' (n 228) 1199.

[273] Advance Care Planning Australia, 'The Importance of Storing Your Patients' Advance Care Planning Documents in My Health Record', *Advance Care Planning Australia* (online, 21 March 2022) <https://www.advancecareplanning.org.au/about-us/news/the-importance-of-storing-your-patients-advance-care-planning-documents-in-my-health-record>; Australian Digital Health Agency (n 270); Royal Australian College of General Practitioners, *Planning and Recording My Future Healthcare Wishes: Advance Care Planning and My Health Record* (Report, 2021) <https://www.racgp.org.au/FSDEDEV/media/documents/Clinical%20Resources/My%20health%20record/ACP-MHR-Information-for-patients.pdf>; Commission on Law and Aging and American Bar Association, *Advance Directives: Counseling Guide for Lawyers* (Report, 2018) ii <https://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/ad-counseling-guide/>.

[274] Department of Health (n 211) 22–23.

[275] Ibid 16.

Another method includes keeping important documents in a folder or envelope that is stored in a known place in a person's home that is easily accessible when required. The process adopted in Alberta, Canada, is referred to as a 'Green Sleeve'; it is a green plastic folder where Advance Care Planning documents are stored.[276] Patients can collect a Green Sleeve from their doctor and are encouraged to bring it along to all healthcare appointments, and to keep it 'on or near their refrigerator at home as emergency medical responders are trained to look for it in that location'.[277] However, only 46% of lawyers surveyed were familiar with the Green Sleeve process, and '[j]ust over one third of lawyers reported that their clients have discussed or shared their Green Sleeve and associated documents during a legal appointment'.[278] Similarly, Hooper et al discovered, '[w]hile most lawyers urge clients to share documents with family and healthcare providers, few have routine practices designed to assist clients in doing so'.[279]

In Australia, it has also been suggested that electronic copies of any Advance Care Planning instruments should be uploaded by an individual to their My Health Record to address issues regarding storage and accessibility.[280] However, there are concerns about persistent low uptake of My Health Record among both patients and clinicians.[281] Further, the creation of a central registry of Enduring Power of Attorney appointments would ensure these instruments were able to be located and accessed as required, and their currency could be confirmed.[282] However, the use and creation of online databases and registries is far more complex when considered against the comparatively simple steps individuals can take to ensure their documents are stored securely within their home and are accessible when required.[283] Further, consideration must be given to individuals with limited or no access to technology, and varying levels of computer

[276] Ries et al (n 8) 692.
[277] Ibid.
[278] Ibid 693.
[279] Hooper, Sabatino and Sudore (n 245) 493.
[280] Advance Care Planning Australia (n 273); Australian Digital Health Agency (n 270) 2; Department of Health (n 211) 13, 15–16, 23; Haining, Nolte and Detering (n 191) 73–74; Royal Australian College of General Practitioners (n 273).
[281] Melissa Davey, 'My Health Record: After 12 Years and more than $2bn, Hardly Anyone is Using Digital Service', *The Guardian* (online, 6 June 2022) <https://www.theguardian.com/australia-news/2022/jun/06/my-health-record-after-12-years-and-more-than-2bn-hardly-anyone-is-using-digital-service>.
[282] Attorney-General's Department, *National Register of Enduring Powers of Attorney* (Public Consultation Paper, April 2021) 4–5 <https://www.ag.gov.au/rights-and-protections/consultations/national-register-enduring-powers-attorney>; Chesterman and Bedson (n 190) 9; Law Council of Australia, *National Register of Enduring Powers of Attorney* (Report, 8 July 2021) 21–22 <https://lawcouncil.au/resources/submissions/national-register-of-enduring-powers-of-attorney>; Lewis (n 108); Wuth (n 255) 17–19.
[283] Law Council of Australia (n 282) 19, 21–22; Australian Health Ministers' Advisory Council (n 14) 35.

literacy,[284] in addition to the significant privacy concerns that may arise from online data bases and potential breaches.[285]

3.8.3.5 Prepared instruments are not followed

Even if Advance Care Planning and APP instruments have been prepared, they may not be followed.[286] Particularly with respect to medical treatment, healthcare providers may revert to 'best interests' decisions, rather than adhering to instructions recorded in Advance Care Directives,[287] and prioritise clinical and ethical considerations ahead of legal compliance or an obligation to adhere to a valid Advance Care Directive.[288] For example, in their interviews with Australian doctors, Moore et al found that despite understanding the significance of the autonomous exercise of creating an Advance Care Directive, 'some doctors experienced deep conflict when weighing up decisions to follow ACDs [Advance Care Directives], in scenarios where they disagreed with the patient's decision'.[289] Further, some doctors reported that they faced opposition from a patient's family when they were making decisions in accordance with the wishes expressed in an Advance Care Directive.[290] Whether or not treatment is considered to be in a patient's 'best interests' is also a key consideration for doctors, with Advance Care Directives regarded by the doctors in this study as 'irrelevant to their decision-making if patients had requested treatment that the doctor perceived to be futile'.[291] Some participants also seemed to be 'most influenced by their assessment of the potential risks and benefits to patients rather than the preferences specified in the ACDs', and included a range of factors, including the patient's age and health status, in their determination.[292] Whether an Advance

[284] Australian Communications and Media Authority, *Communications and Media in Australia: The Digital Lives of Older Australians* (Report, May 2021) <https://www.acma.gov.au/sites/default/files/2021-05/The%20digital%20lives%20of%20older%20Australians.pdf>.
[285] Campbell Kwan, 'Over 65% of Australians across all Age Brackets Worry about Privacy in New Tech', *ZDNET* (online, 24 May 2021) <https://www.zdnet.com/article/over-65-of-australians-across-all-age-brackets-are-worried-about-privacy-issues-in-new-tech/>.
[286] McIlfatrick et al (n 9) 1360; Baron (n 73) 406–407; Batchelor et al (n 2) 176; Rolnick et al (n 3) 530; Waller et al (n 228) 2; Otte et al (n 94) 204; Lund, Richardson and May (n 196) 12; Rhee, Zwar and Kemp, 'Uptake and Implementation of Advance Care Planning in Australia' (n 112) 100; Australian Health Ministers' Advisory Council (n 14) 6; Sabatino (n 271) 221–224.
[287] McIlfatrick et al (n 9) 1360; Batchelor et al (n 2) 176; Moore et al (n 11); Rolnick et al (n 3) 526; Musa et al (n 1) 374; Nauck et al (n 54); Scott et al (n 189) 662; Rhee, Zwar and Kemp, 'Uptake and Implementation of Advance Care Planning in Australia' (n 112) 99.
[288] Moore et al (n 11) 7. See, eg, Ben P White et al, 'Comparing Doctors' Legal Compliance across Three Australian States for Decisions Whether to Withhold or Withdraw Life-Sustaining Medical Treatment: Does Different Law Lead to Different Decisions?' (2017) 16(1) *BMC Palliative Care* 63.
[289] Moore et al (n 11).
[290] Sinclair et al, 'Professionals' Views and Experiences in Supporting Decision-Making Involvement' (n 2) 91; Tran et al (n 11); Masukwedza et al (n 191) 352; Moore et al (n 11) 7.
[291] Moore et al (n 11) 7.
[292] Ibid.

Care Directive could be verified was also a concern for doctors when deciding if the preferences expressed therein were accurate.[293]

3.9 CONCLUSION

This literature review demonstrates that while our evidence base relating to Advance Care Planning is fairly well-established, awareness of, and research about, APP as a comprehensive process of planning for legal, health, financial and personal matters is still developing. While studies have sought to explore perspectives of various groups relating to Advance Care Planning, there is a clear gap relating to the experiences of relevant cohorts relating to the broader process of APP. Further, while existing literature has included professionals, such as doctors and lawyers, in the context of Advance Care Planning, no studies appear to have combined the perspectives of these key informants within a single project, maintaining the siloing of the professions. As such, my research has provided the opportunity for older adults, lawyers and healthcare professionals to share their experiences of engaging with, assisting with the preparation of, or interpreting completed planning instruments, within a single study. This holistic, comprehensive and multidisciplinary examination of APP has produced new data to expand our knowledge of what constitutes high quality APP, barriers to planning and opportunities for improvement.

It has become clear that any form of advance planning, whether it be Advance Care Planning or a more comprehensive process of APP, stems from a desire for individuals to retain some form of control over what may happen to them in the future, as well as reducing the decision-making burden for their loved ones. An older person who chooses to plan ahead ensures they can continue to make choices, with their values and preferences documented and considered in instances of illness, loss of capacity, or even death with respect to making a Will. APP has a dual purpose in preserving someone's wishes while simultaneously preventing legal problems from arising in future.[294] APP is preventive, as it seeks to protect the older person by guarding against financial exploitation[295] and unwanted medical interventions.[296] It also seeks to prevent

[293] Ibid 8.
[294] Greenberg, Weiner and Greenberg (n 68).
[295] Ries (n 253); Lewis (n 108) 42; Australian Law Reform Commission (n 103) 321; Gardiner et al (n 106); Wuth (n 255).
[296] Morrison (n 201) 878; Batchelor et al (n 2) 173; Moore et al (n 11); Arianne Brinkman-Stoppelenburg, Judith AC Rietjens and Agnes van der Heide, 'The Effects of Advance Care Planning on End-of-Life Care: A Systematic Review' (2014) 28(8) *Palliative Medicine* 1000.

unnecessary stress for appointed decision-makers,[297] as they are aware of what the person wants in various legal, health and financial contexts. APP may also prevent confusion for, and conflicts between, family and friends with respect to what a person wants.[298] This clarity also extends to healthcare providers[299] and lawyers,[300] as APP – ideally – provides a clear record of a person's wishes, therefore minimising the potential for miscommunication and misunderstandings. The preventive nature of APP, and its overlap with Therapeutic Jurisprudence and Elder Law, will be examined in the next chapter.

[297] Orsatti (n 13) 157; Bryant et al, 'Inadequate Completion of Advance Care Directives by Individuals with Dementia' (n 5); McIlfatrick et al (n 9) 1356; Batchelor et al (n 2) 173; Detering et al, 'Prevalence and Correlates of Advance Care Directives among Older Australians' (n 6).
[298] Sinclair et al, 'Professionals' Views and Experiences in Supporting Decision-Making Involvement' (n 2) 91; Tran et al (n 11) 318; Detering et al, 'Prevalence and Correlates of Advance Care Directives among Older Australians' (n 6); Marcus Sellars et al, 'Costs and Outcomes of Advance Care Planning and End-of-Life Care for Older Adults with End-Stage Kidney Disease: A Person-Centred Decision Analysis' (2019) 14(5) *PLOS ONE* e0217787:1-11, 2; Dickinson et al (n 5).
[299] Moore et al (n 11) 9; Rolnick et al (n 3).
[300] Ries et al (n 8).

4 THEORETICAL LENS AND CONCEPTUAL FRAMEWORK

4.1 INTRODUCTION

The chapter identifies and discusses the integration of two existing theoretical perspectives, Preventative Law and Therapeutic Jurisprudence, within the broader field of Elder Law, offering a new perspective through which the rationale of Advance Personal Planning (APP) can be understood. The positioning of the inherently preventive nature of planning ahead alongside the focus on the wellbeing of older people, to guard against future personal, legal, financial and health-related issues, is a clear point of distinction in my research. This perspective highlights the range of people involved in planning processes, including the older person, members of their support community, such as family members or appointed decision-makers, and professional advisors, namely lawyers and healthcare providers.

It should be noted at this early point in the chapter that *Elder Law* is recognised as both a field of legal practice and a field of academic study.[1] While the actual practice of Elder Law includes 'counseling older adults on later-in-life planning and related concerns',[2] academic conceptions of Elder Law are defined as 'the study of how the law affects and responds to old age and the experience of getting older'.[3] Further, the concept of *law*, within the context of Elder Law, Therapeutic Jurisprudence, Preventive Law and APP, is interpreted broadly in my research,

[1] Nina A Kohn, 'A Framework for Theoretical Inquiry into Law and Aging' (2019) 21(1) *Theoretical Inquiries in Law* 187, 198 ('A Framework for Theoretical Inquiry').
[2] Ibid 199.
[3] Ibid.

incorporating legislation, common law principles, lawyering practices, legal risks, the resolution of legal conflicts, and litigation, which may involve legal settings such as courts and tribunals. When analysing results from my research, this broad understanding of law provided the lens through which deeper insights could be gained regarding how the law and its processes impact individuals as they age and what role it plays in their experiences.[4]

As noted above, APP is ideally a preventive process aimed at producing positive outcomes for older people and the people who care for them, particularly in light of changing health circumstances and potential periods of incapacity. As such, I have drawn upon literature relating to Preventive Law, Therapeutic Jurisprudence and Elder Law to provide an overarching framework to guide my research, including the development of research instruments and analysis of results. The integration of these theories and their unique application within the field of Elder Law allows for a holistic, comprehensive and informed study of APP. This framework aligns with what Holtz has termed 'the good result',[5] which 'is achieved through time, patience and perseverance'.[6] Holtz explains: 'Whether it be advocacy or counseling, elder law practitioners must be continually ready and willing to provide their clients insight and guidance as they make a variety of life-impacting decisions'.[7] Accordingly, my research advances the understanding of APP as a preventive, collaborative and meaningful process for older adults.

Therapeutic Jurisprudence and Preventive Law have previously been studied together, with the integration of the two theories being termed 'theralaw'.[8] Combining the integrated theories with the field of Elder Law creates a more beneficial model than if theralaw and Elder Law were adopted in isolation; they strengthen one another when used together.[9] While Preventive Law is focused on proactively guarding against conflicts arising in future, it is difficult to understand how such risks can be effectively prevented in an older person's life if professionals lack a complete picture of their personal, legal, financial and health-related circumstances.

[4] Ibid 196.
[5] Gregory T Holtz, 'Understanding the Ethics of Empowerment: An Elder Law Lawyer's Challenge or Obligation' (2017) 38(1) *Northern Illinois University Law Review* 81, 81.
[6] Ibid 87.
[7] Ibid.
[8] Jill Z Barclift, 'Preventive Law: A Strategy for Internal Corporate Lawyers to Advise Managers of Their Ethical Obligations' (2008) 33 *Journal of the Legal Profession* 31, 36.
[9] Bruce J Winick, 'The Expanding Scope of Preventive Law Therapeutic Jurisprudence Symposium' (2002) 3 *Florida Coastal Law Journal* 189; Dennis P Stolle, 'Professional Responsibility in Elder Law: A Synthesis of Preventive Law and Therapeutic Jurisprudence' (1996) 14(4) *Behavioral Sciences & the Law* 459.

Similarly, while a focus on the older person's wellbeing and the enhancement of positive interactions within legal environments are the central tenets of Therapeutic Jurisprudence, these principles require the use of legal tools so they can be operationalised in practice.

One compatible Preventive Law tool is a *legal checkup*. Similar to medical checkups, clients are encouraged to engage with their legal professional when they have a change in circumstances, wish to discuss their health circumstances or personal conflicts, or want to know more about their options for protecting their assets.[10] By adopting a practice grounded in Preventive Law and concerned with guarding against particular legal risks, lawyers are able to respond more easily to therapeutic concerns[11] and actively protect the wellbeing of their clients. While Preventive Law seeks to address 'legal soft spots', including issues such as who can support an older adult to make decisions in future, Therapeutic Jurisprudence helps identify any 'psycholegal soft spots'.[12] Although not significant legal issues in themselves, these psycholegal soft spots may nevertheless have real impact on an individual's wellbeing; they include issues such as making decisions about who an older person would like to be able to visit them at home or in a care facility in future if they can't voice this for themselves.

As such, the combination of Preventive Law and Therapeutic Jurisprudence enhances their flexibility,[13] and represents an important framework through which the wellbeing and quality of life of older adults can be considered.[14] Preventive Law tools provide the necessary foundation for Therapeutic Jurisprudence to be introduced and implemented with confidence within the field of Elder Law. The application of theralaw[15] within the field of Elder Law is a unique approach, highlighting how legal professionals and healthcare providers can work with their older clients and patients to consider their own circumstances, guard against conflicts from arising in future, and prioritise their own wellbeing when planning ahead.

[10] Winick (n 9) 197; Stolle (n 9) 476.
[11] Stolle (n 9) 477.
[12] Winick (n 9) 195; David B Wexler, 'Beyond Analogy: Preventive Law as Preventive Medicine', *National Center for Preventive Law* (Essay, 2000) <http://www.preventivelawyer.org/main/default.asp?pid=essays/wexler.htm> ('*Beyond Analogy*').
[13] Stolle (n 9) 477–478.
[14] MB Kapp, 'A Therapeutic Approach' in Israel Doron (ed), *Theories on Law and Ageing: The Jurisprudence of Elder Law* (Springer, 2009) 31, 43.
[15] Dennis P Stolle and David B Wexler, 'Therapeutic Jurisprudence and Preventive Law: A Combined Concentration to Invigorate the Everyday Practice of Law Essays' (1997) 39 *Arizona Law Review* 25, 28; Wexler, 'Beyond Analogy' (n 12).

4.2 KEY THEORETICAL PERSPECTIVES

4.2.1 Elder Law

The field of Elder Law emerged in the mid-1980s in the United States and has gained increasing attention globally due to the ageing population.[16] The law has a significant role to play in the care of individuals as they age by providing frameworks in which support and care can be provided, governing the role of professionals who assist older people, conferring rights and obligations on appointed decision-makers, and ensuring an older person's wishes are understood and respected.[17] This perspective is echoed in the *Counseling Guide for Lawyers*, prepared by the Commission on Law and Aging and the American Bar Association, in relation to Advance Care Planning:

> Advance care planning takes place over a lifetime. It changes as one's goals and priorities in life change through different stages of life and health conditions. Reflection, discussion, and communication with one's proxy and clinical professionals, along with family, friends, and advisors is essential to having one's wishes understood and honored.[18]

The focus of Elder Law, in relation to advance planning for older adults, is client-centric, as the main purpose is to meet the needs of the particular individual.[19] As Holtz states, the work of Elder Law practitioners should be directed towards 'preserving and protecting the dignity, sanctity, and worth of the elder client's life'.[20] Such direction involves collaboration between legal and health professionals, the older person and members of their support community, including appointed decision-makers.

The concept of ageing often raises concerns regarding vulnerability and capacity.[21] Despite the fact that age is often used as a marker to identify vulnerability,[22] older people should not simply

[16] Israel Doron, '25 Years of Elder Law: An Integrative and Historical Account of the Field of Law and Aging' (2019) 21(1) *Theoretical Inquiries in Law* 1, 2–3; AD Bogutz, 'Elder Law: A Personal Perspective' in Israel Doron (ed), *Theories on Law and Ageing: The Jurisprudence of Elder Law* (Springer, 2009) 1, 2.
[17] Bogutz (n 16) 4.
[18] Commission on Law and Aging and American Bar Association, *Advance Directives: Counseling Guide for Lawyers* (Report, 2018) ii <https://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/ad-counseling-guide/>.
[19] Richard L Kaplan, 'Elder Law as Proactive Planning and Informed Empowerment during Extended Life' (2010) 40(1) *Stetson Law Review* 15, 17.
[20] Holtz (n 5) 85.
[21] See generally Lise Barry, 'Capacity and Vulnerability: How Lawyers Assess the Legal Capacity of Older Clients' (2017) 25(1) *Journal of Law and Medicine* 267 ('Capacity and Vulnerability').
[22] Alexander Antonio Boni-Saenz, 'Age, Equality, and Vulnerability' (2019) 21(1) *Theoretical Inquiries in Law* 161, 162; Barry, 'Capacity and Vulnerability' (n 21) 271.

be labelled as a vulnerable group upon whom assumptions regarding dependence and homogeneity are subsequently imposed. Ageing should be understood as 'a unique and important socio-legal category' that 'simultaneously serves as an involuntary numerical measure of one's time in existence and a rich symbol filled with social meaning'.[23] This powerful articulation of ageing encourages an understanding of age as a distinct marker not only of a person's chronological age, but also in recognition of the wealth of experience and unique perspective of life and society that an older adult has attained. As such, the ageing process can be understood as highly individualised,[24] especially when considering the significant impact determinants of health can have on an individual's longevity, and their overall influence on life expectancy.[25] For example, people who have a stronger socioeconomic position and higher education qualifications are generally healthier, which has a positive influence on their longevity.[26]

While older adults may become vulnerable over time, due to declining health and potentially increased periods of isolation, this does not render them incapable of considering and planning their future wishes and preferences. It simply means they may require a higher level of assistance to record and manage their affairs.[27] If an older person experiences decreased capacity, they can still be supported to exercise their legal rights, as long as they are able to understand the nature and effect of the choices they are making and any documents they are creating. Therefore, reduced or fluctuating cognition should not be a barrier to engaging with forms of later life planning.[28] However, it is often when a client has received a diagnosis, such as dementia, that advance planning begins in earnest.[29] In Australia, the *Clinical Practice Guidelines and Principles of Care for People with Dementia* encourage the provision of legal information so individuals can understand and engage with various forms of planning,

[23] Boni-Saenz (n 22) 161.
[24] Ibid 168; Kohn, 'A Framework for Theoretical Inquiry' (n 1) 189–190.
[25] Australian Institute of Health and Welfare, *Australia's Health 2018* (Australia's Health Series No 16. Report No 16 AUS 221, 2018) <https://www.aihw.gov.au/reports/australias-health/australias-health-2018/contents/about>.
[26] Ibid 179.
[27] LA Frolik, 'Later Life Legal Planning' in Israel Doron (ed), *Theories on Law and Ageing: The Jurisprudence of Elder Law* (Springer, 2009) 11, 12.
[28] Lise Barry, '"He Was Wearing Street Clothes, Not Pyjamas": Common Mistakes in Lawyers' Assessment of Legal Capacity for Vulnerable Older Clients' (2018) 21(1) *Legal Ethics* 3, 10 ('He Was Wearing Street Clothes, Not Pyjamas'); Frolik (n 27) 16.
[29] Elise Mansfield et al, 'Prevalence and Type of Unmet Needs Experienced by People Living with Dementia' (2022) 87(2) *Journal of Alzheimer's Disease* 833; Betty S Black et al, 'Unmet Needs in Community-Living Persons with Dementia Are Common, Often Non-Medical and Related to Patient and Caregiver Characteristics' (2019) 31(11) *International Psychogeriatrics* 1643; Frolik (n 27) 24–25.

including APP, to ensure their wishes are understood and can be implemented by others in the future.[30] If older adults have previously engaged with APP processes, this can relieve some of the physical and emotional burden that may be placed on the older client and their caregivers following a diagnosis of a life-limiting condition or a condition with progressive cognitive decline, such as dementia. Further, if a person has previously completed APP instruments, a new diagnosis concerning their health should trigger a review of any legal appointments or recorded wishes. Communicating with members of the older person's support community, including family members, appointed decision-makers and professional advisors is also a key recommendation. This ongoing approach to APP upholds the principles of Elder Law as person-focused, ensuring the needs of older people are not only understood but successfully met as they age.

4.2.2 Therapeutic Jurisprudence

Therapeutic Jurisprudence, while not a complete theory itself, is a relevant 'field of inquiry'[31] through which my research is focused. Because Therapeutic Jurisprudence is concerned with the effect legal interactions can have on the psychological wellbeing of individuals,[32] it is essential to first examine both the potential therapeutic and antitherapeutic impact of the law, and then work towards increasing the therapeutic aspects of legal support and reducing its antitherapeutic consequences.[33] Therapeutic Jurisprudence also introduces the concept of 'psycholegal soft spots',[34] as noted above. While 'legal soft spots' relate to circumstances that might lead to future legal conflicts for the client, a concept which is highly relevant to Preventive Law, 'psycholegal soft spots' are concerned with the client's social connections and wellbeing, which should be taken into account when attempting to prevent conflict or considering which legal tools are best suited to their situation.[35]

[30] Cognitive Decline Partnership Centre, *Clinical Practice Guidelines and Principles of Care for People with Dementia* (Report, NHMRC Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People, February 2016) 10 <https://cdpc.sydney.edu.au/wp-content/uploads/2019/06/CDPC-Dementia-Guidelines_WEB.pdf>.
[31] David B Wexler, 'From Theory to Practice and Back Again in Therapeutic Jurisprudence: Now Comes the Hard Part' (2011) 37(1) *Monash University Law Review* 33, 33 ('From Theory to Practice and Back Again').
[32] Stolle and Wexler (n 15) 25.
[33] Mark Glover, 'A Therapeutic Jurisprudential Framework of Estate Planning' (2011) 35 *Seattle University Law Review* 427, 431.
[34] Wexler, 'Beyond Analogy' (n 12); Winick (n 9) 195.
[35] Dennis P Stolle et al, 'Integrating Preventive Law and Therapeutic Jurisprudence: A Law and Psychology Based Approach to Lawyering' (1997) 34 *California Western Law Review* 15, 42–43.

The Australian Institute of Health and Welfare (AIHW)[36] has developed a comprehensive conceptualisation of *wellbeing* that is suited to my research. It is a term that should not be understood in isolation; rather, it includes interconnected relationships between contextual factors, determinants of wellbeing, and services and supports that are designed to promote and improve the welfare of individuals.[37] The notion of wellbeing incorporates factors that may impact the quality of life for older adults, including but not limited to: safe and stable housing; the option of continued involvement in the workforce; supportive relationships with those close to them, including family and friends; ease of access to health services; ability to access legal advice; and economic stability.[38] Therefore, it includes notions of legal, social, financial and personal wellbeing. The acknowledgement of relevant contextual factors, including geographical location, rurality, social connections, economic circumstances, and changes associated with ageing, also inform this conceptualisation. The AIHW cites examples of the determinants of wellbeing that underpin overall wellbeing, including 'family functioning, social engagement, material resources, health status, support networks, employment and skills, secure housing, personal factors and behaviours'.[39] Finally, services and supports should consider the ability and ease of older adults to access, or attempt to access, a range of services such as accommodation, employment, disability or income support payments, help around the home, and community groups that may provide vital social connections.[40] This broader understanding of wellbeing is very closely linked to Therapeutic Jurisprudence, but goes further than an individual's psychological wellbeing.

Within the field of Elder Law, the goal of Therapeutic Jurisprudence is to encourage a holistic assessment of the impact legal processes can have on older adults and those around them, as any interactions can have consequences for the wellbeing of all involved.[41] APP has potentially both therapeutic and antitherapeutic effects. Positive effects include: enhancing personal freedom in creating plans; personal connection with and support from key people during the process; and the opportunity for self-expression of wishes and preferences.[42] However, negative consequences, including anxiety associated with mortality and the potential loss of

[36] Australian Institute of Health and Welfare, *Australia's Welfare 2019: Data Insights* (Australia's Welfare Series No 14. Catalogue No AUS 226, 2019) <https://www.aihw.gov.au/reports/australias-welfare/australias-welfare-2019-data-insights/data>.
[37] Ibid 2, 7.
[38] Ibid 2.
[39] Ibid.
[40] Ibid 2, 7.
[41] Kapp (n 14) 31.
[42] Glover (n 33) 444–461.

capacity, disputes regarding estate distribution, conflicts within families, and concerns about the duration and cost of the process, must also be acknowledged.[43] While the promotion of APP as a communicative process is therapeutic on the surface, the nature of the conversations could potentially induce family conflicts regarding finances, privacy, and the roles of different individuals. For example, if an older person discusses their financial circumstances with their family, this could lead to feelings of entitlement by adult children. On the other hand, an older adult may be reluctant to discuss their financial or personal circumstances with others, feeling that such matters are private. Similarly, the selection of an appointed decision-maker could place an older person in a difficult position, especially if other adult children believe they would be more suitable for that role, and seek to assert their opinion in circumstances where they have not been authorised to do so.

Recent therapeutic developments include the recognised movement from 'substituted' to 'supported' decision-making,[44] which was motivated by the shifting international approach to disability under the *Convention on the Rights of Persons with Disabilities*.[45] Supported decision-making 'enables people with cognitive disabilities to exercise their legal decision-making rights',[46] while substituted decision-making occurs 'where other people make decisions on behalf of a person with disability',[47] depriving the person of the opportunity to control their own circumstances. Similarly, at a national level, the Australian Law Reform Commission recommended that supported decision-making be included in the National Decision-Making Principles as part of their *Final Report on Equality, Capacity and Disability in Commonwealth Laws*.[48] The Australian Government has since prioritised supported decision-making in the *National Dementia Action Plan*.[49]

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[43] Barry, 'Capacity and Vulnerability' (n 21) 272; Glover (n 33) 434–443.

[44] Kelly Purser and Karen Sullivan, 'Capacity Assessment and Estate Planning - The Therapeutic Importance of the Individual' (2019) 64 *International Journal of Law and Psychiatry* 88, 89.

[45] *Convention on the Rights of Persons with Disabilities,* opened for signature 30 May 2007, 2515 UNTS 3 (entered into force 3 May 2008).

[46] Office of the Public Advocate, *Supported Decision-Making in Victoria: A Guide for Families and Carers* (Guidelines, October 2020) <https://www.publicadvocate.vic.gov.au/joomlatools-files/docman-files/general/Supported_Decision_Making_in_Victoria.pdf>; 'Supported Decision-Making and Capacity', *NSW Trustee & Guardian* (Web Page, 2020) <https://www.tag.nsw.gov.au/guardianship/supported-decision-making-and-capacity>.

[47] Office of the Public Advocate (n 46) 6.

[48] Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws* (Final Report No 124, August 2014) 63 <https://www.alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-alrc-report-124/>.

[49] Department of Health and Aged Care, *National Dementia Action Plan* (Public Consultation Paper, Australian Government, November 2022) 43 <https://consultations.health.gov.au/++preview++/aged-care-division/ndap-public-

Despite these developments, there are critiques of Therapeutic Jurisprudence. For example, emphasising a therapeutic position may result in the view that older people need to be protected by lawyers, rather than being independent and capable people in their own right. It should be understood that some legal actions, particularly litigation, may produce antitherapeutic effects for the individuals involved, despite the fact that a court may be the only appropriate venue for a successful resolution.[50] Further, the continued promotion of Therapeutic Jurisprudence carries with it the assumption that it is something lawyers are not already striving towards, despite the fact that many practitioners would already be actively promoting these principles. Even if lawyers are adopting Therapeutic Jurisprudence in practice, the legal frameworks with which they must comply, such as the *Guardianship Act 1987* (NSW), contain features that are anti-therapeutic. In the context of APP, anti-therapeutic effects may arise for an older person where a Guardian is appointed, against their wishes and not of their choosing, to manage their affairs.[51] Similarly, the adoption of a Therapeutic Jurisprudence approach may be simply asking too much of lawyers, as they are not formally trained in identifying and safeguarding the psychological wellbeing of clients.[52]

In response to this critique, my conceptualisation of *therapeutic* within APP builds on Holtz' expression of 'the good result'.[53] While lawyers may lack training that would inform the traditional focus of Therapeutic Jurisprudence on the psychological wellbeing of clients, legal practitioners are readily able to collaborate with their client to consider what a good result will be, based on their personal circumstances. As such, within the scope of my thesis, *therapeutic* encompasses legal, financial, social and personal wellbeing. This focus aims to reduce the anti-therapeutic or negative effects of legal interactions between an older person and a lawyer, or between an older person and a legally appointed decision-maker, ensuring there is minimal detrimental impact on the wellbeing of those involved in both the processes of engaging with APP and acting on such planning in future. A shift from the traditional legal transaction approach to a more communicative, holistic process is essential in a realisation of Holtz' conceptualisation of 'the good result', which may be achieved in the following manner:

consultation/supporting_documents/National_Dementia_Action_Plan_consultation%20paper_final18%20Nov.pdf>.

[50] Wexler, 'From Theory to Practice and Back Again' (n 31) 33; Stolle et al (n 35) 30.

[51] See, eg, Anne Connolly, 'Prisoner of the State: What Happens when the State Rules you're Incapable of Looking After Yourself?', *ABC News* (online, 26 March 2023) <https://www.abc.net.au/news/2023-03-26/public-trustee-dementia-aged-care/102078430>.

[52] Barclift (n 8) 37.

[53] Holtz (n 5).

> Accordingly, advising and then achieving a good result on behalf of the client requires that the lawyer ask and then answer the following questions throughout the client representation and engagement: (1) Will the contemplated result avoid evil and sustain, protect and preserve the client or the client's interests? (2) Is the contemplated result a product of the client's true free will and intellect? If the answer to both questions is, 'yes', then a good result has been achieved on behalf of the client. The practitioner can move forward with the representation knowing it is consistent with the client's vision and deeply held beliefs. Consistency occurs because measured effort, beyond mere expediency, has been invested to ensure development of a planning product that is reasoned and coherent.[54]

In sum, the good result 'strives to assure that an individual has freely used his or her intellect and will, and that in doing so, he or she has made a decision that is intrinsically their own. … It suggests a course of action that is consistent with the individual's core beliefs and perspective'.[55] Holtz uses both an Enduring Power of Attorney and an Advance Care Directive as illustrative examples of how a good result can be achieved. In the context of an Enduring Power of Attorney, a good result 'is the product of measured client interaction and involvement' where the lawyer assists the client to understand key concepts through a collaboration, which takes into account their subjective circumstances.[56] Similarly, when preparing Advance Care Directives, the utilisation of templates with no consideration of the client's unique position will not necessarily lead to a good result; '[o]nly a process that weighs and considers the meaning, implication, and import of the choices inherent in advance directive utilization will achieve such a result'.[57] These examples demonstrate how Therapeutic Jurisprudence can be operationalised within the context of Elder Law practice.

4.2.3 Preventive Law

Preventive Law was first articulated by Brown in the 1950s,[58] and developed further under Stolle in the 1990s[59] when the integration of Preventive Law and Therapeutic Jurisprudence was first introduced.[60] Essentially, Preventive Law is a shift in focus away from reacting to a

[54] Ibid 92–93.
[55] Ibid 93–94.
[56] Ibid 103.
[57] Ibid 104.
[58] Louis M Brown, 'The Law Office - A Preventive Law Laboratory' (1956) 104(7) *University of Pennsylvania Law Review* 940.
[59] Stolle et al (n 35); Stolle and Wexler (n 15); Stolle (n 9).
[60] Winick (n 9) 189.

crisis and towards taking active steps to prevent it from occurring in the first place,[61] which is achieved through communication and planning[62] rather than a conflict driven approach.[63] It introduces the concept of 'legal hygiene'[64] and the need for regular 'legal checkups',[65] which are designed to provide a holistic view of the client's life, including their values, finances, concerns and family structure.[66] The goal is to protect the client's interests and proactively guard against future legal conflicts.[67] The early preparation of legal mechanisms is therefore a vital aspect of Preventive Law. It has previously been linked to various fields of law, including commercial,[68] construction,[69] contracts, and dispute resolution.[70] Preventive Law has dual benefits.[71] First, clients are able to actively engage in the process and collaborate with their lawyer, something that is often missing in litigation.[72] At the same time, lawyers work alongside clients, giving them a deeper understanding of any particular issues that may arise in future.[73] This early intervention helps to prevent legal risks from occurring, or minimise their impact if they do eventuate.[74]

The first step in actualising Preventive Law is to gain an understanding of the client's individual problem, and how it can develop over time. Secondly, individual components within the problem need to be considered. Third, interactions between the components should be

[61] Brown (n 58) 942; Thomas D Barton, 'Preventive Law for Multi-Dimensional Lawyers', *National Center for Preventive Law* (Essay, 2000) <http://www.preventivelawyer.org/main/default.asp?pid=essays/barton.htm> ('Preventive Law for Multi-Dimensional Lawyers'); Michael Goldblatt, Robert Hardaway and Robert Scranton, 'Establishing the Mindset of Practicing Preventively', *National Center for Preventive Law* (Essay, 2000) <http://www.preventivelawyer.org/main/default.asp?pid=essays/goldblatt.htm>.
[62] Winick (n 9) 189; Stolle (n 9) 468.
[63] Perry A Zirkel, 'An Ounce of Prevention', *National Center for Preventive Law* (Essay, 2000) <http://www.preventivelawyer.org/main/default.asp?pid=essays/zirkel.htm>.
[64] Ibid.
[65] Winick (n 9) 189; Stolle et al (n 35) 17; Stolle and Wexler (n 15) 25; Stolle (n 9); Harold A Brown, 'Preventive Law - The Next Generation', *National Center for Preventive Law* (Essay, 2000) <http://www.preventivelawyer.org/main/default.asp?pid=essays/ha_brown.htm>; Wexler, 'Beyond Analogy' (n 12); Zirkel (n 63).
[66] Stolle et al (n 35) 32.
[67] Ibid 16; Stolle (n 9) 465.
[68] Barclift (n 8); Paivi Nygren, 'Prevention Is Better than Cure: Insurance Company's View on Preventive Law', *National Center for Preventive Law* (Essay, 2000) <http://www.preventivelawyer.org/main/default.asp?pid=essays/nygren.htm>.
[69] James P Groton, 'Preventive Practices: Lessons from the Construction Industry' in Thomas D Barton (ed), *Preventive Law and Problem Solving: Lawyering for the Future* (Vandeplas Publishing, 2009) 75.
[70] Soili Nysten-Haarala, 'Preventive Law - Some Theoretical and Practical Aspects', *National Center for Preventive Law* (Essay, 2000) <http://www.preventivelawyer.org/main/default.asp?pid=essays/nysten-haarla.htm>.
[71] Barclift (n 8).
[72] Ibid 34.
[73] Ibid 31; Stolle (n 9) 466.
[74] Barclift (n 8) 33–34.

understood. Fourth, the components need to be evaluated in terms of the most appropriate intervention. Finally, various creative options for solving the problem should be formulated, as more than one measure may be required.[75] Accordingly, the preventive lawyer must understand the client's whole environment and how this informs their values and wellbeing.[76] Transparency is key, as the lawyer needs to be provided with all the relevant facts, and the client must be made aware of the applicable law for Preventive Law to be effective.[77]

Like Therapeutic Jurisprudence, critics argue that Preventive Law is redundant because lawyers may already be doing it.[78] Further, they assert clients will become frustrated if they attend a consultation for one purpose and are bombarded with additional perceived problems, which could also give rise to unscrupulous practices for increasing business.[79] While many lawyers are undoubtedly implementing aspects of Preventive Law or Therapeutic Jurisprudence, or both, there is a desire to make the approach more systematic.[80] Given the increasing awareness of elder abuse,[81] and the prevalence of financial abuse in particular,[82] APP has a significant preventive role in protecting older adults in the event they experience future periods of vulnerability or instances of high dependency. To ensure this protective role is realised, APP

[75] Cheng-Pei Lin et al, 'The Conceptual Models and Mechanisms of Action That Underpin Advance Care Planning for Cancer Patients: A Systematic Review of Randomised Controlled Trials' (2019) 33(1) *Palliative Medicine* 5; Thomas D Barton, *Preventive Law and Problem Solving: Lawyering for the Future* (Vandeplas Publishing, 2009) 74–77 ('*Preventive Law and Problem Solving*'); Barclift (n 8); Winick (n 9) 189.
[76] Barton, 'Preventive Law and Problem Solving' (n 75).
[77] Brown (n 58) 947.
[78] Barclift (n 8) 37; Stolle et al (n 35) 17, 19; Stolle and Wexler (n 15) 29.
[79] Stolle et al (n 35) 17; Barclift (n 8) 37.
[80] Stolle and Wexler (n 15) 29.
[81] Lixia Qu et al, *National Elder Abuse Prevalence Study* (Final Report, Australian Institute of Family Studies, July 2021) 1–2 <https://aifs.gov.au/research/research-reports/national-elder-abuse-prevalence-study-final-report>; Australian Institute of Health and Welfare (n 36) xx; Council of Attorneys-General (Australia) and Attorney-General's Department, *National Plan to Respond to the Abuse of Older Australians (Elder Abuse) 2019-2023* (Report, 8 July 2019) <https://www.ag.gov.au/rights-and-protections/publications/national-plan-respond-abuse-older-australians-elder-abuse-2019-2023>; Australian Law Reform Commission, *Elder Abuse - A National Legal Response* (ALRC Report No 131, June 2017) <https://www.alrc.gov.au/publication/elder-abuse-a-national-legal-response-alrc-report-131/>.
[82] Australian Institute of Health and Welfare (n 36) xx; Nola M Ries, 'Enduring Powers of Attorney and Financial Exploitation of Older People: A Conceptual Analysis and Strategies for Prevention' (2022) 34(3) *Journal of Aging & Social Policy* 357, 357; Natalia Wuth, 'Enduring Powers of Attorney: With Limited Remedies - It's Time to Face the Facts' (2013) 7 *Elder Law Review* 1, 1; Sarah Ellison et al, *The Legal Needs of Older People in NSW* (Report, Law and Justice Foundation of New South Wales, December 2004) 272 <https://lawfoundation.net.au/wp-content/uploads/2023/11/54PJR_The-legal-needs-of-older-people-in-NSW_2004.pdf>.

instruments will need to be carefully prepared to minimise the risk that any legal planning tool could 'be abused and transformed from a preventive tool to a harmful one'.[83]

As such, the combination of Preventive Law and Therapeutic Jurisprudence, known as theralaw, provides a holistic, individualised and preventative approach to future legal issues, with a focus on upholding a person's wellbeing and prioritising a collaborative relationship between clients and lawyers. My research foregrounds the practical focus of Preventive Law, highlighting how its associated tools are compatible with the theory underpinning Therapeutic Jurisprudence, recognising that both legal and health professionals play a vital role in understanding the needs, wishes and wellbeing of their clients and patients. This is even more significant when older clients or patients are involved, due to factors such as declining health, periods of incapacity or the potential for elder abuse. Hence, the application of theralaw within the field of Elder Law is vital to my research. Consequently, any engagement with APP should actively include professional perspectives so that any prepared instruments are not only fit for purpose from a legal standpoint, but also tailored to the health and personal circumstance of the older person.

4.3 Conceptual Framework: Vulnerability, Empowerment and Autonomy

Following the integration of the theoretical perspectives of Therapeutic Jurisprudence and Preventive Law within the field of Elder Law, key terms that can inform a holistic understanding of APP for older adults can be conceptualised. While these concepts have informed the development of my research questions, research design and methods, and analysis of results, they also represent an original contribution to the evidence base. The application of theralaw, while previously encouraged by scholars, is being uniquely considered within the field of Elder Law, focusing on how legal interactions, legislation, common law principles, legal conflicts and resolutions affect individuals as they age. A person-centric perspective has been adopted in this research, allowing for deeper consideration of how older adults have experienced APP, and the essential role legal and health professionals play in supporting them

[83] Israel Doron and Iddo Gal, 'The Emergence of Legal Prevention in Old Age: Findings from an Israeli Exploratory Study' (2007) 21(1–2) *Journal of Cross-Cultural Gerontology* 41, 51 ('The Emergence of Legal Prevention in Old Age'). See also Barry, 'He Was Wearing Street Clothes, Not Pyjamas' (n 28) 22.

through planning processes. Key concepts that arise in this area are: vulnerability, empowerment and autonomy.

4.3.1 Vulnerability

Population groups that are stereotyped as vulnerable are subjected to a paternalistic notion of protection that often assumes a lack of capacity and results in an unfounded withdrawal, or lack of recognition, of a person's agency.[84] Increased rates of dependency that people may experience as they age can be wrongly identified as vulnerability, which is subsequently used to reduce or withhold autonomy and only serves to strengthen the misunderstanding that all older people are vulnerable.[85] This undermines the fact that many older adults are physically and cognitively able to manage their own affairs, even if they are viewed by society as a vulnerable group.[86] Despite vulnerability being described as a 'universal, inevitable, enduring aspect of the human condition that must be at the heart of our concept of social and state responsibility',[87] this does not mean it is a static state of being.[88] In contrast, vulnerability should be recognised as experiences 'of chronic and episodic dependency across the lifecourse'.[89]

Building on this understanding of vulnerability as periods of heighted dependency, Hall focuses on the related concepts of undue influence and unconscionability.[90] This perspective helps to avoid ageist stereotypes that are often embedded within the term, and instead focus on relationship-based and circumstantial elements that can make an older person vulnerable.[91] It also individualises the concept, as it can manifest differently for every individual, if at all.[92] Similarly, the Council of Attorneys-General highlighted factors that may increase an older person's vulnerability, including 'isolation from family and friends, cognitive decline, need for care, a history of trauma or family conflict, and language and cultural barriers'.[93] The

[84] Martha Albertson Fineman, '"Elderly" as Vulnerable: Rethinking the Nature of Individual and Societal Responsibility' (2012) 20 *Elder Law Journal* 101, 114–115 ('"Elderly" as Vulnerable').
[85] Ibid 116–117. See also Barry, 'Capacity and Vulnerability' (n 21) 271.
[86] Fineman, '"Elderly" as Vulnerable' (n 84) 116–117.
[87] Martha Albertson Fineman, 'The Vulnerable Subject: Anchoring Equality in the Human Condition' (2008) 20(1) *Yale Journal of Law and Feminism* 1, 8 ('The Vulnerable Subject').
[88] Barry, 'He Was Wearing Street Clothes, Not Pyjamas' (n 28) 6–7.
[89] Fineman, 'The Vulnerable Subject' (n 87) 11, cited in Boni-Saenz (n 22) 166.
[90] MI Hall, 'Equity Theory: Responding to the Material Exploitation of the Vulnerable but Capable' in Israel Doron (ed), *Theories on Law and Ageing: The Jurisprudence of Elder Law* (Springer, 2009) 107.
[91] Ibid 109–110.
[92] Ibid 115.
[93] Council of Attorneys-General (Australia) and Attorney-General's Department (n 81) 30. See also Barry (n 21) 270; Barry, 'He Was Wearing Street Clothes, Not Pyjamas' (n 28) 6–7.

significance of isolation is also recognised by the Australian Association of Gerontology, as it can affect people regardless of their background and subsequently increase opportunities for abuse.[94] Ries also highlights several factors that might increase the vulnerability of older adults within the context of financial exploitation, including 'cognitive impairment, lower numeracy and literacy, physical disability, dependence on others for care, depression and prior life history of trauma or abuse'.[95] Therefore, my conceptualisation of 'vulnerability' recognises that age alone is not determinative. Older adults may experience instances of vulnerability based on their personal or family circumstances, particularly if they need to depend more on others for certain periods of time.

This conceptualisation of vulnerability as flexible periods of heightened dependency has allowed me to appreciate that, despite being perfectly capable, older adults may still find themselves vulnerable in certain situations,[96] including in their relationships with others where an element of influence or control may be exercised. As such, lawyers practising in the field of Elder Law must be able to balance the realities of ageing with the urge to adopt common stereotypes,[97] especially regarding capacity. This approach will ensure the benefits of theralaw are realised, where legal mechanisms are used to proactively guard against future legal issues and protect against undue influence, while taking into account all aspects of a person's wellbeing, including their social, financial and personal circumstances.

4.3.2 Empowerment

While 'empowerment' is cited frequently in the literature, conceptualising the term has been more difficult.[98] Works that adopt a feminist lens are most applicable to the way I have sought to operationalise empowerment, as they include the related concepts of participation, power and control. Karl defines empowerment as 'a process of awareness and capacity building leading to greater participation, to greater decision-making power and control, and to

[94] Australian Association of Gerontology and Older Persons Advocacy Network, *Submission on Australian Guardianship and Administration Council National Elder Abuse Project: Best Practice Resource on Enduring Appointments* (Submission, 6 August 2019) 2. See also Barry, 'Capacity and Vulnerability' (n 21) 273.
[95] Ries (n 82) 361.
[96] Barry, 'He Was Wearing Street Clothes, Not Pyjamas' (n 28) 5; Barry, 'Capacity and Vulnerability' (n 21) 272; Hall (n 90) 107–108.
[97] Fineman, '"Elderly" as Vulnerable' (n 84); Stolle (n 9) 465.
[98] Jan Fook and Christine Morley, 'Empowerment: A Contextual Perspective' in Steven F Hick, Jan Fook and Richard Pozzuto (eds), *Social Work: A Critical Turn* (Thompson Educational Publishing, 2006) 67.

transformative action'.[99] This articulation is well suited to my research, as it facilitates a focus on enhancing older adults' knowledge and awareness of the full range of APP instruments that are available to them. This knowledge enables them to make a wider range of decisions and take control of their current affairs, participating fully in the range of APP discussions and processes, while retaining control through the relevant documents and appointments at a time when they can no longer speak for themselves. While participation is key, it must be meaningful. Oxaal and Baden explain:

> Empowerment is demonstrated by the quality of people's participation in the decisions and processes affecting their lives. In theory, empowerment and participation should be different sides of the same coin. In practice, much of what passes for popular participation is not in any way empowering to the poorest and most disadvantaged people in society.[100]

This understanding of meaningful participation has prompted me to pay greater attention to the process through which instruments are prepared, as well as their quality, therefore understanding that APP completion alone is not a sufficient indicator that instruments have been made effectively or could be used in future.

As Kaplan states, the crux of empowerment of older clients is to ensure the 'person can exercise maximum control over his or her assets and autonomy'.[101] Similarly, Oxaal and Baden assert power 'relates to having decision-making authority, power to solve problems and can be creative and enabling'.[102] As my approach to APP includes prioritising, facilitating and extending the decision-making authority of older clients, these conceptualisations of control and authority have been adopted in my operationalisation of empowerment. The process of planning ahead allows older people to not only record their wishes, values and preferences, but also retain control over the direction of their remaining years. They are able to instruct how they would like their money or assets managed at a later time when they may require support, how they want their property to be distributed following death, appoint people to whom they delegate decision-making responsibility, and specify their preference for healthcare to guide future decisions at a point when they have lost capacity. This control relates to planning for the

[99] Marilee Karl, 'Obstacles and Opportunities' in *Women and Empowerment: Participation and Decision-Making* (Zed Books Ltd, 1995) 14.
[100] Zoë Oxaal and Sally Baden, *Gender and Empowerment: Definitions, Approaches and Implications for Policy* (BRIDGE Report No 40, Institute of Development Studies, January 1997) <https://archive.ids.ac.uk/bridge/bridge-publications/reports/document/A23334.html>.
[101] Kaplan (n 19) 70.
[102] Oxaal and Baden (n 100) 1.

rest of life, not simply the end of life.[103] This conceptualisation embodies the principles of theralaw, as informed participation in APP processes may help to guard against legal conflicts or adverse events from arising in future. Similarly, the exercise of control over future decision-making through APP mechanisms may help to reduce antitherapeutic effects that an older adult may otherwise experience if such advance planning had not occurred.

Within the health promotion context, Mason et al also highlight that empowerment is largely concerned with enabling individuals to recognise and utilise their personal power, with an acknowledgement of others who are involved in any relevant processes.[104] This point has aligned with my understanding of APP, in that it enables individuals to take control over their future while also considering and respecting others who are involved, including family, trusted individuals and appointed decision-makers. The emphasis on self-management within the context of an individual's circumstances is also echoed in the literature relating to social work,[105] health promotion[106] and community development,[107] where 'the rhetoric of empowerment is based on notions of self-help, individual and community responsibility, and "bottom-up" techniques'.[108] The specific context of Elder Law is suited to a modern understanding of empowerment, which 'encourages individuals to assume overall and unfettered responsibility for managing their own destiny and future'.[109] Lawyers and health professionals have a key role to play in promoting APP and ensuring completed instruments safeguard against future legal risks, including circumstances where other people could be exercising undue influence for their own personal motives.[110] Adopting a holistic view of the older adult's life, including their financial, personal, legal and physical wellbeing is essential here, as the best course of action needs to be informed by the older person's circumstances and preferences.

[103] Gail Yapp et al, 'Planning for the Rest-of-Life, Not End-of-Life: Reframing Advance Care Planning for People with Dementia' in Gaynor Macdonald and Jane Mears (eds), *Dementia as Social Experience: Valuing Life and Care* (Routledge, 1st ed, 2018) 134.
[104] Diana J Mason, Barbara A Backer and Catherine Alicia Georges, 'Towards a Feminist Model for the Political Empowerment of Nurses' (1991) 23(2) *Journal of Nursing Scholarship* 72, cited in Christine M Rodwell, 'An Analysis of the Concept of Empowerment' (1996) 23(2) *Journal of Advanced Nursing* 305, 307.
[105] Fook and Morley (n 98) 71.
[106] Jeff French, 'Boundaries and Horizons, the Role of Health Education within Health Promotion' (1990) 49(1) *Health Education Journal* 7, 8.
[107] Daniel S Shah, 'Lawyer for Empowerment: Community Development and Social Change' (1999) 6(1) *Clinical Law Review* 217; CL Herbert, 'The Ideology of Empowerment: Governing Community Development' (1998) 5(3) *Northern Radius* 30.
[108] Fook and Morley (n 98) 72. See also Oxaal and Baden (n 100) 6; Rodwell (n 104) 308.
[109] Holtz (n 5) 82.
[110] Ibid 85. See also Ries (n 82).

Theralaw encourages the notion of increasing and prioritising communication, which serves to enhance an individual's participation and continued involvement in their affairs, helping to 'break down ageist notions that elders must cede control over themselves to others'.[111] Engaging in the process of personal planning can be empowering for individuals,[112] as long as they are provided opportunities for meaningful participation,[113] and are fully informed about the available legal mechanisms and their intended purpose.[114] Preventive Law helps subvert any power imbalance that can exist in lawyer-client relationships by encouraging collaboration and the older adult's active involvement,[115] and proceeding from a perspective of empowerment rather than vulnerability. Communication and participation are vital as they preserve the older adult's autonomy and control over their own affairs,[116] and have the potential to decrease antitherapeutic consequences that may otherwise arise.

4.3.3 Autonomy

Autonomy is very closely linked with the concept of empowerment. Abrams offers a thorough overview of liberal conceptions of autonomy, followed by a feminist restructuring of the term.[117] Similar to the feminist perspective that was introduced in section 4.3.2 in relation to empowerment, this lens provides a perspective that is well suited to the direction I take in my research. Initial liberal interpretations of autonomy were concerned with morals and connections to others, rather than viewing individuals as completely isolated entities.[118] Connected concepts identified by Feinberg include self-directedness, authenticity and self-identity.[119] Authenticity is paramount to my interpretation of autonomy, as it ensures an individual 'is not merely the mouthpiece of other persons or forces. Rather, his tastes, opinions, ideals, goals, values, and preferences are all authentically *his*'.[120] Similarly, self-identity ensures an autonomous person is recognised as an individual, and not only in connection with

[111] Nina Kohn, 'Elder Empowerment as a Strategy for Curbing the Hidden Abuses of Durable Powers of Attorney' (2006) 59(1) *Rutgers Law Review* 1, 53 ('Elder Empowerment as a Strategy').
[112] Glover (n 33).
[113] Purser and Sullivan (n 44) 92.
[114] Kapp (n 14) 32; Doron and Gal (n 83).
[115] Barton, 'Preventive Law for Multi-Dimensional Lawyers' (n 61).
[116] Kohn, 'Elder Empowerment as a Strategy' (n 111).
[117] Kathryn Abrams, 'From Autonomy to Agency: Feminist Perspectives on Self-Direction' (1999) 40 *William and Mary Law Review* 805.
[118] Ibid, citing Joel Feinberg, 'Autonomy' in John Christman (ed), *The Inner Citadel: Essays on Individual Autonomy* (Oxford University Press, 1989) 27, 45.
[119] Feinberg (n 118) 30–43, cited in Abrams (n 117) 809–810.
[120] Feinberg (n 118) 32, quoted in Abrams (n 117) 809–810.

their relationships with other people.[121] Finally, self-direction enables an individual to engage in decision-making that is free from external influences and the instruction of others.[122] This represents a clear connection with theralaw, as any understanding of autonomy must be accompanied by the notion that the process of APP itself should be accessible to older adults, and should address their individual circumstances and needs, with the goal of preparing for the future and protecting against any legal challenges.

Meyers' feminist critique of these liberal conceptions of autonomy offers an alternate view that takes greater account of the role of society, and an individual's position within it, when assessing how achievable autonomy actually is for different groups.[123] She arrives at the conclusion that 'notions of limited autonomy point to an understanding of autonomy as a kind of competency … that makes it possible to act in a self-aware and self-directed fashion'.[124] This conceptualisation is highly applicable to instances where older adults may be wanting to engage in APP, but there are concerns regarding their capacity. This extension of limited autonomy allows for a deeper understanding that, if an individual lacks the ability to self-manage a specific area of their lives, such as their financial affairs, they may still retain the capacity, and autonomy, to make decisions regarding their healthcare. Within this understanding, it must also be acknowledged that decisions occur on a spectrum of complexity, and while an older adult may be able to make simpler, everyday decisions about how to spend their money, they may require support to make more difficult decisions about future health management, the distribution of their property, or the care they would consent to receiving at the end of life.

The notions of participation and control that were raised when conceptualising empowerment surface again.[125] Ellison echoes these concepts through the example of Advance Care Directives, which allow an individual to have control over their healthcare while upholding their autonomy and self-determination during periods of incapacity, ensuring they can continue to participate in future decisions.[126] The Australian Health Ministers' Advisory Council states

[121] Feinberg (n 118) 31–32, quoted in Abrams (n 117) 809–810.
[122] Abrams (n 117) 809–810, citing Feinberg (n 118) 32–34.
[123] Diana T Meyers, 'Personal Autonomy and the Paradox of Feminine Socialization' (1987) 84 *The Journal of Philosophy* 619, cited in Abrams (n 117).
[124] Abrams (n 117) 814–815, citing Meyers (n 123) 627.
[125] Ellison et al (n 82) 156.
[126] Ibid. See also Jane B Baron, 'Fixed Intentions: Wills, Living Wills, and End-of-Life Decision Making' (2020) 87(2) *Tennessee Law Review* 375, 404–405; Yapp et al (n 103); Laura Vearrier, 'Failure of the Current Advance Care Planning Paradigm: Advocating for a Communications-Based Approach' (2016) 28(4) *HEC Forum* 339,

that autonomy is 'generally understood as a person's ability to make self-determining choices and direct his or her own life',[127] which emphasises the concepts of self-direction and control.

Further, Yapp et al promote the benefits of relational autonomy and expanding the concept to include significant relationships within an individual's life.[128] This will necessitate 'a move from the individualist conception of autonomy inherent in a medical approach, to one which better recognises the importance of relationships and the role of family carers',[129] which is likely to be more accessible for those from culturally and linguistically diverse backgrounds who have a less singular approach to decision-making and tend to adopt a familial or community focus.[130]

The traditionally adopted conception of autonomy within health contexts, being the ability to make independent decisions,[131] is unsuitable for my purposes as it fails to account for the participation of people close to older adults in the decision-making process[132] and the potential reliance that may be placed upon them, particularly when faced with a serious diagnosis.[133] Expanding the focus of autonomy beyond a narrow individual conceptualisation has provided stronger connections with theralaw in the context of Elder Law, noting the significant role of appointed decision-makers and the importance of older adults having trusted individuals who can support their choices in future. Relational autonomy provides a stronger foundation for appointed decision-makers to rely upon when supporting an older adult, as it would ensure a greater understanding of the context in which their wishes were recorded, including their self-direction and self-identity.[134] However, familial relationships or caregiver responsibilities can also present potential challenges to autonomous decision-making.[135] As Tobin Tyler highlights, '[b]ecause many older adults depend on caregivers, negotiating independent decision-making is complex. Advocacy should focus on empowering the individual and enabling caregivers to

340; Australian Health Ministers' Advisory Council, *A National Framework for Advance Care Directives* (Report, September 2011) 5 <https://respectingchoices.org/wp-content/uploads/2017/07/a-national-framework-for-advance-care-directives_september-2011.pdf>.

[127] Australian Health Ministers' Advisory Council (n 126) 17.

[128] Yapp et al (n 103). See also Tamryn F Gray et al, 'The Decision Partner in Healthcare Decision-Making: A Concept Analysis' (2019) 92 *International Journal of Nursing Studies* 79.

[129] Yapp et al (n 103) 147.

[130] Ibid. See also Baron (n 126) 404–405.

[131] Gray et al (n 128) 80. See also Baron (n 126) 404–405.

[132] Gray et al (n 128) 80. See also Baron (n 126) 404–405.

[133] Gray et al (n 128) 80.

[134] Yapp et al (n 103).

[135] Elizabeth Tobin Tyler, *Socially Vulnerable Older Adults & Medical-Legal Partnership* (Report, National Center for Medical Legal Partnership, March 2019) 3 <https://medical-legalpartnership.org/wp-content/uploads/2019/03/Socially-Vulnerable-Older-Adults-and-MLP.pdf>.

support the older adult's decisions'.[136] This requires a careful balance between acknowledging the significant role carers or family may play in an individual's life and ensuring that the wishes being communicated are in fact those of the individual.[137] Therefore, prioritising a person-centred approach to healthcare and legal services must take these considerations into account.[138]

In summary, my conceptualisation of autonomy explicitly includes authenticity, meaning decisions that older adults are making are true to, and clearly represent, their values, wishes and preferences, and not those of their advisors or those close to them. Self-direction links into this, as again, decisions must be made according to the personal goals and values that are prioritised by an older person. Partial or limited autonomy is also included to account for instances where an older adult may have competence in one area of their life but might require assistance through APP mechanisms to manage another area. The role and significance of personal relationships is also included, as these connections are an important factor to consider when forming notions of a person's wellbeing. These concepts are essential to understanding how theralaw operates in the field of Elder Law, and how the principles can best be achieved within the context of APP.

4.4 Visual Depiction of Theoretical Framework

The theoretical perspectives and overarching framework discussed in detail throughout this chapter are summarised in Figure 1.

4.5 Conclusion

As the population ages, lawyers and health professionals play an important role in assisting older people to continue taking care of their own affairs autonomously, and to put steps in place for their management in the future. This requires consideration of the older adult's capacity and wellbeing,[139] including what is important to them and what they wish to prepare for, or guard against, legally. These factors embody the principles of theralaw, taking into account an

[136] Ibid 12.
[137] Ibid. See also Australian Guardianship and Administration Council, *Maximising the Participation of the Person in Guardianship Proceedings: Guidelines for Australian Tribunals* (Final Report, June 2019) 3, 11 <https://www.agac.org.au/assets/documents/Guidelines/AGAC-Best-Practice-Guidelines-2019-without-annexures.pdf>.
[138] Tobin Tyler (n 135) 21.
[139] Stolle (n 9) 460.

individual's legal, personal, social and health circumstances to understand what issues can be proactively prevented in future. Lawyers must assist older adults to understand the range of legal protections available to them, and demonstrate how they can be used to record and protect the person's values, wishes and future intentions. Similarly, health professionals provide unique insight regarding an older person's health, including any recent diagnoses or predicted disease trajectories. Both professional cohorts have a key role to play within the field of Elder Law, which has been described as 'a rich mosaic of legal planning that is continually evolving to better meet clients' legal, financial and social needs and concerns'.[140]

Preventive Law helps to not only guard against future legal conflicts, but also unnecessary interferences in a persons' life.[141] It also allows older adults to retain control and plan ahead.[142] This complements APP, as the process of planning ahead accounts for the older adult's health, financial and property distribution wishes at a time when they may no longer be able to speak for themselves or require a level of support to do so. The positive effects are evident, as it allows an older person to 'design the last decades of their lives and define how their rights should be protected',[143] upholding their autonomy and promoting their wellbeing, representing the foundation of Therapeutic Jurisprudence. The unification of Preventive Law and Therapeutic Jurisprudence is not a new concept; theralaw has been recognised for decades. However, the application of this theoretical lens to the process of APP, specifically within the field of Elder Law, distinguishes my research from existing literature. Further, operationalising the key terms of vulnerability, empowerment and autonomy through this perspective has provided a unique conceptual framework through which my study instruments have been prepared, and my results analysed. The methodology adopted in this study is detailed in the following chapter.

[140] Frolik (n 27) 11.
[141] I Doron, 'A Multi-Dimensional Model of Elder Law' in Israel Doron (ed), *Theories on Law and Ageing: The Jurisprudence of Elder Law* (Springer, 2009) 59, 66.
[142] Frolik (n 27) 11.
[143] Doron (n 141) 67.

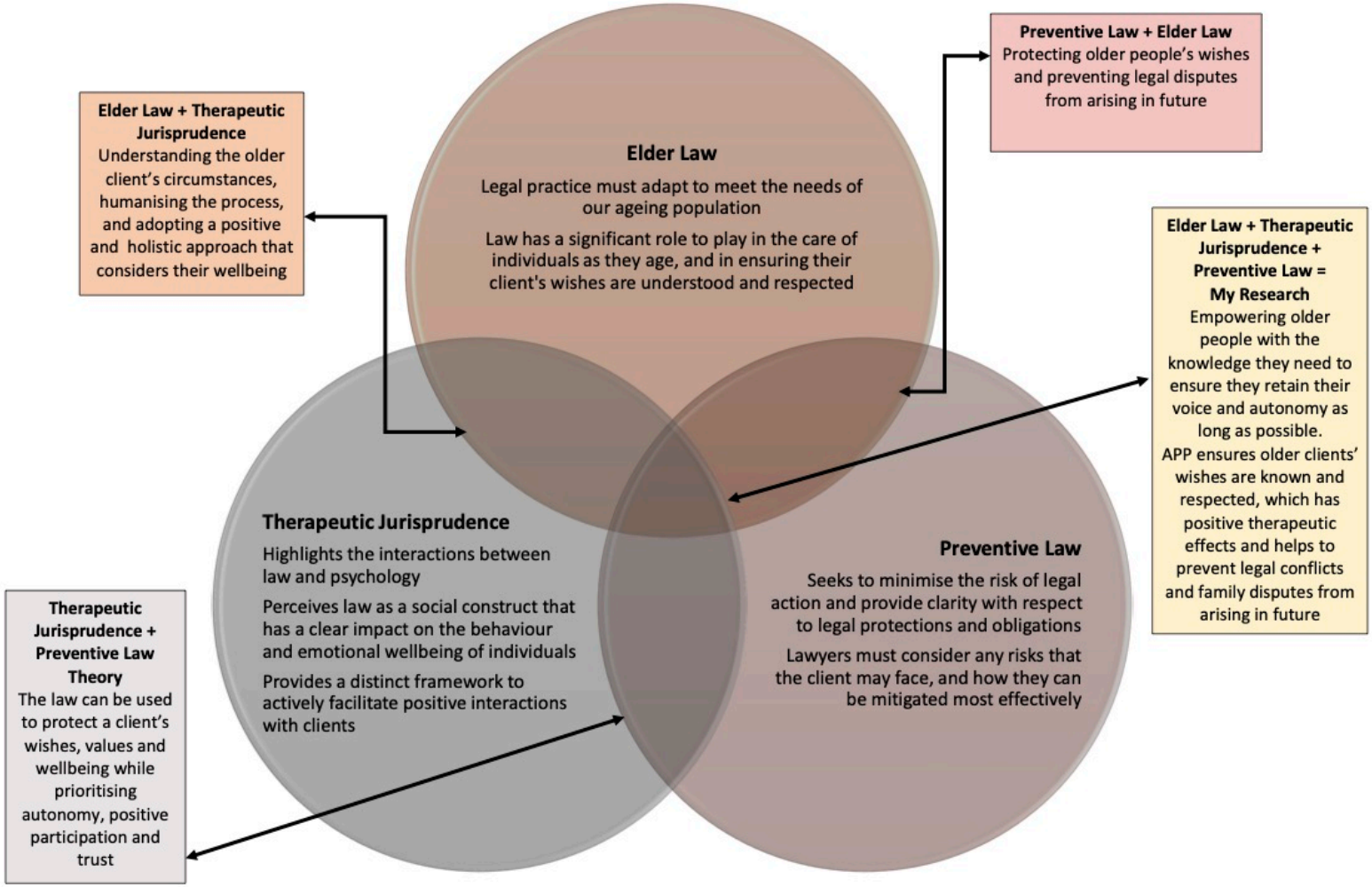

Figure 1. Thesis Theoretical Perspectives and Overarching Framework

5 METHODOLOGY

5.1 INTRODUCTION

To understand current Advance Personal Planning (APP) processes, including barriers to engagement, factors affecting the quality of completed instruments, and barriers that may affect future use of APP documents, it has been necessary to establish a clear and consistent methodology to support my research. The first part of this chapter provides an overview of the context in which my research was conducted and outlines the basis for my mixed methods approach, including parameters. The chapter then examines each component of my study, including background, details of the research instruments, recruitment, sampling, data collection, approach to analysis of results, and demographics. Finally, strengths and limitations of my study are discussed.

5.2 RESEARCH CONTEXT

The overall goal of my thesis was to investigate perspectives on, and experiences with, APP among older people in rural and regional New South Wales (NSW). My inclusion of the views and experiences of older people and professional key informants, recognised as experts with experience advocating for the rights of older adults, including lawyers who assist older adults to complete APP and healthcare workers who are tasked with interpreting completed documents, has allowed me to provide new insights regarding barriers within existing APP systems at three distinct levels: (1) initial engagement with APP; (2) enhancing the quality of completed instruments; and (3) use of prepared instruments in the future. This unique combination of multiple stakeholder perspectives within an integrated study has allowed me to

consider diverse perspectives, leading to informed recommendations at personal, professional and structural levels. The focus on older people in rural and regional areas of NSW has provided a further point of distinction given the additional factors that may arise for populations outside of metropolitan areas,[1] including difficulty accessing services,[2] increased potential for social isolation,[3] higher rates of unemployment,[4] lower levels of education,[5] and language or cultural factors that must be considered for older people from culturally and linguistically diverse or First Nations backgrounds.[6] Data collection questions were also included for lawyers about their experiences of working with older people from First Nations or culturally and linguistically diverse populations, and their use of resources that have been tailored to promote culturally appropriate practice.

As noted in Chapter 1, while financial planners may also have relevant experience through assisting older people to manage and grow their assets, their views were not included in the present study. My focus was instead on legal instruments that older people make as part of APP. Financial planners are not involved in the provision of legal advice or drafting legal documents, such as an Enduring Power of Attorney or a Will, making lawyers the most relevant key

[1] Q Allen et al, 'The Mixed Methods Proposal Introduction' in Jessica T DeCuir-Gunby and Paul A Schutz (eds), *Developing a Mixed Methods Proposal: A Practical Guide for Beginning Researchers* (SAGE, 2018) 45, 47–49.
[2] Lisa Bourke et al, 'Understanding Rural and Remote Health: A Framework for Analysis in Australia' (2012) 18(3) *Health & Place* 496, 496; Karly B Smith, John S Humphreys and Murray GA Wilson, 'Addressing the Health Disadvantage of Rural Populations: How Does Epidemiological Evidence Inform Rural Health Policies and Research?' (2008) 16(2) *Australian Journal of Rural Health* 56, 59; Thomas A Arcury et al, 'The Effects of Geography and Spatial Behavior on Health Care Utilization among the Residents of a Rural Region' (2005) 40(1) *Health Services Research* 135, 136.
[3] Sarah Nouri et al, 'Evaluation of Neighborhood Socioeconomic Characteristics and Advance Care Planning Among Older Adults' (2020) 3(12) *JAMA Network Open* e2029063:1-12; Rodney Lewis, 'Addressing Elder Abuse in Australia: The Case for an Elder Justice Law' (2018) 148 *Precedent* 41; Smith, Humphreys and Wilson (n 2) 57; Rao, Warburton and Bartlett (n 2) 176; Arcury et al (n 2) 135.
[4] Craig Sinclair et al, 'Association Between Region of Birth and Advance Care Planning Documentation Among Older Australian Migrant Communities: A Multicenter Audit Study' (2021) 76(1) *The Journals of Gerontology: Series B* 109, 111; Australian Healthcare Associates, *Exploratory Analysis of Barriers to Palliative Care* (Issues Report on Aboriginal and Torres Strait Islander Peoples, Department of Health, September 2019) 31 <https://www.health.gov.au/resources/publications/exploratory-analysis-of-barriers-to-palliative-care-issues-report-on-aboriginal-and-torres-strait-islander-peoples?language=en>; Rao, Warburton and Bartlett (n 2) 175; Smith, Humphreys and Wilson (n 2) 59; Vearrier (n 2) 347.
[5] Australian Healthcare Associates (n 4); Vearrier (n 2) 347; Karen Detering et al, 'Feasibility and Acceptability of Advance Care Planning in Elderly Italian and Greek Speaking Patients as Compared to English-Speaking Patients: An Australian Cross-Sectional Study' (2015) 5(8) *BMJ Open* e008800:1-7, 4; Smith, Humphreys and Wilson (n 2) 59; Rao, Warburton and Bartlett (n 2) 175.
[6] Gloria T Anderson, 'Let's Talk about ACP Pilot Study: A Culturally-Responsive Approach to Advance Care Planning Education in African-American Communities' (2021) 17(4) *Journal of Social Work in End-of-Life & Palliative Care* 267; Sinclair et al (n 4); Emma Spencer and Eswaran Waran, 'Opening the Lines of Communication: Towards Shared Decision Making and Improved End-of-life Care in the Top End' (2020) 213(1) *The Medical Journal of Australia* 10; Vearrier (n 2) 347.

informants. Similarly, financial planners are not tasked with having to interpret prepared APP documents, such as an Advance Care Directive, in contrast with the health professionals I interviewed. Future research may be useful to explore the intersections and relationships between older people, financial planners, lawyers and health care professionals in the context of APP.

5.2.1 Inquiry Worldview

As the aim of my thesis was to explore the subjective views and understandings of older people and professionals within the specific contexts in which they worked and lived, I consider my research process as most closely aligned with the perspective of social constructivism.[7] The meanings both older people and professionals had developed in relation to their experiences of APP were integral to my research, as I drew upon their perspectives of the current processes.[8] These meanings and perspectives allowed me to explore and interpret issues that may prevent older people from successfully engaging with APP,[9] and highlighted potential areas for improving access pathways, interaction with the full suite of advance planning mechanisms, and factors that may influence the quality and future use of prepared instruments. It has also been important to acknowledge that existing forms of APP and current processes may not meet the needs of some older people, and I needed to refrain from promoting the assumption that completing APP is always the best option.

The social constructivism perspective also promotes respect for 'individual differences rather than employing the traditional aggregation of categories',[10] which ensured that the experiences of older people and professionals in rural or regional areas were not considered to be, nor represented as, homogenous.[11] If similarities were discovered in my analysis of results, either between individuals or between communities, they were not presumed to extend to all rural or regional populations.[12]

[7] John W Creswell, 'Philosophical Assumptions and Interpretive Frameworks' in *Qualitative Inquiry and Research Design: Choosing among Five Approaches* (SAGE, 3rd ed, 2013) 15, 24–25 ('Philosophical Assumptions and Interpretive Frameworks').
[8] Ibid.
[9] Ibid 34.
[10] Ibid.
[11] MR McGrail et al, 'The Planning of Rural Health Research: Rurality and Rural Population Issues' (2005) 5(4) *Rural and Remote Health* 426:1–8, 3.
[12] Bourke et al (n 2) 499.

5.2.2 Approach to Inquiry

I adopted an exploratory phenomenological approach[13] to my research, which involved asking participants to 'describe their experiences'.[14] Put simply, 'a phenomenological study describes the common meaning for several individuals of their lived experiences of a concept or a phenomenon'[15] with a 'focus on describing what all participants have in common as they experience a phenomenon … to reduce individual experiences with a phenomenon to a description of the universal essence'.[16] The perspective of phenomenology links well with social constructivism, as '[m]ultiple realities are constructed through our lived experiences and interactions with others',[17] allowing reality to be 'co-constructed between the researcher and the researched and shaped by individual experiences'.[18] The main phenomena that have been explored in my research are empowerment, autonomy and vulnerability, as explored in Chapter 4.

5.2.3 Subjectivity Statement

I have previously participated in research projects involving older people and the provision of legal education among community groups.[19] This work, and my previous experience in the field of law, have always been inspired by a desire to help others and assist with the dissemination of knowledge so that people can take further control of their circumstances.[20] I became interested in helping older people quite early in my legal studies, based on my family circumstances, which resulted in a personal connection to the research topic.[21] However, as I developed my research proposal, I realised my values and personal experiences were leading to a paternalistic assumption that older people are vulnerable and require protection through the legal system. I challenged this belief through reflexivity,[22] which made me 'conscious of

[13] John W Creswell, 'Five Qualitative Approaches to Inquiry' in *Qualitative Inquiry and Research Design: Choosing among Five Approaches* (SAGE, 3rd ed, 2013) 69, 97 ('Five Qualitative Approaches to Inquiry').
[14] Creswell, 'Philosophical Assumptions and Interpretive Frameworks' (n 7) 15, 25.
[15] Creswell, 'Five Qualitative Approaches to Inquiry' (n 13) 76.
[16] Ibid.
[17] Creswell, 'Philosophical Assumptions and Interpretive Frameworks' (n 7) 36.
[18] Ibid.
[19] For example, see Nola M Ries, Briony Johnston and Shaun McCarthy, 'Legal Education and the Ageing Population: Building Student Knowledge and Skills through Experiential Learning in Collaboration with Community Organisations' (2016) 37 *Adelaide Law Review* 495.
[20] Jessica T DeCuir-Gunby and Paul A Schutz, 'The Role of Theory in Mixed Methods Research' in *Developing a Mixed Methods Proposal: A Practical Guide for Beginning Researchers* (SAGE, 2018) 17, 23.
[21] Allen et al (n 1) 49.
[22] Patrick Ngulube, 'Qualitative Data Analysis and Interpretation: Systematic Search for Meaning' in Elias Rajabalala Mathipa and Mishack Thiza Gumbo (eds), *Addressing Research Challenges: Making Headway for Developing Researchers* (Mosala-Masedi Publishers, 2015) 131, 148; John W Creswell, 'Designing a Qualitative

the biases, values, and experiences' that I carried with me through my research.[23] This reflection led to the adoption of empowerment as a phenomenon, incorporating key elements of participation and control. My shift in perspective clearly removed the blanket assumption that older people are vulnerable and require the protection of others. The focus of my research evolved to communicating with older people to discover more about their participation and engagement with APP, ultimately striving to determine whether the current processes can promote empowerment and autonomy. I wanted to learn more about the barriers that might be preventing participation or engagement with APP processes, as well as barriers to using APP instruments to implement a person's wishes in the future.[24]

5.3 Statement of the Problem and Research Questions

As highlighted in Chapter 1 and Chapter 3, there is a significant body of research about Advance Care Planning, including its prevalence,[25] effectiveness,[26] relevance to particular

Study' in *Qualitative Inquiry and Research Design: Choosing among Five Approaches* (SAGE, 3rd ed, 2013) 42, 47 ('Designing a Qualitative Study').

[23] John W Creswell, 'Writing a Qualitative Study' in *Qualitative Inquiry and Research Design: Choosing among Five Approaches* (SAGE, 3rd ed, 2013) 213, 216.

[24] Creswell, 'Designing a Qualitative Study' (n 22) 48.

[25] Kimberly Buck et al, 'Advance Care Directive Prevalence among Older Australians and Associations with Person-Level Predictors and Quality Indicators' (2021) 24(4) *Health Expectations* 1312; Craig Sinclair et al, 'Advance Care Planning in Australia during the COVID-19 Outbreak: Now More Important than Ever' (2020) 50(8) *Internal Medicine Journal* 918, 919; Karen M Detering et al, 'Prevalence and Correlates of Advance Care Directives among Older Australians Accessing Health and Residential Aged Care Services: Multicentre Audit Study' (2019) 9(1) *BMJ Open* e025255:1-9; Sarah Jeong et al, '"Planning Ahead" among Community-Dwelling Older People from Culturally and Linguistically Diverse Background: A Cross-Sectional Survey' (2015) 24 *Journal of Clinical Nursing* 244; Cheryl Tilse et al, *Having the Last Word? Will Making and Contestation in Australia* (ARC Linkage Project Key Findings, The University of Queensland; Victoria University; Australian Centre for Health Law Research, March 2015) <https://eprints.qut.edu.au/215396/>; Ben White et al, 'Prevalence and Predictors of Advance Directives in Australia' (2014) 44(10) *Internal Medicine Journal* 975.

[26] Juliet Jacobsen, Rachelle Bernacki and Joanna Paladino, 'Shifting to Serious Illness Communication' (2022) 327(4) *JAMA* 321, 321; Karen M Detering et al, 'Organisational and Advance Care Planning Program Characteristics Associated with Advance Care Directive Completion: A Prospective Multicentre Cross-Sectional Audit among Health and Residential Aged Care Services Caring for Older Australians' (2021) 21 *BMC Health Services Research* 700:1–12, 1; Helena Rodi et al, 'Exploring Advance Care Planning Awareness, Experiences, and Preferences of People with Cancer and Support People: An Australian Online Cross-Sectional Study' (2021) 29(7) *Supportive Care in Cancer* 3677, 3677; Frances Batchelor et al, 'Facilitators and Barriers to Advance Care Planning Implementation in Australian Aged Care Settings: A Systematic Review and Thematic Analysis' (2019) 38(3) *Australasian Journal on Ageing* 173, 176; Kimberly Buck et al, *Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services* (Report, Advance Care Planning Australia and Austin Health, October 2019) <https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3668752>; Joshua A Rolnick et al, 'Patients' Perspectives on Approaches to Facilitate Completion of Advance Directives' (2019) 36(6) *American Journal of Hospice & Palliative Medicine* 526; Tilse et al (n 25).

populations,[27] and professional perspectives.[28] In contrast, the literature considering APP is still emerging.[29] My research provides new evidence regarding experiences with and perceptions of APP from the perspective of important stakeholders in these processes, notably older adults for whom APP is encouraged, and the legal and health professionals who are a source of expert advice and assistance. The empirical data gathered from my direct engagement with older people and professionals through in-depth interviews also offers vital information and insights regarding experiences with APP, barriers, and areas of improvement for APP processes generally, with particular reference to rural or regional areas.

As noted above, the overarching goal of my research was to examine experiences with and perspectives of APP among older people in rural and regional NSW, with the aim of identifying barriers within current processes. As set out in Chapter 1, the following research questions[30] were used to direct my study:

1. Are current APP processes clear, transparent and easy to follow from the perspective of older adults living in rural and regional NSW?
2. Are there deficiencies or problems within the current APP processes from the perspective of professional key informants, including lawyers, health professionals and aged care workers?

[27] Catherine L Auriemma et al, 'How Traditional Advance Directives Undermine Advance Care Planning: If You Have It in Writing, You do not Have to Worry About It' (2022) 182(6) *JAMA Internal Medicine* 682; Jamie Bryant et al, 'Inadequate Completion of Advance Care Directives by Individuals with Dementia: National Audit of Health and Aged Care Facilities' (2022) 12 *BMJ Supportive & Palliative Care* e319; Karen M Detering et al, 'Prevalence of Advance Care Planning Documentation and Self-Reported Uptake in Older Australians with a Cancer Diagnosis' (2021) 12(2) *Journal of Geriatric Oncology* 274.

[28] Maria T Carney et al, 'Impact of a Community Health Conversation upon Advance Care Planning Attitudes and Preparation Intentions' (2021) 42(1) *Gerontology & Geriatrics Education* 82; Craig Sinclair et al, 'Professionals' Views and Experiences in Supporting Decision-Making Involvement for People Living with Dementia' (2021) 20(1) *Dementia* 84; Suet Ying Ng and Eliza Lai-Yi Wong, 'The Role Complexities in Advance Care Planning for End-of-Life Care—Nursing Students' Perception of the Nursing Profession' (2021) 18(12) *International Journal of Environmental Research and Public Health* 6574:1–13; Batchelor et al (n 26); Nadia Moore et al, 'Doctors' Perspectives on Adhering to Advance Care Directives When Making Medical Decisions for Patients: An Australian Interview Study' (2019) 9 *BMJ Open* e032638:1-11; Josie Dixon and Martin Knapp, 'Whose Job? The Staffing of Advance Care Planning Support in Twelve International Healthcare Organizations: A Qualitative Interview Study' (2018) 17(1) *BMC Palliative Care* 78:1–16; Nola M Ries et al, 'How Do Lawyers Assist Their Clients with Advance Care Planning? Findings from a Cross-Sectional Survey of Lawyers in Alberta' (2018) 55(3) *Alberta Law Review* 683.

[29] Amy Waller et al, 'Increasing Advance Personal Planning: The Need for Action at the Community Level' (2018) 18(1) *BMC Public Health* 606:1–8.

[30] Jessica T DeCuir-Gunby and Paul A Schutz, 'Asking Appropriate Research Questions' in *Developing a Mixed Methods Proposal: A Practical Guide for Beginning Researchers* (SAGE, 2018) 33, 38.

3. Are there any barriers that are preventing effective engagement with APP from the perspective of older adults and professional key informants?
4. Are there any barriers affecting the quality of completed APP instruments from the perspective of professional key informants?
5. Are there any barriers relating to the future use or effective implementation of APP instruments from the perspective of professional key informants?
6. Do older adults and professional key informants believe current APP processes can be improved? If so, how?

5.4 Components of My Research

I utilised a mixed methods approach in this research,[31] including both quantitative and qualitative components, as outlined below. Including older adults and professional key informants within this research provided a broad range of perspectives that were all linked to the same goal of gaining deeper insight into current APP processes, including barriers, facilitators and opportunities for improvement.[32]

5.4.1 Impacts of Pandemic and Other Disasters on Research

I commenced my PhD in July 2019, and my data collection methods were aligned with the anticipated timeline for the Australian Research Council (ARC) Discovery Project Grant, 'Taking Action: Increasing Advance Personal Planning by Community-Dwelling Older Adults' (DP190100861) that supported my candidature. However, my research was affected by natural disasters in NSW and the global COVID-19 pandemic, which required adaptability and resilience in light of associated delays and restrictions. Extreme bushfires in late 2019 and early 2020 prevented myself and my supervisors from attending regional and rural communities as part of the baseline data collection and community introductions that were vital to the broader ARC project. We had planned to meet face-to-face with older residents, lawyers, and health practitioners working in identified regional areas in early 2020 to build rapport with these

[31] Allen et al (n 1) 47–48; A Coffey et al, 'The Heart of the Mixed Methods Research Plan: Discussing Your Methods Section' in *Developing a Mixed Methods Proposal: A Practical Guide for Beginning Researchers* (SAGE, 2018) 107, 109.
[32] Coffey et al (n 31) 114; Kate Kelley, 'Good Practice in the Conduct and Reporting of Survey Research' (2003) 15(3) *International Journal for Quality in Health Care* 261, 263–264.

communities and provide essential recruitment paths for both my doctoral research and the ARC project as a whole.

These delays were further exacerbated due to travel restrictions and public health guidelines that were implemented from March 2020 due to the COVID-19 pandemic. The restrictions prompted myself and the broader ARC project to direct our attention to recruitment and data collection that could occur online or by telephone, in place of in-community research activities. Rather than personally attending the selected communities, the ARC research team instead spoke remotely with local organisations who distributed information regarding the research project as well as copies of the baseline survey to assist with recruitment. While this was beneficial, given older people were approached directly by familiar people within their community, it provided a smaller pool for recruitment, given that only a few community organisations in limited regions were willing and able to undertake these activities on behalf of the research team. Recruitment advertisements containing a link to an online version of the baseline survey were also placed on Facebook to reach older community members, providing another avenue of communication that did not depend on the community organisations. Despite public health guidelines and travel restrictions easing at the start of 2022, severe flooding in March of that year once again prevented myself and the ARC research team from conducting in-person community events.

Similarly, the inability to visit the communities and speak directly with lawyers and health professionals necessitated me developing an online survey for lawyers working in regional areas. Fortunately, this enabled the collection of data during a time when in-person contact was not permitted. However, the additional strain of the pandemic, coupled with the usual time constraints of professionals, may have affected the number of lawyers who were willing to complete the online survey and take part in a subsequent interview regarding their experiences. Key professional informants working in health and aged care were extremely generous with their time during exceptionally challenging circumstances.

5.4.2 Interviews with Older People

5.4.2.1 Background

Semi-structured interviews were conducted with 22 older people living in regional and rural areas to collect data regarding their engagement and experiences with APP.[33] This study was

[33] Rolnick et al (n 26).

approved by the Human Research Ethics Committee of the University of Technology Sydney (ETH21-5989).

5.4.2.2 Study instrument

A copy of the semi-structured interview guide for older people is reproduced in **Appendix A**. Creswell's recommendation of 'approximately five to seven open-ended questions'[34] was followed. These open-ended questions represented the core of the interview guide and linked to the research questions that addressed the perceptions of older people.[35] The interview sought to explore the experiences of older people and their engagement with APP, including: their uptake of APP; any prompts that led them to engage with APP; whether the process was clear and easy to follow; discussions about their wishes with those around them; age and storage of prepared documents; any barriers that prevented them from engaging more fully with APP; their use of resources; and advantages and disadvantages of APP.

Reliability of the interviews was ensured by following the strategies outlined by Creswell.[36] These included: keeping detailed notes and reflections following interviews with each participant; the use of reliable equipment to record interviews; transcribing interviews verbatim, ensuring a complete record of conversations including any overlapping speech or pauses; and the use of computer software to assist with the organisation and interpretation of results.[37] Each participant was given the option of reviewing the transcript of their interview,[38] allowing them to revisit their contributions and offer additional comments.

5.4.2.3 Recruitment

The recruitment method for this component was integrated within the ARC Discovery Project Grant. Regional and rural communities were selected according to criteria, developed by members of the ARC investigation team with expertise in methodology and statistics, and included: population between 5,000 and 20,000; at least 15% of the total population in the community aged 65 years or over; at least five General Practitioners working in the community;

[34] John W Creswell, 'Data Collection' in *Qualitative Inquiry and Research Design: Choosing among Five Approaches* (SAGE, 3rd ed, 2013) 145, 164 ('Data Collection').
[35] Ibid.
[36] John W Creswell, 'Standards of Validation and Evaluation' in *Qualitative Inquiry and Research Design: Choosing among Five Approaches* (SAGE, 3rd ed, 2013) 243 ('Standards of Validation and Evaluation').
[37] Ibid 253.
[38] Ibid 252. See also David R Thomas, 'Feedback from Research Participants: Are Member Checks Useful in Qualitative Research?' (2017) 14(1) *Qualitative Research in Psychology* 23; Victoria Hagens, Mark J Dobrow and Roger Chafe, 'Interviewee Transcript Review: Assessing the Impact on Qualitative Research' (2009) 9(1) *BMC Medical Research Methodology* 1.

and at least five lawyers working in the community. The baseline survey that was distributed to older people who lived in identified communities as part of the Discovery Project, either in hard copy by community organisations or electronically via Facebook advertisements, contained information regarding my doctoral research. On the final page of the survey, an additional Consent to Contact box was included, asking if respondents would be interested in participating in an interview with me regarding their experiences.

Participants were eligible for my study if they were aged 65 years or over, or 50 years or over for Indigenous people, were able to complete an interview in English, and had completed the ARC baseline survey.

5.4.2.4 Demographics

Twenty-two people aged 65 years or older completed an interview. The average age of participants was 74, with a range of 65-96 years of age. The reported gender identity of participants was equal between females and males. Two participants identified as Aboriginal or Torres Strait Islander. Four participants were born outside of Australia. Half of the participants had completed study at university. Table 1 presents the demographic details of the interviewed older people.

Table 1. Demographics of Interviewed Older People

DEMOGRAPHIC	***n***
Gender	
Female	11
Male	11
Age	
65-69 years	6
70-74 years	6
75-79 years	6
80-84 years	2
85 years and over	2
Identify as First Nations	
Yes	2
No	20
Highest Level of Education Completed	
High School – Year 10	1
High School – Year 12	3
Trade or Vocational Study	7
University – Undergraduate	7
University – Postgraduate	4
Country of Birth	
Australia	18
Other	4
Canada	1
England	2
Germany	1
Region of New South Wales	
Central West	2
Hilltops	1
Hunter	2
Mid North Coast	4
Riverina Murray	12
South East & Tablelands	1

5.4.2.5 Sampling and sample size

Convenience sampling was used to recruit older people from the populations who completed the ARC Discovery Project baseline survey and consented to contact regarding my doctoral research.[39] As this method of recruitment depended on older adults engaging with local organisations or Facebook advertisements where the baseline survey was distributed, half of the eventual sample resided in the Riverina, which is a limitation of the research. However, older people living in the Riverina still expressed differences in their perspectives of, and experiences with, APP. The higher representation of participants from one regional area means that care should be taken when viewing results. The small sample size also does not provide for generalisability, as findings may not be applicable to all older adults living in regional communities. The limitations of this sample are discussed in further detail in section 5.5.1.

Rather than adopting the common criteria of saturation, Vasileiou et al argue for considering data adequacy,[40] acknowledging the influence of factors such as the richness of the collected data, the requirements of the research design, and the nature of the study.[41] Similarly, Malterud et al focus on the power of the information elicited during the qualitative study.[42] They state '[i]nformation power indicates that the more information the sample holds, relevant for the actual study, the lower amount of participants is needed'.[43] Further, in their development of the information power model, Malterud et al cite five key factors that must be considered when planning the sample size of qualitative studies: (1) the breadth of the study aim; (2) the specificity of the sample involved; (3) whether an established theory is being adopted and applied; (4) the quality of the dialogue between the interviewer and participants; and (5) the type of analysis strategy adopted.[44]

My aim of obtaining a deeper understanding of older peoples' experiences and engagement with APP and further exploring barriers and facilitators to APP engagement was fairly narrow, requiring a smaller sample. Further, the participants met the criteria of specificity, as they were

[39] Alan Bryman, 'Sampling in Qualitative Research' in *Social Research Methods* (Oxford University Press, 5th ed, 2015) 416, 419. See also Keith F Punch, 'Collecting Qualitative Data' in *Introduction to Social Research - Quantitative and Qualitative Approaches* (SAGE, 2005) 174, 193.
[40] Konstantina Vasileiou et al, 'Characterising and Justifying Sample Size Sufficiency in Interview-Based Studies: Systematic Analysis of Qualitative Health Research over a 15-Year Period' (2018) 18(1) *BMC Medical Research Methodology* 1.
[41] Ibid 11.
[42] Kirsti Malterud, Volkert Dirk Siersma and Ann Dorrit Guassora, 'Sample Size in Qualitative Interview Studies: Guided by Information Power' (2015) 26(13) *Qualitative Health Research* 1753.
[43] Ibid 1753.
[44] Ibid 1754–1756.

all people aged 65 and over, or 50 and over for Indigenous people, who were living in the community in a regional area of NSW. With regard to specificity, Malterud et al advise:

> To offer sufficient information power, a less extensive sample is needed with participants holding characteristics that are highly specific for the study aim compared with a sample containing participants of sparse specificity. Specificity concerns here participants who belong to the specific target group while also exhibiting some variation within the experiences to be explored.[45]

The specificity of older people still allowed for the emergence of variation between individual participants. While the quality of the dialogue between myself and the participants was difficult to predict, Malterud et al advise '[a] study with strong and clear communication between researcher and participants requires fewer participants to offer sufficient information power than a study with ambiguous or unfocused dialogues'.[46] Further, the quality of dialogue was strengthened due to my extensive work reviewing existing literature on Advance Care Planning, which provided a solid foundation for areas that could be explored in the broader context of APP. Finally, the adoption of an exploratory phenomenological approach also warranted a smaller sample due to 'in-depth analysis of narratives or discourse details from a few, selected participants. … Within an exploratory analysis, the ambition is not to cover the whole range of phenomena, but to present selected patterns relevant for the study aim'.[47] Adopting the information power model,[48] it was anticipated that a sample size of 20 to 30 participants would be appropriate to meet the aims of the study.

5.4.2.6 Data collection

Participants identified via the recruitment method were contacted via phone or email, depending on their preference. Further details were then provided regarding the study, and a Participant Information Statement (**Appendix B**) was sent via post or email. Suitable dates and times were then scheduled for interviews. Up to two reminder emails or phone calls were sent or made, depending on response rates. All interviews were conducted over the telephone and were audio recorded and transcribed, with notes also written during the interviews. The average interview duration was 54 minutes. Participants were given the opportunity to review the

[45] Ibid 1755.
[46] Ibid.
[47] Ibid 1756.
[48] Malterud, Siersma and Guassora (n 42).

transcript of the interview and provide feedback on any points of discussion, clarify any element of the conversation, and request data be omitted prior to analysis.

5.4.2.7 Analysis of results

Qualitative data analysis software NVivo 12[49] was used to collate interview data, which was subsequently coded according to discrete phenomena relating to the lived experiences of older adults, including: prompts; barriers; confidence in planning instruments; advantages of planning ahead; and any perceived risks in the APP process. While multiple coders are usually encouraged in qualitative studies, I acted as the sole coder for the dataset, as is necessitated by the nature of a PhD. This process of utilising a single coder was appropriate in the circumstances, given my role in conducting all the interviews, my familiarity with the dataset, and the adoption of a phenomenological approach that required a high level of reflexivity during coding and analysis.[50]

I commenced the transcript analysis process by gaining a sense of the whole available data.[51] Detailed notes and memos were recorded while reading to highlight connections within and between interviews.[52] First cycle open coding was used to label discrete phenomena within the interview responses as concepts, according to significant statements that emerged in the data.[53] In particular, I noted contributions that could be used to inform the key themes of barriers and areas for improvement. Second cycle selective coding focused on core categories that included more than one concept,[54] such as barriers relating to other issues that emerged in participants' responses, including finances, isolation or lack of access to services. Reponses were then compared both within and across participant groups, including professionals. Further coding cycles were introduced as required when unexpected themes arose within the interview data. Draft results from interviews were sent to participants for their review and additional comments, in the event more abstract thematic coding was required. This technique of 'member

[49] QSR International, 'NVivo Version 12' (Computer Software, 2017) <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>.
[50] Cliodhna O'Connor and Helene Joffe, 'Intercoder Reliability in Qualitative Research: Debates and Practical Guidelines' (2020) 19 *International Journal of Qualitative Methods* 1; John L Campbell et al, 'Coding In-Depth Semistructured Interviews: Problems of Unitization and Intercoder Reliability and Agreement' (2013) 42(3) *Sociological Methods & Research* 294.
[51] John W Creswell, 'Data Analysis and Representation' in *Qualitative Inquiry and Research Design: Choosing among Five Approaches* (SAGE, 3rd ed, 2013) 179, 183 ('Data Analysis and Representation').
[52] Ibid.
[53] Alan Bryman, 'Qualitative Data Analysis' in *Social Research Methods* (Oxford University Press, 5th ed, 2015) 565, 570; Ngulube (n 22) 131; Creswell, 'Data Analysis and Representation' (n 51) 184, 206.
[54] Bryman (n 53) 570; Creswell, 'Data Analysis and Representation' (n 51) 184.

checking' is also recommended by Creswell as it establishes the credibility of the data.[55] The listed strategies also enhanced the trustworthiness of the data, defined by Lincoln and Guba as representing 'credibility, authenticity, transferability, dependability, and confirmability'.[56]

5.4.3 Survey of Lawyers

5.4.3.1 Background

An online survey was completed by 31 legal practitioners, providing insight into their perceptions of and experiences with APP. The survey was adapted from Ries et al's[57] survey of Canadian lawyers, broadening the focus to APP generally. Existing questions were assessed for their relevance to NSW and the focus of my research, and were either amended or substituted with other items that more closely addressed the key themes of this research. Additional questions were added to the survey to take account of the unique environment and population of NSW and the impact of the COVID-19 pandemic. This study was approved by the Human Research Ethics Committee of the University of Technology Sydney (ETH20-5024 and ETH20-5440).

5.4.3.2 Study instrument

A copy of the survey is reproduced in **Appendix C**. The survey was reviewed by two experts in the fields of health behaviour, law and clinical disciplines prior to its administration. Section A of the survey explored lawyers' professional experiences with advising older people on APP, such as the proportion of their practice that involves APP, prompts, barriers, and their reflections on any experiences working with older people from First Nations or culturally and linguistically diverse backgrounds. Section B asked about advantages and disadvantages of APP, with lawyers responding on five-point Likert scales.[58] Section C included questions about factors that may prompt lawyers to have concerns about an older person's decision-making ability and their professional experience, if any, with referring older people for capacity assessments. Section D asked whether the COVID-19 pandemic prompted increased inquiries

[55] Creswell, 'Standards of Validation and Evaluation' (n 36) 252. See also Thomas (n 38); Hagens, Dobrow and Chafe (n 38).
[56] Creswell, 'Standards of Validation and Evaluation' (n 36) 246, citing YS Lincoln and EG Guba, *Naturalistic Inquiry* (SAGE, 1985) 300. See also Coffey et al (n 31) 119; Janice M Morse et al, 'Verification Strategies for Establishing Reliability and Validity in Qualitative Research' (2002) 1(2) *International Journal of Qualitative Methods* 13, 15.
[57] Ries et al (n 28).
[58] Jessica T DeCuir-Gunby and Paul A Schutz, 'Mixed Methods Designs: Frameworks for Organizing Your Research Methods' in *Developing a Mixed Methods Proposal: A Practical Guide for Beginning Researchers* (SAGE, 2018) 83, 88.

regarding APP, the effect of any barriers related to COVID protocols, such as social distancing, and the advantages or disadvantages of older people completing APP in a situation of potentially heightened stress. Some open text boxes were included so that lawyers could expand on their answers to the survey. Section E collected demographic information about lawyers' length of practice experience, size of their organisation, their age and the region of NSW in which they worked.

With respect to the validity of the survey instrument, conceptual clarity was upheld through the consistent use of conceptualised terms.[59] Internal consistency within the survey instrument was established via logical connections between the key themes, chosen methods and survey items, which were ultimately guided by the research questions outlined above.[60] Theoretical rationales for survey items, in connection with the conceptualisation of key terms, ensured internal consistency and content validity in the development of the survey,[61] while the relationship between the survey and qualitative data collection methods also represented external validity.[62]

5.4.3.3 Recruitment

Lawyers for the online survey were recruited through Regional Law Societies in NSW, and The Law Society of New South Wales Strategy and Projects Division. An email describing the survey and purpose of my research was circulated to the Presidents of Regional Law Societies, who were asked to circulate a survey weblink through their usual communication channels. The Law Society of New South Wales Strategy and Projects Division also circulated survey information to the Elder Law, Capacity, and Succession Committee to reach a broader range of legal professionals with specific experience in the field most relevant to my research. This necessitated the survey link going to lawyers working in metropolitan areas, as well as those working in rural and regional areas of NSW, to capture those with particular interest and expertise with regard to Elder Law, capacity, and estate planning. Circulation of the survey information by the Regional Law Societies and The Law Society of New South Wales ensured no personal information was accessed or retained by me in the initial phase of recruitment. When completing the survey, lawyers were able to provide their contact details if they were

[59] Keith F Punch, 'Some Central Issues' in *Introduction to Social Research: Quantitative and Qualitative Approaches* (SAGE, 2005) 14, 22.
[60] Ibid.
[61] Coffey et al (n 31) 119.
[62] Ibid.

interested in receiving information about additional components of my research. This provided a recruitment strategy for the interviews with professional key informants, described below.

5.4.3.4 Demographics

A total of 31 lawyers completed the online survey.[63] The majority of participants (67%) stated they had 10 years or more of practice experience. Most lawyers reported working in small organisations of between two and nine lawyers (57%). Over three-quarters of participants (77%) worked in regional or rural locations covering most areas of NSW. Nearly three-quarters of participants (74%) reported less than half of their practice involved APP work. Over half of the participants identified as female (60%). Almost a quarter of the respondents (23%) were aged 65 and over. One participant declined to answer the demographic questions. The demographic information about the surveyed lawyers is detailed in Table 2 below.

[63] While 38 participants commenced the survey, only 31 completed all responses. As such, analysis beyond demographics is confined to the 31 participants.

Table 2. Demographics of Surveyed Lawyers

DEMOGRAPHIC	***n (%)***
Years of Experience as a Legal Practitioner	
0-4 years	5 (16.7%)
5-9 years	5 (16.7%)
10 years or more	20 (66.7%)
Size of Firm or Organisation	
Sole practice	8 (26.7%)
Small organisation (2-9 lawyers)	17 (56.7%)
Mid-size organisation (10-49 lawyers)	3 (10%)
Large organisation (50 or more lawyers)	2 (6.7%)
Area of New South Wales	
Regional or Rural	23 (76.6%)
Metropolitan	7 (23.3%)
Proportion of Practice Involving Advance Personal Planning	
Less than 25%	14 (36.8%)
25%-49%	14 (36.8%)
50-74%	7 (18.4%)
More than 75%	3 (7.9%)
Advance Personal Planning Instrument 'Often' or 'Usually' Part of Practice	
Will	26 (86.7%)
Enduring Power of Attorney	28 (90.4%)
Enduring Guardian	27 (87.1%)
Advance Care Directive	9 (29%)
Other*	4 (23.5%)
Gender	
Female	18 (60%)
Male	12 (40%)
Age	
25-34 years	5 (16.7%)
35-44 years	5 (16.7%)
45-54 years	6 (20%)
55-64 years	6 (20%)
65 and over	7 (23.3%)
Prefer not to say	1 (3.3%)

*'Other' APP instruments reported by lawyers as part of their practice included: family loan agreements; binding death benefit nominations for Superannuation; and other trust deeds.

5.4.3.5 Sampling and sample size

As detailed above, convenience sampling was used to recruit lawyers through the Regional Law Societies and The Law Society of New South Wales Strategy and Projects Division, given that 'a specific population is identified and only its members are included in the survey'.[64]

Predictions for the sample size of the current study were uncertain, given that I was focused on recruiting lawyers working in regional and rural areas with experience helping older adults to engage with and complete APP. Further, difficulty recruiting lawyers for quantitative studies has been reported in previous research, resulting in low or very low response rates.[65] For example, in a study conducted by Birtwistle on behalf of the New South Wales Law Reform Commission,[66] lawyers in NSW were invited to complete an online survey regarding their experiences dealing with digital assets and records when assisting clients with estate planning and enduring appointments.[67] That survey was advertised on the Law Reform Commission's website, as well as through their mailing list. Information regarding the project was also distributed to NSW Young Lawyers, through a weekly online news publication of The Law Society of New South Wales, and via the social media platform X, previously known as Twitter.[68] Ultimately, only 74 practitioners completed the Birtwistle survey,[69] with some questions receiving even fewer responses.[70]

Further impacting on recruitment, the present study commenced in August 2020, and it is possible that the stress and disruptions related to the COVID-19 pandemic also influenced the response rate. While a larger sample size would have provided more data on regional lawyers' experiences, and potentially ensured statistically significant results, the smaller sample size of 31 was sufficient to highlight important themes that were then explored in detail in subsequent qualitative interviews with professionals. The inclusion of lawyers working in metropolitan areas to capture those with interest and expertise in Elder Law, capacity and estate planning

[64] Kelley (n 32) 264.
[65] For example, see Yair Listokin and Raymond Noonan, 'Measuring Lawyer Well-Being Systematically: Evidence from the National Health Interview Survey' (2021) 18(1) *Journal of Empirical Legal Studies* 4, 8; Ries et al (n 28) 688; Helmes, Lewis and Allan (n 28) 826.
[66] Kathryn Birtwistle, *Access to Digital Records upon Death or Incapacity: Survey Results* (Research Report No 15, New South Wales Law Reform Commission, December 2019) <https://lawreform.nsw.gov.au/documents/Publications/Other-Publications/Research-Reports/RR15.pdf>.
[67] Ibid 2.
[68] Ibid 7.
[69] Ibid.
[70] Ibid 28–42.

was appropriate, especially in light of the smaller sample size, given only 11% of lawyers working in NSW are located in a regional or rural area.[71]

5.4.3.6 Data collection

Regional Law Societies and The Law Society of New South Wales Strategy and Projects Division were asked to disseminate a link to the electronic survey. The survey was administered and managed using REDCap (Research Electronic Data Capture), a secure, web-based software platform designed to support data capture for research studies, hosted at The University of Technology Sydney.[72] A Participant Information Statement (**Appendix D**) was displayed on the initial page of the survey, and participants were asked if they agreed to proceed with the survey after reviewing the study information. The survey then followed, with branching logic employed to ensure participants only received questions that were relevant, based on their previous responses. Finally, a Consent to Contact page was included as the last page of the survey, asking participants if they were interested in receiving information regarding other aspects of the study, including participation in a telephone interview. Up to two reminder emails were sent to Presidents of the Regional Law Societies and The Law Society of New South Wales Strategy and Projects Division to request re-circulation of the survey link, depending on response rates.

5.4.3.7 Analysis of results

Excel was used to record the survey data, which was then analysed using descriptive statistics.[73] Where participants had written a free text response in the available boxes throughout the survey, this data was extracted and analysed thematically.

5.4.4 Interviews with Professionals

5.4.4.1 Background

Qualitative interviews were conducted with 28 professionals who had experience advocating for the rights of older adults, assisting older adults to complete APP, or interpreting completed documents. Discussion with these experts allowed for deeper exploration and analysis of their

[71] Urbis, '2023 Annual Profile of Solicitors NSW: Final' (4 June 2024) 1, 14.
[72] See Paul A Harris et al, 'Research Electronic Data Capture (REDCap)—A Metadata-Driven Methodology and Workflow Process for Providing Translational Research Informatics Support' (2009) 42(2) *Journal of Biomedical Informatics* 377; Paul A Harris et al, 'The REDCap Consortium: Building an International Community of Software Platform Partners' (2019) 95 *Journal of Biomedical Informatics* 103208:1–10.
[73] Kelley (n 32) 265.

engagement with older people and their perspectives relating to APP.[74] This study was approved by the Human Research Ethics Committee of the University of Technology Sydney (ETH20-5024 and ETH21-6622).

5.4.4.2 Study instrument

A copy of the semi-structured interview guide for professionals is reproduced in **Appendix E**. Creswell's recommendation of 'approximately five to seven open-ended questions'[75] was again followed. Questions were directed to: the nature of their professional role; professionals' perceptions of APP, including quality and confidence; any perceived barriers that may be preventing older people from engaging with APP; advantages and disadvantages of APP for older people; challenges associated with interpreting or implementing completed instruments; and any areas for improvement in the current processes. Reliability of the interviews was again ensured by following the strategies outlined in 5.4.2.2.[76]

5.4.4.3 Recruitment

As noted above, professional key informants were defined as experts working in the fields of law, health and ageing with experience in either preparing or interpreting APP instruments. Recruitment occurred via two methods. Firstly, lawyers who completed the online survey and gave consent for further contact were sent an invitation to participate in an interview. Secondly, professionals with expertise in legal and health disciplines were identified due to their experience in particular legal, health or ageing roles via professional networks and through searching relevant organisation websites. Professionals who participated in the interviews included: emergency medicine practitioners; intensive care clinicians; nurses with experience in palliative or end-of-life care; General Practitioners; academics; a law enforcement professional with expertise in preventing and responding to elder abuse; and employees of organisations that advocate for older people, such as Dementia Australia and the NSW Trustee & Guardian. An email invitation that contained a Participant Information Statement (**Appendix F**) was sent to the identified professionals, asking if they would be willing to take part in an interview regarding their experiences with APP.

[74] Punch (n 39) 177.
[75] Creswell, 'Data Collection' (n 34) 164.
[76] Creswell, 'Standards of Validation and Evaluation' (n 36) 253.

5.4.4.4 Demographics

Twenty-eight key informants took part in the interviews. The scope of professional experience was broad, with 11 participants working in a legal role, 17 in the fields of health and ageing, and one participant working in law enforcement. Eleven participants had worked in their field of practice for over 30 years, while eight had between 16 and 20 years of experience. Five participants had been working in their field for 10 years or less. The age of participants ranged from 35 to 77, with an average age of 56 years. Fifteen of the participants identified as female, while 13 identified as male. Table 3 presents the demographic details of the interviewed professionals.

Table 3. Demographics of Interviewed Professionals

DEMOGRAPHIC	***n***
Years of Experience in Current Role	
0-10 years	5
11-20 years	8
21-30 years	4
More than 30 years	11
Area of Professional Expertise	
Law	12
Lawyer	11
Law Enforcement	1
Healthcare	16
Medicine	10
Nursing	5
Other	1
Gender	
Female	15
Male	13
Age	
35-44 years	4
45-54 years	9
55-64 years	6
65 and over	9

5.4.4.5 Sampling and sample size

Expert sampling[77] and snowball sampling[78] were used to identify and recruit professional key informants for interviews regarding their experiences with APP.[79] Professionals were identified via expert sampling, and were subsequently asked if they could recommend colleagues who might be interested in taking part in an interview. The lone law enforcement professional who participated was identified via snowball sampling. Due to these methods, the geographic area in which key informants were located expanded beyond rural and regional areas. This is appropriate, given older people in rural and regional areas are commonly referred to and receive services from professionals working in larger regional and metropolitan areas. It also allowed for insights from experts with a greater depth of experience.

In considering the sample size of my qualitative study, I again applied the factors outlined by Malterud et al[80] to my research. The aim of my research to better understand professionals' perceptions of APP and illuminate areas for improvement could be considered quite narrow and specific, thereby warranting a smaller sample of participants.[81] As all participants recruited were professionals with expertise in the preparation or implementation of APP instruments, this could be considered high specificity, while also highlighting variation between experiences such as those of a lawyer practicing in the field of Succession Law and nurses specialising in the field of end-of-life care. The quality of the dialogue between myself and the participants was again high. Finally, the phenomenological approach also reduced the number of participants required to achieve sufficient information power.[82]

5.4.4.6 Data collection

Professionals who were identified through the sampling methods discussed above were sent an invitation via email and provided with a copy of the Participant Information Statement. Suitable dates and times were then scheduled for the interviews, depending on participant availability.

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[77] Michael Quinn Patton, 'Expert Sampling' in Bruce B Frey (ed), *The SAGE Encyclopedia of Educational Research, Measurement, and Evaluation* (SAGE, 2018) 648.
[78] Toni Crouse and Patricia A Lowe, 'Snowball Sampling' in Bruce B Frey (ed), *The SAGE Encyclopedia of Educational Research, Measurement, and Evaluation* (SAGE, 2018) 1532; Julian Kirchherr and Katrina Charles, 'Enhancing the Sample Diversity of Snowball Samples: Recommendations from a Research Project on Anti-Dam Movements in Southeast Asia' (2018) 13(8) *PLoS ONE* e0201710:1-17.
[79] Jennifer A Parsons, 'Key Informant' in Paul Lavrakas (ed), *Encyclopedia of Survey Research Methods* (Sage, 2011) 406; Geoff Payne and Judy Payne, 'Key Informants' in *Key Concepts in Social Research* (SAGE, 2011) 135.
[80] Malterud, Siersma and Guassora (n 42).
[81] Ibid 1754.
[82] Ibid 1754–1756.

Up to two reminder emails were sent, depending on response rates. Professionals also had the opportunity to recommend colleagues suitable for participation, either in addition to or instead of their own involvement. The interview guide was then administered as individual interviews over the telephone or via web conference, depending on participant preference. All interviews were audio recorded and transcribed. Notes were also taken during the interviews. The average interview duration was 51 minutes. Participants were given the opportunity to review the interview transcript, provide feedback or clarification of any points, and request data be omitted prior to analysis if necessary.[83]

5.4.4.7 Analysis of results

The analysis techniques outlined in 5.4.2.6 were again adopted for this participant group. Draft results were again sent to participants for their review and additional comments. This thematic analysis of the data[84] situated my research within the existing literature and expanded the current knowledge base, given the paucity of research with professionals, especially with lawyers, regarding the broader processes involved in APP. Due to my role in conducting all interviews, my familiarity with the data, and the need for reflexivity during coding and analysis, in addition to the nature of a PhD project, I again acted as the sole coder of the dataset.[85]

5.5 Strengths and Limitations of the Study

5.5.1 Interviews with Older People

The semi-structured interviews with older people provide new empirical data regarding engagement with APP. The use of in-depth interviews allowed for more detailed exploration of key themes, compared to surveys[86] or audits.[87] The results also relate to older adults living in regional and rural areas, as opposed to adults in general,[88] individuals living with specific

[83] Thomas (n 38); Hagens, Dobrow and Chafe (n 38).
[84] Louise Doyle et al, 'An Overview of the Qualitative Descriptive Design within Nursing Research' (2020) 25(5) *Journal of Research in Nursing* 443; Annelie J Sundler et al, 'Qualitative Thematic Analysis Based on Descriptive Phenomenology' (2019) 6(3) *Nursing Open* 733; Bryman (n 53) 579; Virginia Braun and Victoria Clarke, 'Using Thematic Analysis in Psychology' (2006) 3(2) *Qualitative Research in Psychology* 77.
[85] O'Connor and Joffe (n 50) 5; Campbell et al (n 50).
[86] Rodi et al (n 26); Marcus Sellars et al, 'Personal and Interpersonal Factors and their Associations with Advance Care Planning Documentation: A Cross-Sectional Survey of Older Adults in Australia' (2020) 59(6) *Journal of Pain and Symptom Management* 1212.
[87] Buck et al (n 25).
[88] Sonja McIlfatrick et al, '"It's Almost Superstition: If I Don't Think about It, It Won't Happen". Public Knowledge and Attitudes towards Advance Care Planning: A Sequential Mixed Methods Study' (2021) 35(7) *Palliative Medicine* 1356.

conditions[89] or those receiving end-of-life care.[90] The findings provide insight regarding motivations for planning ahead and opportunities for improvement in existing APP processes, rather than limiting the scope of inquiry to Advance Care Planning. While a majority of participants resided in the Riverina region of NSW, as discussed above, there was representation from several regions across the state. Participants were also equally split with respect to gender identity.

While noting the unique and differing experiences for Indigenous people and those from culturally and linguistically diverse backgrounds, only two older adults identified as First Nations. As the completion of the ARC baseline survey was the only recruitment path for this study, First Nations people and those from culturally and linguistically diverse backgrounds were not able to be targeted in recruitment and their participation was incidental. The lack of participation of people from culturally and linguistically diverse backgrounds was not unexpected, given people from these populations tend to concentrate in urban areas in Australia.[91] As such, a relatively small proportion of their cohorts reside in rural NSW. Similarly, research has indicated Indigenous people may not wish to engage with civil law processes generally, due to the impact of past negative experiences with Anglo legal systems, which may also influence their willingness to engage with APP.[92]

The ARC Discovery Project baseline survey and my interviews were conducted in English. Given this was a PhD project, funding was not available to translate study materials or engage interpreters. Similarly, no culturally and linguistically diverse organisations were engaged in recruitment for the baseline survey. Focusing on the unique perspectives of First Nations older adults and their experiences of access to justice, as well as the perspectives of those with diverse backgrounds, represent significant areas for future research, given they were beyond the scope of the current thesis.

As participants were recruited as part of a larger project on APP, their views were likely to represent people who had interest in, or experiences relevant to, planning ahead. Perspectives of people who have less awareness of existing processes, or have not felt ready or able to

[89] Rodi et al (n 26); Detering et al (n 27).
[90] Helen Close et al, 'Qualitative Investigation of Patient and Carer Experiences of Everyday Legal Needs towards End of Life' (2021) 20 *BMC Palliative Care* 47:1–13.
[91] Siqin Wang et al, 'Tracking the Settlement Patterns of CALD Populations in Australia: A Census Based Study from 2001 to 2021' (2023) 141 *Cities* 104482.
[92] Chris Cunneen and Melanie Schwartz, 'Civil and Family Needs of Indigenous People in New South Wales: The Priority Areas', (2009) 32(3) *University of New South Wales Law Journal* 725.

participate in APP processes, may not be represented in the current data. The sample were also highly educated, with half of the participants having completed tertiary study. This could represent a limitation, given this may correlate with increased willingness to engage with APP. Finally, sexuality was not explicitly raised by any of the interviewees. As such, the experiences and perspectives of older adults who identify as members of the LGBTQI+ community require further exploration, with particular sensitivity towards their experiences, including the involvement of same-sex or gender diverse partners.

5.5.2 Survey of Lawyers

Interestingly, nearly three quarters of the lawyers who participated in the survey indicated that less than half their practice involved APP. This means that a larger proportion of participants had established more of a generalist practice in their rural or regional community, as is often the case for those working in regional areas, so it is not unexpected that APP would account for less than half of their regular work. However, this result also indicates that speaking directly with lawyers who work predominantly in the field of APP would be beneficial, as they could provide insight into the efficacy of current processes and direct attention to the areas in most urgent need of improvement.

This quantitative study provides vital empirical data regarding regional lawyers' experiences of assisting older adults to engage in APP. It expands on findings from existing literature relating to the narrower process of Advance Care Planning and examines prompts, barriers, benefits and risks of available mechanisms that safeguard clients' preferences and wishes relating to finances and legal matters, in addition to their healthcare considerations. Preliminary findings from this survey were used to direct the focus of further research, including the qualitative interview study with expert key informants working in the fields of law, health and ageing.

As previously mentioned, the response rate to the online lawyer survey was low, meaning the sample size was a significant limitation. However, this is not uncommon in quantitative studies of lawyers.[93] Over half (57%) of the participants reported working in small organisations, and 67% stated they had 10 years or more of practice experience. This may impact the generalisability of my findings, as the insights gained from the data may not represent the experiences of lawyers with fewer years of practice, those working in larger organisations, or

[93] See, for example, Birtwistle (n 65).

professionals who operate more of a specialised practice. As noted above, 74% of respondents reported that less than half of their practice involved APP, meaning it would be beneficial to speak with legal practitioners for whom this area of practice consumes a greater proportion of their workload as they may be able to provide further insight relating to assisting older adults in this specific area. Finally, 63% of participants were aged 45 and over. While this allowed for exploration of lawyers' experiences across a longer period of time, further investigation may be required with respect to the perspectives of younger practitioners.

5.5.3 Interviews with Professionals

Unlike past research in this area, my study includes key informant perspectives from both legal and health experts in the broader context of APP. Insights from several professional areas are combined, rather than examining the experiences and perspectives of lawyers[94] and clinicians[95] separately. It also provides insight from professionals at three phases of the process: (1) lawyers who assist clients to engage with and prepare APP documents; (2) health professionals who interpret and implement completed instruments relating to treatment and end-of-life care; and (3) professionals who investigate the aftermath of poor-quality APP resulting in elder abuse or other issues stemming from misuse, which may include those working in law enforcement, health, and aged care. The in-depth interviews allowed for deeper exploration of professional experiences, perspectives and suggestions. The detailed and nuanced data obtained from expert opinions enhances understanding of current processes and their operation in practice. These insights also highlight several opportunities for improvement that could be adopted by expert key informants.

The majority of professional informants were located in NSW, which aligns with the scope of my research. However, these results may not be generalisable to other jurisdictions. As such, it would be beneficial for further studies to include expert key informants from across Australia, allowing for deeper examination of similar and diverging perspectives relating to engagement, quality and future use of APP instruments. Due to the nature of the key informant approach, participants were considered experts in their field of practice. However, this is also a limitation as the study did not account for the perspectives and experiences of younger professionals, or those recently entering the professions. Similarly, the sample size means the results cannot be

[94] Ries et al (n 28); Helmes, Lewis and Allan (n 28).
[95] Moore et al (n 28); Dixon and Knapp (n 28); Joel J Rhee, Nicholas A Zwar and Lynn A Kemp, 'Why Are Advance Care Planning Decisions Not Implemented? Insights from Interviews with Australian General Practitioners' (2013) 16(10) *Journal of Palliative Medicine* 1197.

generalised across NSW, nor across entire cohorts of legal, medical and aged care professionals. While some interviews highlighted the needs and experiences of diverse populations, including people living with a disability, and people belonging to First Nations or culturally and linguistically diverse communities, this was not a key focus of contributors, which is also an opportunity for future research.

5.6 CONCLUSION

Due to the emerging nature of APP studies and the siloes in existing research between the perspectives of older people and legal and health professionals, a methodology that drew together these perspectives in a single study was essential to ensuring new, cohesive data could be collected. This is a unique approach that offered original insights. The identification of relevant quantitative and qualitative components within this research, the selection of key cohorts, and the use of credible analysis techniques were essential to producing reliable results. The findings from my study will be examined in the following chapters.

6 STUDY FINDINGS: GENERAL VIEWS OF ADVANCE PERSONAL PLANNING AND BARRIERS TO ENGAGEMENT

6.1 INTRODUCTION

This chapter presents findings from my research concerning barriers to the completion of Advance Personal Planning (APP). These barriers are addressed from different perspectives, including lawyers' perceptions of barriers that may prevent older clients from engaging in APP, and self-reported barriers for older people living in regional New South Wales (NSW). Other key informants offer additional perspectives, reflecting on factors that can undermine their confidence in helping older adults to engage with planning processes. The integration and thematic review of these three distinct but related perspectives present a new understanding of how a holistic perception of, and approach to, APP can lead to more successful engagement in the future. These findings are essential to making informed recommendations for improvements and recognising where future research is required.

6.2 BACKGROUND

Existing studies relating to Advance Care Planning have mostly utilised quantitative methods, including surveys[1] and audits,[2] rather than qualitative methods. Other research has focused on specific population groups, such as those aged 18 and over,[3] people living with specific conditions,[4] or those receiving end of life care,[5] rather than older adults as a general cohort. Additional consideration is also needed for the experiences of those in rural and regional communities, as people living in these areas may experience geographic isolation, and difficulty accessing relevant medical and legal services.[6] There also tends to be a concentration of older adults in these areas compared with younger cohorts.[7]

The perspectives of Australian healthcare professionals have been explored broadly in relation to certain aspects of Advance Care Planning, including their adherence to Advance Care Directives,[8] and the relevance of Advance Care Planning for professionals working in dementia and palliative care.[9] The prevalence and quality of Advance Care Directives have been examined among certain population groups in Australia, including older adults,[10] people living

[1] Marcus Sellars et al, 'Personal and Interpersonal Factors and their Associations with Advance Care Planning Documentation: A Cross-Sectional Survey of Older Adults in Australia' (2020) 59(6) *Journal of Pain and Symptom Management* 1212.
[2] Kimberly Buck et al, 'Advance Care Directive Prevalence among Older Australians and Associations with Person-Level Predictors and Quality Indicators' (2021) 24(4) *Health Expectations* 1312.
[3] Sonja McIlfatrick et al, '"It's Almost Superstition: If I Don't Think about It, It Won't Happen". Public Knowledge and Attitudes towards Advance Care Planning: A Sequential Mixed Methods Study' (2021) 35(7) *Palliative Medicine* 1356.
[4] Karen M Detering et al, 'Prevalence of Advance Care Planning Documentation and Self-Reported Uptake in Older Australians with a Cancer Diagnosis' (2021) 12(2) *Journal of Geriatric Oncology* 274.
[5] Helen Close et al, 'Qualitative Investigation of Patient and Carer Experiences of Everyday Legal Needs towards End of Life' (2021) 20 *BMC Palliative Care* 47:1–13.
[6] Pamela Harvey et al, 'Rural Health Services' Relationships with Patients: An Enabler and a Barrier to Advance Care Planning' (2019) 27(6) *The Australian Journal of Rural Health* 563; Karly B Smith, John S Humphreys and Murray GA Wilson, 'Addressing the Health Disadvantage of Rural Populations: How does Epidemiological Evidence Inform Rural Health Policies and Research?' (2008) 16(2) *Australian Journal of Rural Health* 56; MR McGrail et al, 'The Planning of Rural Health Research: Rurality and Rural Population Issues' (2005) 5(4) *Rural and Remote Health* 426:1–8.
[7] Australian Bureau of Statistics, 'Regional Population by Age and Sex' (28 September 2023) <https://www.abs.gov.au/statistics/people/population/regional-population-age-and-sex/latest-release>; McGrail et al (n 6).
[8] Nadia Moore et al, 'Doctors' Perspectives on Adhering to Advance Care Directives When Making Medical Decisions for Patients: An Australian Interview Study' (2019) 9 *BMJ Open* e032638:1-11.
[9] Craig Sinclair et al, 'Professionals' Views and Experiences in Supporting Decision-Making Involvement for People Living with Dementia' (2021) 20(1) *Dementia* 84; Louise Robinson et al, 'A Qualitative Study: Professionals' Experiences of Advance Care Planning in Dementia and Palliative Care, "A Good Idea in Theory but …"' (2013) 27(5) *Palliative Medicine* 401.
[10] Buck et al (n 2); Irfana Musa et al, 'A Survey of Older Peoples' Attitudes towards Advance Care Planning' (2015) 44(3) *Age and Ageing* 371.

with dementia,[11] and individuals receiving treatment for cancer.[12] Available studies have also considered the experiences of people residing in aged care facilities and accessing health services in the community.[13] In recent research, the highest prevalence of Advance Care Planning documents in Australian communities was found among people residing in aged care facilities.[14] However, these instruments are most commonly made by other people on behalf of the older person, rather than a legally enforceable statutory instrument that has been made by the older person themselves.[15] Factors associated with planning completion include: discussing the process with someone else;[16] being female;[17] older age;[18] the presence of two or more health conditions;[19] having children;[20] owning property;[21] receiving palliative care;[22] other self-protective behaviours, such as regular legal check-ups;[23] and Anglo Celtic heritage.[24]

Studies have identified relevant barriers to engaging with advance planning from the perspective of older people, such as: a general lack of awareness and understanding of available

[11] Jamie Bryant et al, 'Inadequate Completion of Advance Care Directives by Individuals with Dementia: National Audit of Health and Aged Care Facilities' (2022) 12 *BMJ Supportive & Palliative Care* e319; Sellars et al (n 1).
[12] Detering et al (n 4); Helena Rodi et al, 'Exploring Advance Care Planning Awareness, Experiences, and Preferences of People with Cancer and Support People: An Australian Online Cross-Sectional Study' (2021) 29(7) *Supportive Care in Cancer* 3677.
[13] Frances Batchelor et al, 'Facilitators and Barriers to Advance Care Planning Implementation in Australian Aged Care Settings: A Systematic Review and Thematic Analysis' (2019) 38(3) *Australasian Journal on Ageing* 173; Detering et al (n 4).
[14] Buck et al (n 2).
[15] Ibid 1315–1317.
[16] Sellars et al (n 1).
[17] Buck et al (n 2).
[18] Cheryl Tilse et al, *Having the Last Word? Will Making and Contestation in Australia* (ARC Linkage Project Key Findings, The University of Queensland; Victoria University; Australian Centre for Health Law Research, March 2015) <https://eprints.qut.edu.au/215396/>; Michael R Greenberg, Marc Weiner and Gwendolyn B Greenberg, 'Risk-Reducing Legal Documents: Controlling Personal Health and Financial Resources' (2009) 29(11) *Risk Analysis* 1578.
[19] Buck et al (n 2).
[20] Tilse et al (n 18); Greenberg, Weiner and Greenberg (n 18).
[21] Tilse et al (n 18); Greenberg, Weiner and Greenberg (n 18).
[22] Kimberly Buck et al, *Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services* (Report, Advance Care Planning Australia and Austin Health, October 2019) <https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3668752>; Robinson et al (n 9).
[23] Greenberg, Weiner and Greenberg (n 18).
[24] Sarah Jeong et al, '"Planning Ahead" among Community-Dwelling Older People from Culturally and Linguistically Diverse Background: A Cross-Sectional Survey' (2015) 24 *Journal of Clinical Nursing* 244.

instruments;[25] poor understanding of legal rights;[26] difficulty accessing information about planning, including the lack of readily available translated materials for people belonging to culturally and linguistically diverse groups;[27] the perception of planning as irrelevant or too confronting to think about;[28] cost;[29] and family conflict.[30]

My research utilises a unique approach in providing a comparison of perspectives from the three cohorts involved to produce an understanding of their general views of APP, as well as barriers to engagement for older adults living in regional NSW. Additional insights are provided by lawyers and professional key informants, presenting a contrast between relevant professionals' perceived motivations and barriers, and older adults' self-reported motivations and barriers.

6.3 Prevalence of APP Among Older People in Regional NSW

All of the 22 older adults who participated in an interview for this study had completed a Will. Sixteen reported having appointed an Enduring Power of Attorney. Fifteen had named someone as their Enduring Guardian, while only seven participants had written an Advance Care

[25] Craig Sinclair et al, 'Association Between Region of Birth and Advance Care Planning Documentation Among Older Australian Migrant Communities: A Multicenter Audit Study' (2021) 76(1) *The Journals of Gerontology: Series B* 109 ('Association Between Region of Birth and Advance Care Planning Documentation'); Jane B Baron, 'Fixed Intentions: Wills, Living Wills, and End-of-Life Decision Making' (2020) 87(2) *Tennessee Law Review* 375; Sophie Trarieux-Signol et al, 'Advance Directives from Haematology Departments: The Patient's Freedom of Choice and Communication with Families. A Qualitative Analysis of 35 Written Documents' (2018) 17 *BMC Palliative Care* 10:1-12.

[26] Close et al (n 5); Sarah Ellison et al, *The Legal Needs of Older People in NSW* (Report, Law and Justice Foundation of New South Wales, December 2004) <https://lawfoundation.net.au/wp-content/uploads/2023/11/54PJR_The-legal-needs-of-older-people-in-NSW_2004.pdf>.

[27] Marcus Sellars et al, 'Public Knowledge, Preferences and Experiences about Medical Substitute Decision-Making: A National Cross-Sectional Survey' [2021] *BMJ Supportive & Palliative Care* (advance):1-21; Craig Sinclair et al, 'A Public Health Approach to Promoting Advance Care Planning to Aboriginal People in Regional Communities' (2014) 22(1) *Australian Journal of Rural Health* 23; D Visala Rao, Jeni Warburton and Helen Bartlett, 'Health and Social Needs of Older Australians from Culturally and Linguistically Diverse Backgrounds: Issues and Implications' (2006) 25(4) *Australasian Journal on Ageing* 174; Ellison et al (n 26).

[28] Julie L Masters, Lindsey E Wylie and Sarah B Hubner, 'End-of-Life Planning: Normalizing the Process' (2022) 34(4) *Journal of Aging & Social Policy* 641; McIlfatrick et al (n 3); Batchelor et al (n 13); Moore et al (n 8); Ian A Scott et al, 'Difficult but Necessary Conversations — The Case for Advance Care Planning' (2013) 199(10) *The Medical Journal of Australia* 662.

[29] Close et al (n 5); Sandra Thompson et al, 'Passing on Wisdom: Exploring the End-of-Life Wishes of Aboriginal People from the Midwest of Western Australia' (2019) 19(4) *Rural and Remote Health* 5444:1–9; Robinson et al (n 9).

[30] Karen M Detering et al, 'Organisational and Advance Care Planning Program Characteristics Associated with Advance Care Directive Completion: A Prospective Multicentre Cross-Sectional Audit among Health and Residential Aged Care Services Caring for Older Australians' (2021) 21 *BMC Health Services Research* 700:1–12; Julien Tran et al, 'Systematic Review and Content Analysis of Australian Health Care Substitute Decision Making Online Resources' (2021) 45(3) *Australian Health Review* 317; Ellison et al (n 26).

Directive. Nearly all participants reported making or updating one of their APP documents in the last five years, with Advance Care Directives being reviewed or created most recently. Enduring Guardian and Enduring Power of Attorney appointments were mixed with respect to currency, and Wills ranged from two years to over 20 years old. As indicated in Chapter 5, this cohort was highly educated, with over half of the participants having completed a university qualification. This could offer an explanation as to the high prevalence of APP instruments among those who participated in an interview, as well as their high engagement with lawyers in their preparation.

The uptake of APP instruments reported by participants in this study was similar to established literature.[31] Participants noted their experience with factors unique to their regional and rural locale, including a lack of availability of health and financial services,[32] such as not having a resident General Practitioner and closure of the local branch of their bank. One lawyer who completed an interview as a key informant commented on their experience as a practitioner working in a regional area:

> In the rural areas, in broad [b]rush, I would answer that there is less knowledge and there's less ability to go to professional services, whether advocates or lawyers, to get help. There's just more exploitation in the bush. … the sad cases are more just outright oppression by children who don't have any legal status. They just persuade their parents to take out a mortgage on the family home, and then spend the money themselves. … They just pressure the parent. (Key Informant 6, Lawyer)

However, older adults did not report the same access issues with respect to legal services, as almost all participants had engaged a lawyer to prepare their planning instruments. The Australian Institute of Health and Welfare has specifically identified ease of access to health services, ability to access legal advice, and economic stability as factors that contribute to, or

[31] Buck et al (n 2); Cheryl Tilse et al, 'Making and Changing Wills: Prevalence, Predictors, and Triggers' (2016) 6(1) *SAGE Open* 1.
[32] Lisa Bourke et al, 'Understanding Rural and Remote Health: A Framework for Analysis in Australia' (2012) 18(3) *Health & Place* 496; McGrail et al (n 6).

detract from, an individual's wellbeing.[33] Similarly, the regional location of older adults may have a significant effect on their support network and social connections,[34] as evidenced below.

6.4 Motivations for Planning Ahead

6.4.1 Older Adults' Self-Reported Motivations

6.4.1.1 Peace of mind and a sense of safety

Several older adults who participated in an interview noted that having their wishes recorded gave them peace of mind. One participant shared their engagement with APP had left them feeling '[s]ecure in that knowledge and you don't have to worry about something at the last minute, I suppose' (Participant 12). Some participants also recognised the importance of APP in providing a safety net in the event of a period of incapacity: 'It's something that you're supposed to do in case you could lose your marbles. Which fortunately I haven't done, I'm still managing my own affairs, but it's there in case of emergencies. I could have an accident or anything could happen' (Participant 7).

Another participant described APP as an important safeguard for the future: 'It just makes your life run so much easier. You're not worrying from day-to-day what's around the corner and what will we have to do next, sort of thing? It's forward planning' (Participant 13). One participant shared: 'You just don't know when it's going to happen or to what extent you may have to call on those plans. So it's really just a safeguard in the event that it's needed' (Participant 20). These motivations clearly highlight the principle that planning ahead is not simply for the end of life, but for the rest of life as well. APP can provide a safety net in circumstances where a person is experiencing a heightened period of dependency, for example after being in an accident, and requires increased support for a certain period of time. It is not only relevant if a person is acutely unwell or approaching the end of life.

6.4.1.2 Previous experiences

Experience as a caregiver for another person, or a recent change in health circumstances, also enlivened desires to safeguard for the future: 'My wife was ill for about 17 months, and terminally ill, and I looked after her. And at that point, it became apparent to me that I needed

[33] Australian Institute of Health and Welfare, *Australia's Welfare 2019: Data Insights* (Australia's Welfare Series No 14. Catalogue No AUS 226, 2019) 2 <https://www.aihw.gov.au/reports/australias-welfare/australias-welfare-2019-data-insights/data>.
[34] Ibid 7.

to get these things organised' (Participant 1). These shared experiences again demonstrate the significance of considering all aspects of an older adult's wellbeing, including their health, finances and interpersonal relationships.

6.4.1.3 Relieving burden for decision-makers

Almost half of the participants believed planning ahead made things easier for their decision-makers if they were ever called upon to make choices on the person's behalf. As one participant expressed: 'It is your decision for whatever might happen and if you have it in writing, ready ... [n]obody has to make the hard decisions for you' (Participant 8). Another participant specifically stated they '[didn't] want to be a burden on anybody' (Participant 10). This concept of relieving others of burden is connected to relational autonomy, and understanding how decisions are influenced by, and go on to affect, other people within a support community.

6.4.1.4 Preventing family conflict

Some participants appreciated the opportunity to prepare for the future and prevent family tensions. One participant was conscious of the financial consequences of potential conflict, noting they did not want their family to 'spend a fortune on bloody lawyers to fight over it' (Participant 17). Another participant explicitly highlighted the value of planning in preventing conflict: 'I really feel that the planning ahead is extremely important when you've got families that may not be in agreement. And that's where it comes into its own' (Participant 18). These perspectives clearly relate to Preventive Law and Therapeutic Jurisprudence. Participants are wanting to proactively guard against future conflict, while accounting for their own wellbeing and that of others who are involved in planning ahead.

6.4.2 Professional Perceptions of Motivations

The 31 lawyers who completed the online survey noted several circumstances that 'sometimes' or 'often' prompt older people to engage in APP, including: a client has received a medical diagnosis or is experiencing deteriorating health; APP conversations have been initiated by a lawyer; or the client has had a discussion with family or friends. The least reported prompt was a client having had a discussion with a financial planner, banker or advisor. These factors align

with those discussed in the literature, including declining health,[35] the death of someone close to them,[36] discussions with family,[37] or speaking with a professional about planning ahead.[38]

In relation to declining health, one lawyer noted this as a relevant factor for younger clients, indicating that these prompts may be relevant across all age groups and not just for older adults. These factors also support my comprehensive conceptualisation of wellbeing that includes 'family functioning, social engagement, material resources, health status, support networks, employment and skills, secure housing, personal factors and behaviours'.[39] This holistic understanding of wellbeing goes beyond consideration of psychological wellbeing only, which is the traditional focus of Therapeutic Jurisprudence.[40]

6.5 Barriers to Engagement

6.5.1 Older Adults' Self-Reported Barriers

6.5.1.1 Plans may not be followed

Despite the significant motivations that emerged from the data, around a quarter of the older adult participants reported concerns that prepared plans may not be enacted in future. A few participants thought there may be risks if someone had appointed a decision-maker who may not act in their best interests: 'I don't know that you can write it all down so tightly that you are going to get your own wishes, anyway. Because every document, every discussion is open to another interpretation' (Participant 5). This comment highlights the need for ongoing communication with appointed decision-makers to ensure wishes and values are understood, something that will be explored further in the next chapter.

6.5.1.2 Plans may not represent future wishes

Some participants noted that wishes expressed in the present may not reflect what they would like to happen in future. Others believed that even if you have instruments in place, other people will still have to make difficult decisions, especially regarding end of life care. One participant

[35] Nola M Ries et al, 'How do Lawyers Assist their Clients with Advance Care Planning? Findings from a Cross-Sectional Survey of Lawyers in Alberta' (2018) 55(3) *Alberta Law Review* 683, 688–689.
[36] Greenberg, Weiner and Greenberg (n 18) 1582–1584.
[37] Sellars et al (n 1) 1212.
[38] Grace W Orsatti, 'Attorneys as Healthcare Advocates: The Argument for Attorney-Prepared Advance Healthcare Directives' (2022) 50(1) *Journal of Law, Medicine & Ethics* 157, 157.
[39] Australian Institute of Health and Welfare (n 33) 2.
[40] Dennis P Stolle and David B Wexler, 'Therapeutic Jurisprudence and Preventive Law: A Combined Concentration to Invigorate the Everyday Practice of Law Essays' (1997) 39 *Arizona Law Review* 25, 25.

shared their personal experience as an Enduring Guardian and having to make decisions relating to their mother's care, which led to this resignation with respect to future risks:

> I have learnt, in the last three years, that even though all this stuff is in place, you do not get out of having to make the hard decisions. … [H]aving these things in place, it's all good and well, but you've really got to think about the fact that the person who is answerable does the final thing. … But [even with] that directive, you're still naming somebody who has to make some sort of choices further along the line. (Participant 18)

The participant further shared: 'I made sure everything was in place. I thought, goody, it's all in place now, we know her wishes, she's not going to [be] resuscitated, she doesn't want this, she doesn't want any heroic measures, etc' (Participant 18). However, as this participant continued to explain, despite their mother having made the relevant plans and appointments, the participant was frequently contacted by their mother's healthcare practitioner to ask what course should be taken in her treatment, requiring the participant to make difficult decisions.

6.5.1.3 Planning ahead not considered necessary

In contrast to having experienced the consequences of acting upon planning instruments for another person, some participants stated they simply had not thought about planning ahead or considered it necessary to complete certain instruments, such as creating an Advance Care Directive: 'I think because we're both fortunate, we've got good health, we don't give it a lot of thought. … [W]hile everything's going fine, it's okay' (Participant 11). Another participant stated they had no intention of appointing an Enduring Guardian, choosing not to dwell on any risks that may arise in future:

> I will not appoint one because I am lucky enough to be compos mentis. And dementia is not an issue in my family, and therefore I am very unlikely to become … incapable of making my own decisions. … I just can't be bothered to even think about it much, but I know that my sister, who is the only remaining family member, would look after me regardless. (Participant 14)

6.5.1.4 No trusted person to appoint

Not having a person to appoint as a decision-maker was also a significant factor that had prevented some older adults from completing the full range of available APP mechanisms. Several participants spoke about how they lived alone in a regional area, which impacted their choices when considering whether to appoint a decision-maker, and who to appoint.[41] One

[41] For a similar finding, see Close et al (n 5).

participant in particular had relocated to a small community to care for her elderly mother, but due to her isolation she felt unable to appoint an Enduring Guardian or Enduring Power of Attorney for herself. This concern was also raised by one of the key informants, highlighting that relational autonomy needs to consider the support a person can, or cannot, draw from their community:

> [F]or Advanced Care and Enduring Guardianship, I have struck that problem quite a few times. … [T]hey don't have anybody in their community that they want to do it with. … [I]t's amazing how many people just don't have anybody that they would trust. (Key Informant 1, Lawyer)

This is in contrast to the professional experience of another key informant, who noted:

> I find older people tend to be fairly clear on who they trust and who they have ongoing relationships with. When you advise them about obligations of the Attorney and discuss it with them, in most families they're pretty clear who they want to act in that role. … What I recommend to older people is that they have a discussion with the family as to why they've appointed that person to avoid future difficulties down the track. … Occasionally, you might get an older person that trusts a child, but there might be some indicators there that the trust might be a bit misplaced. You just talk it through. (Key Informant 7, Lawyer)

One older person did not feel they had someone they trusted to appoint as their Enduring Power of Attorney, citing financial privacy concerns: 'Now, I haven't selected a preferred person. That's all for the financial issues, because as I say, I think that can be a bit of a problem… I don't want people knowing how much or how little money I've got' (Participant 1). Another participant felt they had no options for appointing a decision-maker due to their limited family and social network: 'Now, this is where it gets difficult. I have to have some conversations with people because I have a very small family. And I am an adoptee. So that makes it even smaller. … So, yes, that one is one of the complications that a lot of people don't think about' (Participant 18).

These are significant issues for older adults living alone in rural and regional communities. A response may be found in strategies such as community outreach and education sessions delivered by local legal practitioners and/or healthcare providers regarding APP instruments, their distinct purposes, and options for appointing decision-makers. These activities may help to address the broad range of available planning mechanisms, and the people who can act in

these roles, including lawyers or the NSW Trustee and Guardian, if a person does not have family close by who they want to appoint.

6.5.1.5 Not ready to engage

Other older adult participants were simply not ready to engage in the process: 'I have a hang up about dying, so for me, I probably have thought, oh well, I'll do it a bit later' (Participant 14). Some participants perceived the process as too confronting, were indecisive regarding their future wishes, or preferred not to think about planning processes: 'I am a dreadful procrastinator. … It's hard to think of yourself as old' (Participant 16).

Such comments reflect the enduring perception that APP is only for the very end of life and is more relevant for people of advanced age. However, while all older adult participants reported having a Will, meaning they had all engaged in the only document that operates after death, the cited barriers to engagement apply to their perspective of 'living' documents, including Advance Care Directives, and Enduring Guardian and Enduring Power of Attorney appointments. This area warrants further investigation to discover why people who don't wish to think about dying, or consider themselves as old, feel comfortable preparing a Will but not engaging with other instruments that can ensure their control over the rest of their life, and appoint trusted individuals from their support community to assist them with decision-making in the future.

6.5.2 Professional Perceptions of Barriers

Similar to the barriers that were reported by older people, lawyers who completed the online survey noted several factors that 'sometimes' or 'often' prevent older adults from engaging with APP, including: clients not feeling ready to engage in APP; clients being concerned about family conflict; or clients not believing APP is needed. The least reported barrier was concerns that instruments could not be changed. Professional key informants also cited fear of upsetting family by raising the subject,[42] and older adults not feeling ready to engage with APP processes.[43] However, they also suggested a lack of knowledge or understanding regarding the

[42] Key Informant 1 (Lawyer); Key Informant 5 (Lawyer); Key Informant 8 (Emergency Clinician); Key Informant 10 (Nursing: End of Life); Key Informant 12 (General Practitioner); Key Informant 13 (Law Enforcement); Key Informant 15 (Lawyer); Key Informant 19 (Senior Clinician); Key Informant 20 (Nursing: Aged Care); Key Informant 26 (Nursing: Emergency); Key Informant 28 (Lawyer).

[43] Key Informant 1 (Lawyer); Key Informant 6 (Lawyer); Key Informant 7 (Lawyer); Key Informant 13 (Law Enforcement); Key Informant 15 (Lawyer); Key Informant 16 (Palliative Care Clinician); Key Informant 18 (General Practitioner); Key Informant 19 (Senior Clinician); Key Informant 22 (General Practitioner); Key Informant 26 (Nursing: Emergency).

various instruments,[44] the cost and time associated with the process,[45] not having a trusted person to appoint as their decision-maker,[46] and cultural factors including language barriers[47] were preventing their older clients and patients from engaging with APP.

6.5.2.1 Reluctance to confront the future

Like a number of the older people who were interviewed, two lawyers raised the psychological hurdle of considering future wishes. One stated: '[T]hey don't want to turn their mind to what happens with disaster planning. … It's a psychological thing. That's the biggest barrier' (Key Informant 1, Lawyer). Another related: 'I think a lack of knowledge, a lack of belief that it's critical. But mostly, I would say, it's human nature … [to] put it off' (Key Informant 6, Lawyer). This reluctance to consider future circumstances, coupled with a lack of education regarding the various APP instruments and how they operate, are key barriers to engagement.

6.5.2.2 Difficult interpersonal relationships

One General Practitioner gave the example of strained interpersonal relationships between an older person and their children as a key barrier, noting that even if an older person has discussed their wishes with their family, there can be no 'hard outcome to any of these discussions' (Key Informant 12, General Practitioner). Disagreement or estrangement within families can lead to conflict and complicate decision-making in future. The absence of family support can impede older adults from wanting to engage with APP, or leave them with a lack of confidence in the plans they have made. Once again, this highlights the significance of professionals considering an individual's wellbeing and relational autonomy when evaluating their ability to engage with APP and plan ahead effectively.

[44] Key Informant 1 (Lawyer); Key Informant 2 (Lawyer); Key Informant 4 (Lawyer); Key Informant 5 (Lawyer); Key Informant 6 (Lawyer); Key Informant 7 (Lawyer); Key Informant 10 (Nursing: End of Life); Key Informant 11 (Nursing: End of Life); Key Informant 15 (Lawyer); Key Informant 16 (Palliative Care Clinician); Key Informant 18 (General Practitioner); Key Informant 19 (Senior Clinician); Key Informant 22 (General Practitioner); Key Informant 27 (Psychiatrist).

[45] Key Informant 1 (Lawyer); Key Informant 3 (Lawyer); Key Informant 4 (Lawyer); Key Informant 6 (Lawyer); Key Informant 7 (Lawyer); Key Informant 15 (Lawyer); Key Informant 18 (General Practitioner); Key Informant 22 (General Practitioner); Key Informant 24 (Lawyer); Key Informant 27 (Psychiatrist).

[46] Key Informant 1 (Lawyer); Key Informant 2 (Lawyer); Key Informant 7 (Lawyer); Key Informant 21 (Health Services Researcher); Key Informant 22 (General Practitioner); Key Informant 23 (Lawyer): Key Informant 26 (Nursing: Emergency).

[47] Key Informant 3 (Lawyer); Key Informant 5 (Lawyer); Key Informant 6 (Lawyer); Key Informant 11 (Nursing: End of Life); Key Informant 12 (General Practitioner); Key Informant 13 (Law Enforcement); Key Informant 16 (Palliative Care Clinician); Key Informant 18 (General Practitioner); Key Informant 19 (Senior Clinician); Key Informant 24 (Lawyer); Key Informant 27 (Psychiatrist).

This sentiment was also shared by a legal key informant, who emphasised the feelings of shame that can accompany family conflict: 'I think, firstly, it's the issue of shame. The shame factor, when it comes to their own family, where they know that there is a problem internally, and they're a bit hesitant to mention that' (Key Informant 5, Lawyer).

The absence of a stable family structure to support APP is therefore a key barrier to engagement. Fear of conflict, or a lack of familial support for an older person's autonomy, can limit their ability to fully participate in planning ahead and thereby undermine their capacity to exercise power and control over their future.

6.5.2.3 Lack of education regarding APP

The need for further APP education for older adults, and professions at large, was raised by one lawyer. Such education would ensure individuals are aware not only of the range of instruments available, but their distinct purposes and when they begin to operate: 'The first is lack of education, on behalf, not only of the people in the community. You know, the man or woman on the bus. But, also on the part of professionals' (Key Informant 15, Lawyer).

6.5.2.4 Culturally and linguistically diverse communities

Over half of the lawyers who responded to the online survey indicated they had worked with clients from either First Nations or culturally and linguistically diverse populations. Lawyers noted they had encountered difficulties when attempting to engage clients from these cohorts in APP activities, with 88% indicating they 'sometimes' or 'often' had concerns about the influence or involvement of family members or friends of the older person. Similarly, 75% of lawyers considered a lack of trust in the legal system or legal processes to be a barrier to engagement, while 56% mentioned the difficulty of older people's reluctance to discuss death or end of life. Language difficulties were also recognised by 53% of respondents.

One legal key informant, who identified as a First Nations Person, noted that Wills are becoming increasingly important documents for First Nations Peoples with regard to their wishes surrounding their burial and final resting place:

> [W]e look at it from a more of a cultural aspect, but in the community, what is really important is not what assets we have, but rather where we'd like to be buried. … And they're asking, we would like to have a Will drafted, because I'm afraid that I won't be next to, say, my parents or my grandparents. I want to return back to Country and I want to be buried back in Country. (Key Informant 5, Lawyer)

Only four of the 31 lawyers who completed the survey reported they had used resources that were specifically tailored to promote culturally appropriate practice, including brochures, training, or the retention of qualified, independent interpreters. In an open text box for this survey question, one lawyer stated that they 'normally try and provide the work in cooperation with other groups (multicultural societies, refugee societies, or local Aboriginal corporations) so that any and all cultural issues can be discussed and addressed'. These findings indicate a clear need for further awareness and knowledge among lawyers of existing research and best practice to ensure APP processes are both culturally appropriate and accessible.[48]

Given that cultural barriers have been specifically identified as a factor that may increase an older person's vulnerability,[49] there is an apparent need among professionals for increased understanding of available resources and extant studies in this area. Further, as Yapp et al explain, relational autonomy, including consideration of personal relationships and the role that family members play in caregiving roles, has increased significance for older adults from culturally and linguistically diverse communities, who may adopt a less singular approach to decision-making.[50] Additional education for lawyers, such as the Palliative Care Australia

[48] For research that has been conducted in this area see Gloria T Anderson, 'Let's Talk about ACP Pilot Study: A Culturally-Responsive Approach to Advance Care Planning Education in African-American Communities' (2021) 17(4) *Journal of Social Work in End-of-Life & Palliative Care* 267; Sinclair et al, 'Association Between Region of Birth and Advance Care Planning Documentation' (n 25); Emma Spencer and Eswaran Waran, 'Opening the Lines of Communication: Towards Shared Decision Making and Improved End-of-life Care in the Top End' (2020) 213(1) *The Medical Journal of Australia* 10; NSW Health, *NSW Plan for Healthy Culturally and Linguistically Diverse Communities: 2019-2023* (Policy Directive No PD2019_018, May 2019) <https://www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2019_018.pdf>; Amanda Pereira-Salgado, Patrick Mader and Leanne M Boyd, 'Advance Care Planning, Culture and Religion: An Environmental Scan of Australian-Based Online Resources' (2018) 42(2) *Australian Health Review* 152; Gail Yapp et al, 'Planning for the Rest-of-Life, Not End-of-Life: Reframing Advance Care Planning for People with Dementia' in Gaynor Macdonald and Jane Mears (eds), *Dementia as Social Experience: Valuing Life and Care* (Routledge, 1st ed, 2018) 134; Eswaran Waran, Sharon Wallace and Jonathan Dodson-Jauncey, 'Failing to Plan is Planning to Fail: Advance Care Directives and the Aboriginal People of the Top End' (2017) 206(9) *The Medical Journal of Australia* 377; Laura Vearrier, 'Failure of the Current Advance Care Planning Paradigm: Advocating for a Communications-Based Approach' (2016) 28(4) *HEC Forum* 339; Karen Detering et al, 'Feasibility and Acceptability of Advance Care Planning in Elderly Italian and Greek Speaking Patients as Compared to English-Speaking Patients: An Australian Cross-Sectional Study' (2015) 5(8) *BMJ Open* e008800:1-7; Prue Vines, *Aboriginal Wills Handbook: A Practical Guide to Making Culturally Appropriate Wills for Aboriginal People* (NSW Trustee and Guardian, 2nd ed, 2015) <https://www.tag.nsw.gov.au/sites/default/files/2021-08/Aboriginal-Wills-Booklet-3rd-Edition-2020_Web%20version.pdf>.

[49] Council of Attorneys-General (Australia) and Attorney-General's Department, *National Plan to Respond to the Abuse of Older Australians (Elder Abuse) 2019-2023* (Report, 8 July 2019) 30 <https://www.ag.gov.au/rights-and-protections/publications/national-plan-respond-abuse-older-australians-elder-abuse-2019-2023>; Lise Barry, '"He Was Wearing Street Clothes, Not Pyjamas": Common Mistakes in Lawyers' Assessment of Legal Capacity for Vulnerable Older Clients' (2018) 21(1) *Legal Ethics* 3, 6–7 ('He Was Wearing Street Clothes, Not Pyjamas'); Lise Barry, 'Capacity and Vulnerability: How Lawyers Assess the Legal Capacity of Older Clients' (2017) 25(1) *Journal of Law and Medicine* 267 ('Capacity and Vulnerability').

[50] Yapp et al (n 48) 147. See also Baron (n 25) 409–410.

resource on Indigenous Advance Care Plans,[51] and for individuals through the Australian Indigenous HealthInfoNet,[52] should also be promoted to increase awareness about culturally appropriate APP. One legal key informant suggested the need for additional funding to make translators more accessible for clients, as this was the main barrier they faced in their practice:

> [Y]ou have to have someone to help you speak the languages. So I think, if there could be a bit more government funding than I'm aware of, to have it, so the Law Society or with the Public Trustee, I could actually say, you need to ring this number, to get a Mandarin, or Cantonese speaking, those are my biggest groups. … If you need to speak to a client, individual who only speaks Cantonese, you ring your telephone interpreter service. And then they arrange for a Cantonese interpreter to make the call for the client. It's a great service. So I would say, for my clients, language is the biggest barrier. (Key Informant 6, Lawyer)

Finally, one key informant explored the challenge that can arise when both a healthcare professional and an older patient are from culturally or linguistically diverse backgrounds. Language difficulties, a lack of appropriately translated resources, and cultural barriers to discussing death and dying with the older person and their family can impact the ability to have effective planning conversations and clearly articulate the benefits of the process:

> There's a lot of jargon there… If you're having a discussion with families, to help them explain about the forms. Explain it all to them in a language they understand. So that can be challenging. You've got people where English isn't their first language as well, from a health professional perspective as well as the older person's perspective, and families. (Key Informant 16, Palliative Care Clinician)

6.5.2.5 Lack of finances or access to resources

The relevance of financial wellbeing was discussed by one legal key informant, who discerned the connection between this issue and the ability to access services, particularly if older people live in an area that necessitates travel to visit a professional:

> I think cost is a big one. So, if people can't afford it, that's definitely one. … I think they are the main things for people. Access, if you don't have a lot of money, you live with public

[51] 'Discussing Choices – Indigenous Advance Care Plans', *Palliative Care Australia* (Web Page, 2024) <https://palliativecare.org.au/resource/discussing-choices-indigenous-advance-care-planning/>.
[52] 'Planning Ahead – Publications', *Australian Indigenous HealthInfoNet* (Web Page, 2024) <https://healthinfonet.ecu.edu.au/learn/health-system/palliative-care/planning-ahead/publications/>.

> transport, you don't have a car, all of those things make access difficult. (Key Informant 24, Lawyer)

These findings demonstrate more work is needed in the community to disseminate the preventive benefits of APP,[53] especially with respect to protection against elder abuse[54] and safeguards in instances of vulnerability or heightened dependency.[55] However, there is a simultaneous need to ensure access to services, especially for older adults living in regional areas, who may not have the range of choice or continuity of care that is available for older adults in metropolitan areas.

6.6 Advantages of Planning Ahead for Older People

Lawyers who responded to the online survey believed that older people who engage with APP are able to ensure their wishes and preferences are known, and that their wellbeing is prioritised through personalised planning. These factors were also reiterated during my interviews with older people. Key informants who completed an interview provided a similar perspective, and delineated the principal advantages of planning ahead, which include: planning makes things easier for decision-makers and clinicians;[56] the process can be empowering for patients and clients;[57] the person's wishes are known and can be respected;[58] plans provide vital guidance for clinicians;[59] and future conflict can be prevented.[60] As stated by one lawyer who lives with

[53] Dennis P Stolle et al, 'Integrating Preventive Law and Therapeutic Jurisprudence: A Law and Psychology Based Approach to Lawyering' (1997) 34 *California Western Law Review* 15, 32.
[54] Lixia Qu et al, *National Elder Abuse Prevalence Study* (Final Report, Australian Institute of Family Studies, July 2021) 1–2 <https://aifs.gov.au/research/research-reports/national-elder-abuse-prevalence-study-final-report>; Council of Attorneys-General (Australia) and Attorney-General's Department (n 49).
[55] Martha Albertson Fineman, 'The Vulnerable Subject: Anchoring Equality in the Human Condition' (2008) 20(1) *Yale Journal of Law and Feminism* 1, 8 ('The Vulnerable Subject').
[56] Key Informant 3 (Lawyer); Key Informant 5 (Lawyer); Key Informant 7 (Lawyer); Key Informant 9 (Nursing: End of Life); Key Informant 10 (Nursing: End of Life); Key Informant 11 (Nursing: End of Life); Key Informant 16 (Palliative Care Clinician); Key Informant 17 (Intensive Care Clinician); Key Informant 19 (Senior Clinician); Key Informant 23 (Lawyer); Key Informant 24 (Lawyer).
[57] Key Informant 1 (Lawyer); Key Informant 4 (Lawyer); Key Informant 5 (Lawyer); Key Informant 6 (Lawyer); Key Informant 7 (Lawyer); Key Informant 14 (Intensive Care Clinician); Key Informant 15 (Lawyer); Key Informant 18 (General Practitioner); Key Informant 25 (Nursing: Dementia Care).
[58] Key Informant 1 (Lawyer); Key Informant 5 (Lawyer); Key Informant 7 (Lawyer); Key Informant 8 (Emergency Clinician); Key Informant 16 (Palliative Care Clinician); Key Informant 18 (General Practitioner); Key Informant 20 (Nursing: Aged Care); Key Informant 23 (Lawyer); Key Informant 24 (Lawyer).
[59] Key Informant 9 (Nursing: End of Life); Key Informant 10 (Nursing: End of Life); Key Informant 16 (Palliative Care Clinician); Key Informant 17 (Intensive Care Clinician); Key Informant 18 (General Practitioner); Key Informant 19 (Senior Clinician); Key Informant 20 (Nursing: Aged Care); Key Informant 26 (Nursing: Emergency).
[60] Key Informant 1 (Lawyer); Key Informant 2 (Lawyer); Key Informant 5 (Lawyer); Key Informant 7 (Lawyer); Key Informant 13 (Law Enforcement); Key Informant 15 (Lawyer); Key Informant 16 (Palliative Care Clinician); Key Informant 28 (Lawyer).

a disability: 'The main narrative is not only to disabled people, but to all people, is that you get to determine, at a time suiting you, what you want done when you're no longer able to indicate yourself' (Key Informant 4, Lawyer).

The benefit of being able to choose your appointed decision-makers, and those you trust to support you in managing your affairs during a period of heightened dependency, was discussed by another legal key informant. They also mentioned the interpersonal and preventive benefits associated with this form of planning, highlighting the interaction of Preventive Law and Therapeutic Jurisprudence:

> The main benefit is choosing who you want to manage your affairs. That's your best way of resolving any conflict, because that person can hold up that document and say, I've been given authorisation to make these decisions. It's power of self-determination of older people to make their own choices. (Key Informant 7, Lawyer)

This preventive benefit was echoed by another legal key informant:

> If people go to the trouble of having these conversations, then it's to have a better outcome. Better chances of having a result that you're happy with. And yes, … we can sometimes manage family relationships better. If we know that there's potential conflict on the horizon, we can manage that. (Key Informant 1, Lawyer)

The advantages for an individual's wellbeing do not just apply to the person making the document. They also extend to the person who has been appointed as decision-maker, allowing them to experience comfort in knowing they were acting in accordance with the person's wishes:

> Part of the benefit of having an advance care plan documented and discussed, or directive, is that as a family member you can have a sense of … not satisfaction, it's not the right word. But a sense of that you did the right thing by your loved one because this is what they asked you to do or what they said. That has a massive impact on people's grieving journey. (Key Informant 11, Nursing: End of Life)

A lawyer who participated in the key informant interviews also recognised this benefit, noting the need for Enduring Guardians to have confidence in the decisions they are making. This once again invokes consideration of wellbeing and relational autonomy, encouraging people to understand how planning decisions can impact others within their support community:

> Having something that takes your Guardians off the hook and doesn't make them feel responsible for having made a very important decision. And distressing decision, where there could be differences of opinion between the Guardians as to what they should do. … [W]e do as we are directed. That's the responsibility of the Guardians, it's as simple as that. (Key Informant 3, Lawyer)

Finally, key informants considered that participating in APP represents the components of empowerment, being participation, power and control. This element of control, which can often be lacking as an individual ages, was explicitly recognised by the following key informant:

> For the person, it's having an element of control in a part of their life that there's often lack of control or there isn't any. I often say, and this is through personal experience, that once your loved one goes into aged care, the facility owns them. (Key Informant 25, Nursing: Dementia Care, End of Life)

These reported advantages largely mirror factors cited in the extant literature, including that a person's preferences and wishes are known,[61] decisions are made easier for an individual's family,[62] and disputes may be prevented in future.[63] These benefits clearly represent the goals of Preventive Law. Rather than responding retrospectively to conflict, Preventative Law instead encourages active prevention through communication and planning.[64] It also acknowledges the role of important people in an older person's life, and allows for consideration of relational autonomy, which necessitates 'a move from the individualist conception of autonomy inherent in a medical approach, to one which better recognises the importance of relationships and the

[61] Buck et al (n 2); Yapp et al (n 48) 136; Elizabeth Weathers et al, 'Advance Care Planning: A Systematic Review of Randomised Controlled Trials Conducted with Older Adults' (2016) 91 *Maturitas* 101, 102; Nola M Ries, Briony Johnston and Shaun McCarthy, 'Legal Education and the Ageing Population: Building Student Knowledge and Skills through Experiential Learning in Collaboration with Community Organisations' (2016) 37 *Adelaide Law Review* 495, 501; Karen M Detering et al, 'The Impact of Advance Care Planning on End of Life Care in Elderly Patients: Randomised Controlled Trial' (2010) 340 *BMJ* c1345:1-9, 5.

[62] Buck et al (n 2); Moore et al (n 8); Josie Dixon and Martin Knapp, 'Whose Job? The Staffing of Advance Care Planning Support in Twelve International Healthcare Organizations: A Qualitative Interview Study' (2018) 17(1) *BMC Palliative Care* 78:1–16, 2; Ellison et al (n 26) 153–154.

[63] Yapp et al (n 48) 148; Amy Waller et al, 'Increasing Advance Personal Planning: The Need for Action at the Community Level' (2018) 18(1) *BMC Public Health* 606:1–8; Ian J Hamilton, 'Advance Care Planning in General Practice: Promoting Patient Autonomy and Shared Decision Making' (2017) 67(656) *British Journal of General Practice* 104, 104; Hillary D Lum, Rebecca L Sudore and David B Bekelman, 'Advance Care Planning in the Elderly' (2015) 99(2) *Medical Clinics of North America* 391, 393.

[64] Bruce J Winick, 'The Expanding Scope of Preventive Law Therapeutic Jurisprudence Symposium' (2002) 3 *Florida Coastal Law Journal* 189; Dennis P Stolle, 'Professional Responsibility in Elder Law: A Synthesis of Preventive Law and Therapeutic Jurisprudence' (1996) 14(4) *Behavioral Sciences & the Law* 459; Thomas D Barton, 'Preventive Law for Multi-Dimensional Lawyers', *National Center for Preventive Law* (Essay, 2000) <http://www.preventivelawyer.org/main/default.asp?pid=essays/barton.htm>; Michael Goldblatt, Robert Hardaway and Robert Scranton, 'Establishing the Mindset of Practicing Preventively', *National Center for Preventive Law* (Essay, 2000) <http://www.preventivelawyer.org/main/default.asp?pid=essays/goldblatt.htm>.

role of family carers'.[65] One lawyer who responded to the survey explicitly stated that engaging in the planning process can feel 'empowering for the client', again enlivening our understanding of the key elements of meaningful participation, power and control.[66]

6.7 Disadvantages of Planning Ahead for Older People

When asked about any disadvantages of older people engaging with APP, lawyers who completed the online survey agreed that mechanisms could be misused to exploit older people, while the inappropriate influence of others can also be a significant concern. Another clear disadvantage is the lack of review of prepared documents. Similarly, several disadvantages were also noted by key informants, including: the risk that documents may not be current;[67] prepared plans may not be enacted in future;[68] patients or clients may not understand the distinction between, and need for, different documents;[69] and an inappropriate person could be appointed as a decision-maker.[70]

The need to clearly understand the difference between planning mechanisms, especially those that apply within the healthcare context, was explored further by a key informant who works as an end of life nurse:

> I think perhaps one of the risks is people not understanding the distinction [between] the advance care plan [which guides healthcare decisions but is not legally enforceable] and an advance care directive. And that goes for both families, patients, and us as clinicians. You can write an advance care directive on the back of an envelope, [and] as long as it's signed and dated, and you have sound mind when you wrote it, [it must be followed]. (Key Informant 11, Nursing: End of Life)

A unique perspective was provided by a police officer with extensive experience responding to elder abuse cases. This key informant commented on the importance of carefully preparing

[65] Yapp et al (n 48) 147.
[66] Zoë Oxaal and Sally Baden, *Gender and Empowerment: Definitions, Approaches and Implications for Policy* (BRIDGE Report No 40, Institute of Development Studies, January 1997) 7 <https://archive.ids.ac.uk/bridge/bridge-publications/reports/document/A23334.html>; Marilee Karl, 'Obstacles and Opportunities' in *Women and Empowerment: Participation and Decision-Making* (Zed Books Ltd, 1995) 14.
[67] Key Informant 2 (Lawyer); Key Informant 5 (Lawyer); Key Informant 8 (Emergency Clinician); Key Informant 11 (Nursing: End of Life); Key Informant 23 (Lawyer).
[68] Key Informant 1 (Lawyer); Key Informant 12 (General Practitioner); Key Informant 17 (Intensive Care Clinician); Key Informant 25 (Nursing: Dementia Care).
[69] Key Informant 3 (Lawyer); Key Informant 11 (Nursing: End of Life); Key Informant 16 (Palliative Care Clinician); Key Informant 19 (Senior Clinician).
[70] Key Informant 2 (Lawyer); Key Informant 5 (Lawyer).

instruments at a time when the older person has capacity, ensuring trusted individuals are appointed:

> I just think sometimes too if the instruments have been done in a flawed sense, either by the parties, or by the advocate, it's difficult to overturn or change it. Especially if the older person [is] frail and suffered a decline. So if they're put in place without much thought, and a lot of people don't look at what they sign, or they don't consider, and it's … Not all of us probably, but everyone does it in every contract probably. Especially if it's a complicated instrument. When they realise what the implications of the instrument are and they want to change it, it's very, very difficult. (Key Informant 13, Police)

Despite the clear benefits of older adults engaging with APP, significant disadvantages remain. There is an evident critical need for professionals, both from legal and health fields, to be involved in assisting older adults to plan ahead, ensuring any instruments account for and are tailored to their individual circumstances. Interpersonal relationships must also be considered, with an understanding that any appointed decision-makers should be trusted members of the older person's support community.

6.8 Professional Challenges when Assisting with APP

6.8.1 Siloed Professions

A distinct disadvantage of the current siloed professional approach is that health and legal professionals do not know whose role it is to raise and continue APP discussions, even within their own cohorts:

> I think that is a big one, not knowing whose responsibility it is [to initiate planning discussions regarding Advance Care Planning]. So, a lot of the time people think it's the general practitioner's responsibility. Other times people think it's the specialist's responsibility. I can tell you from sitting on this side, it's everyone's responsibility. (Key Informant 10, Nursing: End of Life)

In the online survey, lawyers' perceptions of healthcare planning, and whether legal professionals should assist older people with completing Advance Care Directives as a specific form of APP, were enlightening. While 58% of lawyers indicated preparing Advance Care Directives is 'rarely' in the scope of their practice, 65% of participants reported experience with assisting older people to draft Advance Care Directives. These participants noted the most

common challenges that arise in this process are: difficulty drafting Advance Care Directives that can be applied in specific medical situations; concerns that conversations may upset an older person; and a self-perceived lack of knowledge regarding health sector policies and practices. This point is of interest; even though respondents reported Advance Care Directives as the least prevalent among the four APP instruments, behind Wills, Enduring Powers of Attorney, and Enduring Guardian appointments, nearly two-thirds of respondents still had experience preparing this instrument.

6.8.2 Lack of Consistent Templates for Advance Care Directives

The 17 lawyers who had assisted older people to prepare Advance Care Directives reported in the survey that they had used 11 different sources for templates. These responses reveal that there is no agreed form or universally accepted template for Advance Care Directives, which is particularly relevant for lawyers practicing in NSW where Advance Care Directives are common law instruments with no standard legislative form available. This lack of agreement regarding the form of Advance Care Directives may impact the quality of prepared instruments.[71] Two survey respondents also noted that in their experience, directive statements are commonly included in Enduring Guardian appointment forms, with respect to the functions and limits of the guardianship appointments or other directions, rather than preparing a separate document. While this inclusion does provide some guidance for a decision-maker if called upon to make a healthcare or personal decision on behalf of another, it does not allow for the same level of detailed instructional and value statements that can be included in an Advance Care Directive. This, in turn, may undermine the confidence of decision-makers and the quality of any decisions they may be required to make in future. Moreover, this could lead to further conflict, which may result in individuals having to engage with the legal system and subsequently experiencing antitherapeutic consequences.

[71] Ina Carola Otte et al, 'The Utility of Standardized Advance Directives: The General Practitioners' Perspective' (2016) 19(2) *Medicine, Health Care and Philosophy* 199; Tim Luckett et al, 'Advance Care Planning in 21st Century Australia: A Systematic Review and Appraisal of Online Advance Care Directive Templates against National Framework Criteria' (2015) 39(5) *Australian Health Review* 552; Friedemann Nauck et al, 'To What Extent Are the Wishes of a Signatory Reflected in Their Advance Directive: A Qualitative Analysis' (2014) 15 *BMC Medical Ethics* 1.

6.8.3 Lack of Time and Variability of Professional Education

Key informants also raised professional barriers, including: time constraints;[72] lack of knowledge of the legal status of various instruments;[73] the uncomfortable nature of discussions;[74] and the lack of compulsory legal education for law students regarding estate law.[75] Those working in emergency settings and end of life care drew attention to the fact that time is a luxury they cannot afford, and in the absence of previous discussion and documentation, it is difficult to engage in thoughtful planning conversations:

> But it's having the time. Normally when they fill [Advance Care Directives] out is when you're in an emergency. Instead of having those discussions prior, and in a compassionate way that's not going to misrepresent the patient's medical status at the time, where they feel that they're dying tomorrow. Or the doctor's keeping a secret from them because they want this form filled out. (Key Informant 9, Nursing: End of Life)

This sentiment was echoed by another key informant, working in health services research:

> And of course, the time is the main variant, which is, you need a proper conversation and, ideally, you need to have this conversation several times because people change their mind as the disease progresses. But in times of crisis, you don't have that actually. (Key Informant 21, Health Services Researcher)

One legal key informant drew attention to their own profession's lack of education, noting that succession law is not a compulsory subject for law students:

> Succession is not part of the Priestly 11 [compulsory legal education].[76] And some universities don't even teach it. … So I'm taken back that it's not just the professionals, the barriers. It's the universities who taught the professionals. (Key Informant 15, Lawyer)

[72] Key Informant 1 (Lawyer); Key Informant 8 (Emergency Clinician); Key Informant 9 (Nursing: End of Life); Key Informant 10 (Nursing: End of Life); Key Informant 11 (Nursing: End of Life); Key Informant 12 (General Practitioner); Key Informant 16 (Palliative Care Clinician); Key Informant 18 (General Practitioner); Key Informant 20 (Nursing: Aged Care); Key Informant 21 (Health Services Researcher); Key Informant 22 (General Practitioner); Key Informant 27 (Psychiatrist).

[73] Key Informant 10 (Nursing: End of Life); Key Informant 11 (Nursing: End of Life); Key Informant 15 (Lawyer); Key Informant 16 (Palliative Care Clinician); Key Informant 19 (Senior Clinician); Key Informant 20 (Nursing: Aged Care); Key Informant 21 (Health Services Researcher); Key Informant 22 (General Practitioner).

[74] Key Informant 11 (Nursing: End of Life); Key Informant 14 (Intensive Care Clinician); Key Informant 19 (Senior Clinician); Key Informant 20 (Nursing: Aged Care); Key Informant 25 (Nursing: Dementia Care); Key Informant 26 (Nursing: Emergency).

[75] Key Informant 3 (Lawyer); Key Informant 15 (Lawyer).

[76] The Priestly 11 refers to 11 compulsory subjects that must be completed by students during their legal education in order to be admitted to legal practice in Australia.

This lack of compulsory education for law students means that many new lawyers have little to no knowledge of, or experience with, the vital components of APP, including Wills and appointments of enduring representatives. Increased knowledge about succession law, and how best to prepare relevant APP instruments, may improve the quality of Will-making and other aspects of estate planning.

Education is not only vital for legal professionals, but health practitioners as well. One General Practitioner took time to reflect on the lack of knowledge among their peers regarding the legal aspects of APP, highlighting the risks this poses for the accurate dissemination of APP information:

> [W]hen I speak with GPs [General Practitioners] and non-GP specialists, and other nurses and other people, when I do talks and stuff like that, a lot of those people have a lack of certainty and they're not really confident about their knowledge of these issues. And sometimes, they give away incorrect information. (Key Informant 22, Academic & General Practitioner)

6.8.4 Disparate Legislative Framework

In addition to these professional barriers, several structural barriers were discussed in the interviews, including: not knowing whose role it is to commence planning discussions;[77] difficulties associated with the existing legislative framework;[78] technical barriers that prevent systems from working efficiently;[79] the lack of funding in this field;[80] and ageist attitudes within society.[81]

One legal key informant believed the disparate APP framework, with every Australian state and territory adopting a generally similar approach but differing documents and terminology, is undermining confidence and knowledge of APP:

[77] Key Informant 1 (Lawyer); Key Informant 3 (Lawyer); Key Informant 8 (Emergency Clinician); Key Informant 9 (Nursing: End of Life); Key Informant 10 (Nursing: End of Life); Key Informant 11 (Nursing: End of Life); Key Informant 12 (General Practitioner); Key Informant 17 (Intensive Care Clinician); Key Informant 18 (General Practitioner); Key Informant 19 (Senior Clinician); Key Informant 20 (Nursing: Aged Care); Key Informant 27 (Psychiatrist).
[78] Key Informant 5 (Lawyer); Key Informant 7 (Lawyer); Key Informant 10 (Nursing: End of Life); Key Informant 15 (Lawyer); Key Informant 16 (Palliative Care Clinician); Key Informant 17 (Intensive Care Clinician); Key Informant 23 (Lawyer).
[79] Key Informant 8 (Emergency Clinician); Key Informant 11 (Nursing: End of Life); Key Informant 12 (General Practitioner); Key Informant 18 (General Practitioner); Key Informant 22 (General Practitioner).
[80] Key Informant 10 (Nursing: End of Life); Key Informant 12 (General Practitioner); Key Informant 17 (Intensive Care Clinician); Key Informant 21 (Health Services Researcher); Key Informant 22 (General Practitioner).
[81] Key Informant 8 (Emergency Clinician); Key Informant 12 (General Practitioner); Key Informant 13 (Law Enforcement); Key Informant 15 (Lawyer); Key Informant 21 (Health Services Researcher).

> And the thing was, is that I find it odd. … We have a uniform … Evidence Act, and yet in each state and territory, we've got different legislation when it comes to Wills, estate, probates, and you name it, and I think that's what sometimes will scare some clients away from actually making a Will, or doing directives, or estate planning. (Key Informant 5, Lawyer)

This concern was shared by another key informant, who emphasised that concerns regarding the recognition of documents across states is particularly concerning for older adults in border towns:

> If there was uniformity, a national document, it would be much better for older people across Australia, because everyone would then know that their document is valid across the country. And also, we do get a lot of confusion in people that live near the border. … There's all that confusion about whether their documents will be acknowledged. And that's governed by the legislation of each state. (Key Informant 7, Lawyer)

6.8.5 Ageism

Five key informants suggested that another significant factor is at play – ageism.[82] While APP may be targeted towards older people due to a belief that planning ahead is only relevant for the end of life, there is a general lack of respect for older adults in society.[83] As one key informant noted, '[n]obody cares about the elderly. This society is elder-averse' (Key Informant 21, Health Services Researcher). Such prejudicial attitudes towards older people and ageing in general means that discussions regarding death and dying are often difficult and uncomfortable, both for the older adult and professionals involved:

> And without having that discourse of everyone ages, everyone's going to die, what does it mean to have a good death or a good life? What does that look like? … At the moment, I think talking about ageing, and particularly death, is still difficult. Palliative care, for instance, I think advance care planning leads on to that. And just ageing in general, how we care for older people, particularly those who have lost their agency … We think of society as being progressive, but I think they're actually still fairly difficult conversations to have. (Key Informant 12, General Practitioner)

[82] Key Informant 8 (Emergency Clinician); Key Informant 12 (General Practitioner); Key Informant 13 (Law Enforcement); Key Informant 15 (Lawyer); Key Informant 21 (Health Services Researcher).
[83] Veronika Bílková, 'COVID-19 and Older Persons – In Need of a Comprehensive Human Rights Approach' (2022) 14(1) *Journal of Human Rights Practice* 267, 279.

Within these conversations, the perception of ageing is often merged with disability, which blankets all older people as vulnerable and ignores the nuance between adults who are ageing and those who are living with a disability:

> I don't understand the resistance [to Elder Law]. Part of me says it's ageism. It's just old people. And the way governments conflate ageing and disability. Ah, well, you're old so you must be disabled. … And that is something that really makes my hackles rise. Because they are both extremely important areas. And quite discreet. (Key Informant 15, Lawyer)

These insights provide a comprehensive overview of factors, at individual, professional and societal levels, that are preventing older adults from engaging with APP, affecting the ability of professionals to effectively work with older adults to plan ahead, and undermining the benefits that arise from their engagement. Consideration of these factors, and suggested recommendations, will be explored further in Chapter 9.

6.8.6 Capacity

Just under half of the lawyers who responded to the online survey indicated they 'sometimes' have concerns related to an older client's capacity. According to these professionals, the most common prompts for capacity concerns include: the older person resides in an aged care facility; the person is aged 85 years or older; and the person has received a diagnosis of dementia. Fears of undue influence were thought to have just as significant an impact on capacity as the diagnosis of a neurocognitive condition.

A total of 71% of the survey respondents had referred an older person for a capacity assessment with a health professional, with referrals most often made to a General Practitioner or a Geriatrician. Notably, 64% of these participants reported they had encountered issues accessing appropriately qualified health professionals to conduct the assessments. The main reported difficulties included: health professionals not responding to correspondence; the variable standard of capacity assessments; a shortage of qualified professionals in regional areas; a reluctance on the part of health professionals to conduct assessments; a lack of understanding regarding the relevant tests for legal capacity; and the expense and time associated with seeking a professional opinion. A shortage of suitable professionals to conduct capacity assessments and long wait times are two key barriers noted in the recent *National Dementia Action Plan*

consultation paper.[84] One lawyer also noted older clients may be concerned that a finding of incapacity could subsequently be used for other purposes, such as appointing a decision-maker to manage their financial affairs.

Survey responses on the issue of capacity present clear concerns regarding the lack of standardisation of documentation for requesting, and receiving, capacity assessments;[85] lack of meaningful communication between legal and healthcare practitioners;[86] and limited education and training about the standard of legal capacity.[87] Matters are further complicated when we consider that capacity is flexible, and not static,[88] meaning that professionals need to be considerate of factors that may support or enhance an older person's ability to participate in the decision-making process.[89] This introduces an additional layer of complexity as a person's level of cognition may have changed between consultations.[90]

During my interviews with key informants, one lawyer discussed the siloed nature of the health and legal professions, and stressed the need for more cross-disciplinary collaboration to develop a clearer understanding of capacity:

> I then say, during that conversation, if there's a need for more sophisticated advance care planning, then I'm not equipped to do that. You should be having that discussion with your doctor. … Some doctors, and GPs [General Practitioners] in particular, have got a reasonable awareness of all of that. But they think that's the beginning and end of their responsibility, and that's where the disconnect it. … They've got no idea that there's a difference between mental capacity and legal capacity. (Key Informant 3, Lawyer)

[84] Department of Health and Aged Care, *National Dementia Action Plan* (Public Consultation Paper, Australian Government, November 2022) 33–34 <https://consultations.health.gov.au/++preview++/aged-care-division/ndap-public-consultation/supporting_documents/National_Dementia_Action_Plan_consultation%20paper_final18%20Nov.pdf>.
[85] Kelly Purser and Karen Sullivan, 'Capacity Assessment and Estate Planning – The Therapeutic Importance of the Individual' (2019) 64 *International Journal of Law and Psychiatry* 88, 90.
[86] Barry, 'Capacity and Vulnerability' (n 49) 278; Kelly J Purser and Tuly Rosenfeld, 'Evaluation of Legal Capacity by Doctors and Lawyers: The Need for Collaborative Assessment' (2014) 201(8) *The Medical Journal of Australia* 483, 484.
[87] Barry, 'Capacity and Vulnerability' (n 49) 282; The Law Society of New South Wales, *When a Client's Mental Capacity is in Doubt: A Practical Guide for Solicitors* (Guidelines, 2016) 4 <https://www.lawsociety.com.au/sites/default/files/2018-03/Clients%20mental%20capacity.pdf>; Purser and Rosenfeld (n 86) 483.
[88] Hamilton (n 63) 104; LA Frolik, 'Later Life Legal Planning' in Israel Doron (ed), *Theories on Law and Ageing: The Jurisprudence of Elder Law* (Springer, 2009) 11.
[89] See, eg, The Law Society of New South Wales (n 87) 19–22.
[90] Barry, 'Capacity and Vulnerability' (n 49) 271.

Despite professional guidelines being available, including a recent best practice guide for legal practitioners,[91] findings from the survey reveal there is a perceived lack of an endorsed model that can be followed by lawyers and other service providers when assessing capacity.[92] These findings demonstrate an overt lack of concrete guidance regarding the preferred form of assessment, when it should be requested, and the professional who is best placed to determine whether an older client has the decision-making capacity to engage in APP. While planning mechanisms can help to safeguard an older person's legal, financial and personal interests, their misuse could also give rise to opportunities for abuse or exploitation.[93] However, the best chance of success for professionals relies on a collaborative approach to capacity assessment. As Purser and Rosenfeld point out, despite the distinct separation between health professionals and lawyers, 'the professions together possess the skills necessary to satisfactorily assess capacity'.[94] Purser and Rosenfeld propose an initial assessment be conducted by the legal professional, followed by a clinical assessment by a healthcare provider, if it is required.[95] The final step is a 'determination of whether the individual has legal capacity for the specific task in question',[96] accounting for the fluid nature of a person's decision-making ability. Such an interprofessional method would allow both professional groups to have greater insight regarding a person's wellbeing,[97] which may enliven concerns regarding any vulnerability or periods of heightened dependency,[98] as well as providing an assessment of whether they have been able to meaningfully participate in the decision-making process.[99]

One legal key informant, who lives with a disability, noted how capacity assessments and the basic task of taking instructions can be further complicated when you are working with clients who are living with a disability:

[91] Law Council of Australia, *Best Practice Guide for Legal Practitioners on Assessing Mental Capacity* (Report, June 2023) <https://lawcouncil.au/publicassets/50c04353-6a0a-ee11-9482-005056be13b5/Best%20Practice%20Guide%20for%20Legal%20Practitioners%20on%20Assessing%20Mental%20Capacity%20June%202023.pdf>.
[92] Purser and Sullivan (n 85) 91; Waller et al (n 63) 2; Ries, Johnston and McCarthy (n 61) 514.
[93] Council of Attorneys-General (Australia) and Attorney-General's Department (n 49); Nola M Ries, 'Enduring Powers of Attorney and Financial Exploitation of Older People: A Conceptual Analysis and Strategies for Prevention' (2022) 34(3) *Journal of Aging & Social Policy* 357; Barry, 'Capacity and Vulnerability' (n 49) 273.
[94] Purser and Rosenfeld (n 86) 483.
[95] Ibid 484. See also The Law Society of New South Wales (n 87) 4.
[96] Purser and Rosenfeld (n 86) 484. See also Laura L Sessums, Hanna Zembrzuska and Jeffrey L Jackson, 'Does this Patient have Medical Decision-Making Capacity?' (2011) 306(4) *JAMA* 420.
[97] Australian Institute of Health and Welfare (n 33).
[98] Martha Albertson Fineman, '"Elderly" as Vulnerable: Rethinking the Nature of Individual and Societal Responsibility' (2012) 20 *Elder Law Journal* 101; Fineman, 'The Vulnerable Subject' (n 55).
[99] Oxaal and Baden (n 66) 7; Karl (n 66) 14.

> You can add a layer of complexity, re disability, because if somebody is only partially verbal, or they're verbal to a point, where only certain people can understand them, and I've known people like this. They would have a lot of trouble making any sort of legal document. Because the first point that the solicitor would have to establish, would be, I don't understand them. Can I rely on their carer, the person responsible, whoever they bring along, to reliably, independently translate their intentions in their terms, so that I can faithfully produce a document they want? And then they say, in physical incapacities, how do I get them to a position where they can sign a legal document? And before I even get there, how can I be confident, with all of those problems, that they have legal capacity to sign a document, and that they understand what this means? … I wish there was a simple answer, but there isn't. (Key Informant 4, Lawyer)

6.8.7 Professional Reasons for Not Assisting with APP

The 11 lawyers who indicated they did not assist clients with Advance Care Directives in the online survey noted several factors that stopped them from engaging in this practice, including: feeling they do not know enough about the medical context of Advance Care Directives; believing this instrument is not part of a lawyer's role; and lack of knowledge of health sector policies and practices. These findings demonstrate the evident need for, and importance of, medico-legal partnerships and interprofessional collaboration.[100]

Further education, for both legal and health professionals, may help to overcome the siloed nature of the professions,[101] and lead to a greater awareness and understanding of how Advance Care Planning, and APP more broadly, can be delivered more holistically.[102] By adopting an interprofessional approach to planning ahead, older patients and clients will receive the expert insights of both groups,[103] while the professionals involved can also work to provide the highest level of patient- and client-centred services that truly account for an older person's preferences and wellbeing.[104]

[100] Orsatti (n 38) 163–164; Ries et al (n 35) 695; Sarah Russell, 'Advance Care Planning: Whose Agenda is it Anyway?' (2014) 28(8) *Palliative Medicine* 997, 998.
[101] Suet Ying Ng and Eliza Lai-Yi Wong, 'The Role Complexities in Advance Care Planning for End-of-Life Care – Nursing Students' Perception of the Nursing Profession' (2021) 18(12) *International Journal of Environmental Research and Public Health* 6574:1–13; Dixon and Knapp (n 62); Ries et al (n 35) 695; Barry, 'Capacity and Vulnerability' (n 49) 282.
[102] Ries et al (n 35) 695.
[103] Orsatti (n 38).
[104] Mark Glover, 'A Therapeutic Jurisprudential Framework of Estate Planning' (2011) 35 *Seattle University Law Review* 427; MB Kapp, 'A Therapeutic Approach' in Israel Doron (ed), *Theories on Law and Ageing: The Jurisprudence of Elder Law* (Springer, 2009) 31.

6.8.8 The Impact of COVID-19

While lawyers who completed the online survey did not report the pandemic had resulted in a significant increase in inquiries for legal information or advice about APP, there were significant professional barriers during this time. The most common was not being able to visit older clients in person, followed by difficulties with witness requirements, and older clients being concerned about travelling to lawyers' premises. These barriers were overcome through the use of phone and video consultations, and audio-visual links to verify witness requirements. Almost half (45%) of the survey respondents believed the pandemic had created 'some' anxiety for older clients.

When asked to consider the advantages of older people completing APP in a situation such as COVID-19, survey respondents believed such planning would provide guidance for family, friends or appointed decision-makers in the event the person became seriously ill. Further, it encouraged people to actively think about something they may have been putting off. Similarly, there were perceived disadvantages for older people completing APP during a public health emergency. Just under half of respondents agreed there may be the potential for abuse, exploitation, or manipulation if the preparation of documents has been motivated or instigated by others. One-third of participants noted the process may be rushed, with less time for careful consideration.

Recently, researchers have sought to examine the impact of the COVID-19 pandemic on the wellbeing of older people. The need for stay-at-home orders increased isolation of older adults, meaning they may have been separated from their support community for long periods of time.[105] Such circumstances also had a significant impact on the autonomy of all individuals, including older adults, and ageist beliefs were normalised when society at large was prioritising the health and wellbeing of younger adults.[106] In a post-COVID landscape, legal and health professionals must work to restore respect for older adults,[107] taking the time to understand their circumstances, preferences and wellbeing.[108] From this understanding, older adults can

[105] Bílková (n 83) 270–271; Cristina Voinea, Tenzin Wangmo and Constantin Vică, 'Respecting Older Adults: Lessons from the COVID-19 Pandemic' (2022) 19(2) *Journal of Bioethical Inquiry* 213, 215.
[106] Voinea, Wangmo and Vică (n 105) 215–216.
[107] Ibid 218.
[108] Bílková (n 83) 281.

be provided with the opportunity to meaningfully engage with APP, ensuring any prepared instruments are tailored to their circumstances and safeguard their future wishes.

6.9 CONCLUSION

This chapter presents key findings from my study relating to general perceptions of APP and barriers to engagement from the combined perspective of three cohorts: older adults; lawyers working in regional areas; and professional key informants. Their contributions offer new insights, while supporting conclusions from existing literature. These initial themes relating to general attitudes towards APP and barriers to engagement underpin the findings presented in the following chapter, which concern factors that affect the quality of completed APP instruments and the ease, or difficulty, of implementing them in future. Clear connections have been drawn between these findings and the theoretical lens of 'theralaw', being the combination of Therapeutic Jurisprudence and Preventive Law, within the broad field of Elder Law. These results provide a baseline for other researchers hoping to conduct studies relating to engagement with APP, and offer preliminary guidance for those working in policy and advocacy roles with respect to how barriers to engagement within current planning systems could be overcome. This chapter also offers reflection for areas of future research, which will be detailed further in Chapter 9.

7 Study Findings: Barriers to High Quality Advance Personal Planning and Challenges when Implementing Completed Instruments

7.1 Introduction

This chapter presents findings from my research regarding factors that may undermine the quality, and successful implementation, of Advance Personal Planning (APP) instruments from the perspective of older adults and professional key informants. Importantly, this research includes the views of lawyers as key informants, which provide an informed perspective on the advantages, disadvantages, barriers and opportunities for improvement within the context of APP for older people. To my knowledge, this is one of the first domestic studies to qualitatively examine lawyers' perspectives and experiences of assisting older adults to engage in, and ultimately complete, APP mechanisms.

In addition to eliciting the perspectives of lawyers, this study also involved interviews with other professionals working in healthcare and policing, whose perspectives provide unique insight regarding older adults who have prepared APP instruments, and those who haven't. Professionals were asked about factors that may affect the quality of APP instruments and their experiences with implementing completed plans in practice. Further, professionals were asked about how APP instruments may be implicated in the abuse of older people, both through the

presence and absence of such planning.[1] This study is the first of its kind to combine these professional perspectives and provide new insights from experts working in this area about the preparation, completion and use of APP instruments, as well as strategies for guarding against the abuse or manipulation of older people. The inclusion of the perspective of older adults is also significant, as it allows for comparison between professionals' perspectives of the benefits of APP and best practice, and what is actually being achieved, as revealed by the lived experiences shared by older adults.

This chapter demonstrates that despite the higher rates of prevalence of some APP instruments among the cohort of interviewed older adults, there are deficiencies in the quality of prepared instruments, which undermine the potential for planning instruments to be successfully implemented in future. These findings reveal gaps in knowledge and practices for older adults and professionals. This chapter will also briefly identify areas for improvement, with recommendations and areas for future research addressed in Chapter 9.

7.2 How Do Professionals Define High Quality APP?

Key informants interviewed in this study identified several factors as important to high quality APP, including: patients or clients actually understanding what it is they are documenting;[2] the completion of the full range of instruments applicable to the person's circumstances;[3] planning that is personalised to the individual circumstances of the patient or client;[4] and the appointment of trusted decision-makers.[5] Communication was emphasised as a key feature of high quality planning by several key informants.[6] Plans with the capacity to be dynamic[7] and

[1] Michael Quinn Patton, 'Expert Sampling' in Bruce B Frey (ed), *The SAGE Encyclopedia of Educational Research, Measurement, and Evaluation* (SAGE, 2018) 648.
[2] Key Informant 10 (Nurse – End of Life); Key Informant 18 (General Practitioner); Key Informant 20 (Nurse – Aged Care); Key Informant 21 (Health Services Researcher); Key Informant 24 (Lawyer); Key Informant 27 (Psychiatrist); Key Informant 28 (Lawyer).
[3] Key Informant 1 (Lawyer); Key Informant 2 (Lawyer); (Key Informant 3 (Lawyer); Key Informant 4 (Lawyer); Key Informant 5 (Lawyer); Key Informant 6 (Lawyer); Key Informant 7 (Lawyer); Key Informant 22 (General Practitioner); Key Informant 23 (Lawyer).
[4] Key Informant 2 (Lawyer); Key Informant 3 (Lawyer); Key Informant 5 (Lawyer); Key Informant 7 (Lawyer); Key Informant 10 (Nurse – End of Life); Key Informant 23 (Lawyer); Key Informant 28 (Lawyer).
[5] Key Informant 1 (Lawyer); Key Informant 2 (Lawyer); Key Informant 7 (Lawyer); Key Informant 21 (Health Services Researcher); Key Informant 22 (General Practitioner); Key Informant 23 (Lawyer); Key Informant 26 (Nurse – Emergency).
[6] Key Informant 20 (Nurse – Aged Care); Key Informant 21 (Health Services Researcher); Key Informant 22 (General Practitioner); Key Informant 26 (Nurse – Emergency).
[7] Key Informant 3 (Lawyer); Key Informant 19 (Senior Clinician); Key Informant 22 (General Practitioner); Key Informant 27 (Psychiatrist).

interpretable,[8] thus being not too prescriptive and applicable across a range of circumstances, were also recommended. Finally, planning should be done early[9] and adopt a collaborative approach with competent professional advisors.[10]

7.2.1 Understanding the Instruments

Health professionals recognised the need to ensure older adults are aware of the instrument they are making and when it begins to operate, as this provides the foundation for prioritising the individual in their care and choices:

> Well, I think the first point, the first part is the patient themselves or the person themselves, that they know what it is and what the purpose of it is, and that they agree with it. And so, I think if we talk about person-centred or patient-centred healthcare, that's always a starting point, is the person themselves. (Key Informant 18, General Practitioner)

This sentiment was shared by a legal key informant, who noted older clients need to be fully informed about the various APP instruments to understand their application and purpose:

> First of all, customers have to be informed about their options. So, no matter what document they're making, whether it's a Will, a Power of Attorney or an Enduring Guardian document, they have to know what's available to them in those and be able to speak to somebody who has sufficient knowledge to explain the concept in plain English. Because some people, they need to see what the practical implications are. (Key Informant 24, Lawyer)

Further, it is essential older people are aware of the full ramifications of having documented their wishes. This concern was raised by one key informant who stated:

> I think, when the patient has something in writing, we need to honour their wishes. I think quality is also in relation to making sure that the people who sign an Advance Care Directive, for example, have totally understood what they mean by those words. High quality means there is enough literacy amongst the people who have signed those documents. (Key Informant 21, Health Services Researcher)

[8] Key Informant 1 (Lawyer); Key Informant 3 (Lawyer); Key Informant 17 (Intensive Care Clinician).
[9] Key Informant 15 (Lawyer); Key Informant 17 (Intensive Care Clinician); Key Informant 20 (Nurse – Aged Care); Key Informant 21 (Health Services Researcher); Key Informant 22 (General Practitioner); Key Informant 27 (Psychiatrist).
[10] Key Informant 6 (Lawyer); Key Informant 23 (Lawyer); Key Informant 24 (Lawyer); Key Informant 27 (Psychiatrist).

As such, it is essential that professionals work with older adults to ensure they understand not only the range of APP instruments available to them, but also the distinct purpose and limits of each. It is through this knowledge that APP instruments can realise their preventive benefits, guarding against conflict and preserving an older person's autonomy in future.

7.2.2 Completing all Planning Instruments

One legal professional noted that additional APP instruments are often considered through the preparation of a Will, making this the best opportunity to discuss the full range of APP with older clients:

> [It's] the Will that triggers everything. It's very rarely that I get direct approaches, even for Powers of Attorney or Enduring Guardianship documents. You do have the planning conversation with people because they say, it's either time to update, or it's time to do a Will. … The very best time to have the overarching discussion on all of the issues that you're talking about, is really triggered by the Will. (Key Informant 3, Lawyer)

The significance of completing the full range of available financial and health-related planning instruments is increasingly recognised, with one lawyer offering the following reflection:

> Ask me that 20 years ago and I would have said, no just use a Will. … But now, particularly older people, I always suggest that they consider all that, because otherwise you never know when you're going to use it. (Key Informant 2, Lawyer)

One legal key informant reflected on the unique philosophies that underpin health-related APP instruments, highlighting how the completion of all available APP instruments can help to ensure an older person's wishes are implemented in future:

> Advance Care Directives are important because, under the *Guardianship Act*, the philosophy of the Act is that the Guardian protect the welfare of the older person. There's an argument there that they need to preserve life, so an Advance Care Directive gives an older person the opportunity, while they've got capacity, to state what treatments they want to refuse if they have a terminal or life-limiting condition, so that document is important if an older person wants to specify any medical procedures they don't want to receive and then the Guardian could rely on that document when giving instructions to medical staff. (Key Informant 7, Lawyer)

These shared insights demonstrate how an older person's wishes can be accurately and wholly understood through the completion of the full range of APP instruments. Such understanding

can help members of an older adult's support community, including family members, appointed decision-makers and professionals, to implement their wishes in future, taking account of their wellbeing and ensuring their preferences are realised.

7.2.3 Personalised Planning

In addition to ensuring the completion of all available APP instruments, key informants stressed the importance of ensuring any planning is personalised to an older person's individual circumstances. The need to tailor plans to an older person's needs certainly applies to health-related instruments, but one lawyer used the example of a Will to demonstrate how planning should be personalised as much as possible:

> So the Will, for example, advanced personal planning, you have to take into consideration the whole dynamic of the family. So, it's not simply them coming in and saying they want to give the whole estate to three kids. Well, do any of the kids have any disabilities or any acquired needs? Do they require someone to look after the assets? Does someone require a place to live? That perhaps one of the children have a drug habit, alcoholism. Anything like that. And then you can obviously make the Will a little bit bespoke to that client. So that it meets the needs of the client, rather than just a generalised Will. [There are] massive implications if it's not [personalised]. Could be a blended family. It could be big assets, small assets, whatever it is that needs to fit the needs of the whole family and the client. (Key Informant 23, Lawyer)

The need to understand the whole picture, taking account of the older person's wellbeing, financial circumstances, health preferences and social connections, was echoed by another key informant:

> So, I think quality advance planning has to involve getting a good picture of the client and their relationships, and in particular, their dependants, or those who look to the client by way of dependence. That's the start of it, I think. So, in effect, it often becomes a form-filling exercise, but it shouldn't be because I'm aware of all the traps down the road. (Key Informant 28, Lawyer)

The depiction of the role of personalised planning in guarding against future legal conflicts is a clear fulfilment of the principles of Preventive Law. Further, the explicit consideration of an older person's wellbeing also engages our understanding of Therapeutic Jurisprudence, providing a clear application of theralaw within the field of Elder Law.

7.2.4 Trusted Decision-Makers

The appointment of a trusted decision-maker was discussed by key informants as a central element of high-quality APP. As one key informant explained: 'As long as you nominate somebody you trust, and that person is going to actually reflect your wishes in whatever decisions happen' (Key Informant 21, Health Services Researcher).

While professional bodies, such as the NSW Trustee and Guardian, can be appointed as a decision-maker on behalf of an older person, one lawyer expressed some concern about these arrangements:

> We've got an issue that perhaps a public guardian is going to be appoint[ed]. Which is … They do a fabulous job, but at the end of the day, your family is the ones who know you best. So, you would want your family to make the decisions about you. (Key Informant 23, Lawyer)

Finally, one key informant working in healthcare noted the appointment of trusted decision-makers needs to be fortified through clear communication regarding the older person's wishes and plans, in light of their individual circumstances:

> An inclusive and realistic discussion of goals of care held with the patient and/or family and carers in a compassionate and person-centred manner [will improve quality of APP]. (Key Informant 26, Nurse: Aged Care)

7.2.5 Other Factors Affecting Quality

Key informants stated that communication is a major factor that can influence the quality of APP. The need to engage in conversations that allow open discussion, and are tailored to the older person's level of understanding, is vital to ensuring APP instruments are of high quality:

> Communication is the key, open communication, and it may take a while to get there. You've got to bring people along for the ride and provide them information and allow them to digest it. That's why it's so important to be done early. It's not something that should be done in a rush. (Key Informant 20, Nurse: Aged Care)

Engaging in this communication early in the process, rather than leaving it to situations of emergency or crisis, allows for a full consideration of the older person's views, wishes and preferences, which may go far beyond their plans for future healthcare:

> I think quality … involves several conversations. It shouldn't be a one-off. And in roles, okay, there is not just healthcare, but also spiritual care and some other preferences that people may

> have, given their cultural backgrounds, or, I don't know, political views or anything else. (Key Informant 21, Health Services Researcher)

> I think a lot of good planning would involve, not only preparing documents and communicating that, but also having conversation around that. And building trust and relationships around those documents as well. (Key Informant 22, General Practitioner)

This notion of trust around the documents can be achieved through engaging competent professional advisors, allowing for a collaborative approach to APP with the older person and their support community. Such collaboration and professional guidance can help to ensure plans are dynamic to, and interpretable across, potential future events. As one key informant stated: 'It's got to be collaborative. It's got to be informed' (Key Informant 27, Psychiatrist). Another related:

> It's planning that speaks, that conveys the feelings of the person involved in a way that they can be interpreted by the family and the doctor who need to interpret them when the time comes. (Key Informant 17, Intensive Care Clinician)

7.3 Barriers to High Quality APP

The main reported barriers affecting the quality of instruments relate to the currency and consistency of the documents. Key informants reported concerns regarding documents that have not been reviewed for some time,[11] or instances where instruments are not tailored to the individual patient or client's circumstances.[12] The discomfort of professionals in engaging in meaningful planning conversations,[13] and the reported reluctance of older people to have conversations with family about their wishes,[14] were also mentioned as key factors. Further

[11] Key informant 1 (Lawyer); Key informant 7 (Lawyer); Key informant 11 (Nurse – End of Life); Key informant 15 (Lawyer); Key Informant 16 (Palliative Care Clinician); Key Informant 19 (Senior Clinician); Key Informant 23 (Lawyer); Key Informant 27 (Psychiatrist).
[12] Key Informant 3 (Lawyer); Key Informant 8 (Emergency Medicine Clinician); Key Informant 12 (General Practitioner); Key Informant 16 (Palliative Care Clinician); Key Informant 17 (Intensive Care Clinician); Key Informant 19 (Senior Clinician); Key Informant 22 (General Practitioner); Key Informant 27 (Psychiatrist).
[13] Key Informant 8 (Emergency Medicine Clinician); Key Informant 11 (Nurse – End of Life); Key Informant 12 (General Practitioner); Key Informant 18 (General Practitioner); Key Informant 19 (Senior Clinician); Key Informant 20 (Nurse – Aged Care); Key Informant 26 (Nurse – Emergency).
[14] Key Informant 9 (Nurse – End of Life); Key Informant 11 (Nurse – End of Life); Key Informant 12 (General Practitioner); Key Informant 16 (Palliative Care Clinician); Key Informant 18 (General Practitioner); Key Informant 19 (General Practitioner).

barriers to high quality APP discussed by key informants include lack of knowledge of the distinct purpose of different instruments, and when legal documents begin to operate.

7.3.1 Completed Documents Not Reviewed Regularly

Nearly all of the 22 older adults who were interviewed reported making or updating one of their APP instruments in the last five years, with Advance Care Directives being created most recently. Appointments of an Enduring Guardian or Enduring Power of Attorney were mixed with respect to currency, and Wills ranged from having been made two years ago to over 20 years ago. This suggests that Wills were perceived as more static instruments, whereas appointments of decision-makers or Advance Care Directives could be seen as needing more regular updates.

Determining a specific review timeframe for completed documents is complicated.[15] As the following key informant explains, it is difficult to evaluate if wishes truly are current, even if a relatively short period of time has lapsed:

> What is the relevance of something that was signed only five years ago? Can we actually say that because the person said they wanted this five years ago, do they actually still want that now? It's a bit of a grey stuff area, which is why I spend more of my time talking about, find out who your person responsible is [according to a statutory hierarchy in NSW legislation] and talk to them. (Key Informant 11, Nursing: End of Life)

This contribution highlights the significance of communication, especially between an older person and their appointed decision-maker or Person Responsible. Such conversations can help an appointed decision-maker or Person Responsible to better understand an older person's recorded wishes in an Advance Care Directive, allowing them to make informed decisions in future that truly align with and represent the older person's values and preferences.

Concern regarding the currency of wishes was echoed by a legal professional, who offered the following observation:

[15] Kimberly Buck et al, 'Advance Care Directive Prevalence among Older Australians and Associations with Person-Level Predictors and Quality Indicators' (2021) 24(4) *Health Expectations* 1312; Jane B Baron, 'Fixed Intentions: Wills, Living Wills, and End-of-Life Decision Making' (2020) 87(2) *Tennessee Law Review* 375.

> People tend to see it, in my experience, more as a one-off. You need to remind them that if they make it and more than two to five years pass, they really need to update it to show that their wishes are still current. (Key Informant 7, Lawyer)

The 'set and forget' approach was highlighted by another key informant. Even if documents do not require updating, the lack of review at regular intervals presents a disadvantage where older adults have taken the time to plan ahead but may not have revisited their plans in light of their current circumstances:

> [T]hat's probably the main risk. They don't update them frequently enough. Or just, you don't even have to update them, you just need to review them and if you're happy with them, that's okay. But then if you obviously highlight that there's an issue there, get the document updated. (Key Informant 23, Lawyer)

7.3.2 Documents are Inconsistent

One key informant, who worked as an intensive care specialist, highlighted the difficulties that arise when documents have been poorly drafted, or drafted with insufficient medical guidance, resulting in inconsistent instructions[16] or directions that do not actually reflect the person's wishes:

> [I]f someone says, I don't want ventilation, but they don't really understand what ventilation means. And so they may write something that's rather more broad than they actually mean. And there is that worry that they might write, I don't want to be resuscitated, but [what they really mean is] … I don't want to be resuscitated to come out badly. … So they can be more broad. If they're not written well, they can be broader and take in stuff that people didn't actually intend. (Key Informant 17, Intensive Care Specialist)

This reflection makes it explicitly clear that there is a critical need for older adults to be communicating with their healthcare professionals and care team, either to understand their disease trajectory or just to have a more informed perspective of medical circumstances that can arise in future. Further, resources relating to Advance Care Directives should include clear definitions of medical interventions, including circumstances when they may be used, to allow older adults to fully consider their preferences for care. This will allow for the creation of

[16] Similar concerns were expressed by: Key Informant 3 (Lawyer); Key Informant 8 (Emergency Clinician); Key Informant 12 (General Practitioner); Key Informant 16 (Palliative Care Clinician); Key Informant 19 (Senior Clinician); Key Informant 22 (General Practitioner); and Key Informant 27 (Psychiatrist).

informed documents that are more likely to represent an older person's wishes and are consistent with their preferences.

However, one key informant noted some professionals may feel discomfort when initiating or continuing planning conversations,[17] meaning that older adults are continuing to miss out on key medical perspectives that could result in higher quality APP instruments: 'Some professionals do not know how to introduce [the topic of planning ahead] and have a thorough, honest and respectful conversation with people' (Key Informant 26, Nursing: Emergency & Aged Services).

While there are resources available for clinicians relating to initiating planning conversations,[18] this perspective indicates that there may be a need for healthcare systems and individual practices to encourage clinician use of relevant resources.

7.3.3 Documents Not Tailored to Individual Circumstances

Following on from consistency, considering an older person's wellbeing is vital when preparing APP instruments and tailoring plans to their individual circumstances. Adopting this approach ensures preparations account for the person's financial circumstances, legal needs, social connections and healthcare preferences. Engaging in this holistic consideration allows both older people and members of their support community to truly understand their values, wishes and preferences, and is vital in facilitating high quality APP. As stated by one key informant:

> Our objective should be to put a document in place that suits them specifically in … the shape of their assets. And also takes into account the potential need to change those assets, due to factors that come about, because our average age is getting higher. And we are encountering more health issues as we get older. (Key Informant 3, Lawyer)

Similar perspectives were offered by two other lawyers working in the field of APP:

[17] The issue of discomfort initiating planning conversations was also raised by: Key Informant Key Informant 8 (Emergency Clinician); Key Informant 11 (Nurse – End of Life); Key Informant 12 (General Practitioner); Key Informant 18 (General Practitioner); Key Informant 19 (Senior Clinician); and Key Informant 20 (Nurse – Aged Care).

[18] 'Starting the Conversation', *Advance Care Planning Australia* (Web Page, 29 September 2023) <https://www.advancecareplanning.org.au/understand-advance-care-planning/starting-the-conversation>; 'Advance Care Planning – Information for Health Professionals', *NSW Health* (Web Page, 29 November 2021) <https://www.health.nsw.gov.au:443/patients/acp/Pages/health-professionals.aspx>; Advance Care Planning Australia, *Factsheet for Healthcare Professionals: What Is Advance Care Planning?* (Factsheet, Austin Health, 2018).

> I think it's important that they don't just try and knock something up, copying a friend's one [Will, Advance Care Directive or Enduring Appointment], or something that they found on the internet. That they actually get professional help to do it. … Penny wise, pound foolish. So don't do it. That's what I tell people. Be prepared to spend some money and get this done properly. (Key Informant 6, Lawyer)

> I think education is really important, because we take for granted our knowledge … People do have a thirst for knowledge about their options with these documents. The more information that gets out there, the more informed people are when they see a solicitor. And if they're more informed, they're more likely to make a document that is suitable for their needs, because they've had the opportunity to get more information and to receive educations. … I think people feel more comfortable seeing a solicitor and getting the documents prepared when they've had the opportunity to gather as much information about them as they can. (Key Informant 7, Lawyer)

7.3.4 Lack of Communication with Support Community

Key informants recognised communication as a key factor influencing the quality of prepared planning instruments.[19] However, the limited communication reported by the older people interviewed and those close to them, including family, friends, appointed decision-makers, regarding their wishes in the event of serious illness or injury, or their end of life preferences, was alarming.[20]

Despite not having explicitly discussed their preferences in detail, most participants thought their loved ones would simply know what to do if needed in future: 'I haven't really had the discussion but she knows. … I would assume that she would understand my wants' (Participant 2). Another explained:

> Well, not exactly, I suppose, but we just, you know, it'll be up to the girls to decide that what, depending on whether [their spouse is] alive, or I'm alive, whichever one goes first, or whatever, we don't know that, do we? (Participant 9)

[19] Key Informant 9 (Nurse – End of Life); Key Informant 11 (Nurse – End of Life); Key Informant 12 (General Practitioner); Key Informant 16 (Palliative Care Clinician); Key Informant 18 (General Practitioner); Key Informant 19 (Senior Clinician); Key Informant 20 (Nurse – Aged Care); Key Informant 21 (Health Services Researcher); Key Informant 22 (General Practitioner); Key Informant 26 (Nurse – Emergency).

[20] The following older people who completed an interview said they had not discussed their wishes with their family or appointed decision-makers: Participant 1; Participant 2; Participant 3; Participant 4; Participant 5; Participant 6; Participant 8; Participant 10; Participant 15; Participant 16; Participant 17; Participant 20.

Similarly, another participant shared:

> I guess my husband and I have only talked about the end of life decisions that you might make if you had a stroke, I haven't really talked about that probably so much with the kids. You just assume that one of us is going to be able to make a decision for the other when the time comes. So we haven't actually probably broached that with them. (Participant 15)

Another participant acknowledged they had only had a cursory conversation about their wishes with their son, and recognised more in-depth discussion would be needed going forward:

> No. I haven't. … We haven't discussed it with [our son] at all. He just knows, we've given him a copy. So possibly, that's something we should do ourselves, is just outline, well to the three of them, possibly what's entailed. (Participant 4)

The lack of detailed communication between older people and their families or appointed decision-makers is a significant factor that can undermine the quality of prepared instruments. In the absence of clear conversations regarding an older person's values, wishes and preferences, particularly in light of a diagnosis of a life-limiting or terminal illness, it may be much more difficult to successfully interpret their prepared documents.

7.3.5 Difficulty Accessing Consistent Healthcare

Of the 22 older adults interviewed, almost all reported contacting a lawyer to make their APP documents. No difficulties were reported with accessing legal services in regional communities. However, some participants spoke of difficulties accessing a consistent healthcare provider in their area. When asked if they had communicated with their doctor when preparing an Advance Care Directive or Enduring Guardian appointment, or a financial advisor when appointing their Enduring Power of Attorney, most older adults said they had only spoken with their lawyer. One participant shared the following:

> No, no. Well, it was one of these things. It's mainly a legal and personal thing. … I suppose we did it, just between ourselves and the lawyer. So, well, I suppose the doctor could have had some input, but I don't think, when we made it, we were thinking of all these things happening anyway. (Participant 12)

This perspective reveals that even when making legal documents that are related to their health status, older people may still wish to distance themselves from thinking too much about future

illness or injury. Consequently, they are not recognising the benefits of involving their healthcare providers in the preparation of APP instruments.

Encouraging early involvement of appointed decision-makers and healthcare providers in the planning process can increase the likelihood that preferences are followed in the event these individuals are called upon to make choices on the older person's behalf.[21] Further education and ongoing communication may encourage normalisation of the concept of future planning.[22] Rather than viewing APP as only for the end of life, older people should be encouraged to view planning as preparing for the rest of life,[23] ensuring their wishes and preferences are not only known but can be used to shape their remaining years. This shift in attitude can provide greater opportunities for person-centred care to be realised, with any future decisions being made according to the older person's wishes and preferences.

7.3.6 Lack of Knowledge Regarding Distinct APP Documents

One legal key informant suggested that the lack of education for older adults around the separate documents is undermining APP, as older adults believe they have completed all relevant planning when in fact they are not engaging with the full suite of available instruments:

> I honestly believe that they think that their Will takes care of everything. And I also believe that if they have a Power of Attorney, or Enduring Power of Attorney, then the attorney can make a decision. In relation to – should they be in hospital – as to whether or not maybe a life support system can be turned off or not [which are decisions for an Enduring Guardian]. (Key Informant 5, Lawyer)

Such misunderstandings provide a strong rationale for supporting a more holistic, collaborative approach to APP. Further guidance should also be provided to older people and their support communities regarding when documents begin to operate, and periods in which appointed decision-makers can act:

[21] Maria T Carney et al, 'Impact of a Community Health Conversation upon Advance Care Planning Attitudes and Preparation Intentions' (2021) 42(1) *Gerontology & Geriatrics Education* 82.
[22] Department of Health, *National Framework for Advance Care Planning Documents* (Report, May 2021) 6 <https://www.health.gov.au/resources/publications/national-framework-for-advance-care-planning-documents?language=en>.
[23] Gail Yapp et al, 'Planning for the Rest-of-Life, Not End-of-Life: Reframing Advance Care Planning for People with Dementia' in Gaynor Macdonald and Jane Mears (eds), *Dementia as Social Experience: Valuing Life and Care* (Routledge, 1st ed, 2018) 134.

> Well, first of all, we're reminded, and the person knows when they're completing this document, or the family, that it doesn't come into effect until the person loses their ability to express their wishes and make decisions. So that needs to be clear. Because while the person is able to communicate, and make these decisions, it's invalid, it doesn't come into play. It's not acted on. (Key Informant 16, Palliative Care)

Interestingly, most older adults who participated in an interview noted that they did not receive information regarding the role of their appointed decision-makers, which led to some confusion regarding their powers. One stated: 'I don't remember this being the case, no, I don't remember that there was any opportunity to put those things in place' (Participant 6). Another related: 'No, I don't think so. I think we just left it with the solicitor, and they'll just go from there' (Participant 9).

There is an evident need for improved and increased education, not only for older adults in the community, but for healthcare professionals working in fields where they are required to interpret and implement prepared instruments. For older people, this is particularly critical for understanding the difference between decision-makers who are authorised to make financial rather than healthcare choices, and when these appointments begin to operate. For health professionals, the need for further training regarding the legal status of completed instruments is apparent:

> [T]here's a bit of misunderstanding in the community that Power of Attorney covers everything, and so we need to explain to people that, in New South Wales, there are actually two documents for two separate areas of decision-making. I think it's important to have a Guardian as well as a Power of Attorney, because it's different types of decisions that the Guardian makes. If there is conflict in the family, you want to make it clear who makes those different types of decisions. It's also important that the Attorney and the Guardian get on, because they complement each other. (Key Informant 7, Lawyer)

Following this exploration of perceptions of high-quality APP, this chapter will now examine confidence in the future use of prepared APP instruments, and barriers to their successful implementation.

7.4 Confidence of Older Adults in the Future Use of Completed Instruments

7.4.1 Confidence in Appointed Decision-Makers

Older adults were questioned on how confident they felt about their appointed decision-makers making decisions that would align with their wishes and preferences in the future. Almost all participants reported feeling very confident in their choice of decision-makers, with the majority having selected their spouse or child as their Enduring Guardian or Enduring Power of Attorney. One related: 'Well, I wouldn't have done it if I didn't feel confident about it. No, I trust the kids' (Participant 7). Another shared: 'We have a close relationship with our kids and I'm absolutely one hundred percent confident in the decisions that they would make for us would be what we want' (Participant 15).

However, one participant commented on the potential discomfort that can arise for both the older person and the appointed decision-maker when making arrangements and discussing plans:

> I don't think you can be confident, because it's not an easy thing to do, and it's a very emotional situation and as such, you really just have to hope that they can ... Put it this way, it's a job that you really don't want to give to anybody, but somebody would have to be nominated to do it. … It's a not a very desirable situation to have to discuss with anybody, but you would hope that they would do it and do it well, and do it with a minimum impact on themselves. (Participant 1)

This notion of 'not wanting to give anybody the job' indicates that older people often do not wish to burden the people around them to act on their behalf. Further, it recognises that appointed decision-makers may be required to make difficult decisions, even in circumstances where APP instruments have been prepared. This contribution highlights the need to consider the wellbeing and vulnerability of all parties involved, including members of the older person's support community, when taking into account relational autonomy.

7.4.2 Confidence in Future Use of Completed Instruments

Older adults were also asked about their confidence in their completed plans, and whether they believed they were more likely to have their wishes upheld by having engaged with APP. Responses were mixed, with most participants noting they were hopeful, but realistic that their plans may not be carried out to the letter. One related: 'I think so. If you've got it in writing it's

... Maybe they can't do what you want but at least they can try. … Yes. It gives them a clue as to what you want' (Participant 2). Another explained:

> I think in most reasonable families it is probably going to happen, but we all know that you've got families where there is potential separation of the decision-making … We've got two educated children and three grandchildren, and we know what we want is not necessarily what they want. … [T]hey have also got very strong wills as well, … who knows what will happen? (Participant 5)

One participant recognised the benefit of making an Advance Care Directive in preparation for the future, but admitted they would probably only make one when necessary:

> [I]f I had a heart attack or something like that, then I'd think about doing the Advance Care Directive as in when it would be needed rather than in advance. It's quite a good thing to do in advance. As we know, that's what Wills and things are, but I think … It's not exactly doing it on the fly, but just depending on how things go, then if there was a need, do one. (Participant 22)

This perspective highlights how APP is often perceived as planning for the end of life, rather than the rest of life. If APP was reframed as an opportunity to plan for the remaining decades of life, rather than only for the final stages, it may encourage more older people to engage in APP earlier and prepare relevant instruments well ahead of any serious issues or crisis arising.

7.5 Confidence of Professionals in the Future Use of Completed Instruments

Key informants reported mixed levels of confidence relating to the future use of completed instruments. While it was generally agreed that the instruments had the potential to be effective, the need for careful preparation,[24] better education for patients and clients,[25] and increased communication[26] were flagged as key factors that influenced confidence in future use.

[24] Key Informant 5 (Lawyer); Key Informant 15 (Lawyer); Key Informant 22 (General Practitioner); Key Informant 23 (Lawyer).
[25] Key Informant 10 (Nurse – End of Life).
[26] Key Informant 12 (General Practitioner); Key Informant 20 (Nurse – Aged Care).

7.5.1 Importance of Appointing a Reliable Decision-Maker

Key informants expressed more confidence about the future use of completed instruments when reliable decision-makers had been appointed. One stated: 'I'm confident when people are confident about the people that they appoint' (Key Informant 1, Lawyer). Another explained:

> I find older people tend to be fairly clear on who they trust and who they have ongoing relationships with. When you advise them about obligations of the [Power of] Attorney and discuss it with them, in most families, they're pretty clear who they want to act in that role. … What I recommend to older people is that they have a discussion with the family as to why they've appointed that person to avoid future difficulties down the track. There might be non-acceptance of who they've chosen [and it's good] to try and resolve that early on. (Key Informant 7, Lawyer)

However, both legal and healthcare professionals voiced concern about the selection of inappropriate decision-makers by older people, and the consequences of older people failing to discuss their future wishes and preferences with appointed people: 'I think that the documents are a great help, but you can never protect against human misbehaviour' (Key Informant 6, Lawyer).

This notion of 'misbehaviour by inappropriate decision-makers' was also raised by a key informant with extensive experience in policing and responding to elder abuse:

> The problem is that in my experience, that people who are determined to exploit an older person are pretty ruthless. And they will find a way around any legal instrument. Especially if they have a criminal intent. … [O]ften a lot of the abuse revolves around conflict between family members, or those that see themselves as having an interest in the older person's affairs. (Key Informant 13, Police)

These contributions demonstrate the critical need for older people to carefully select their appointed decision-makers, and for professionals to be vigilant regarding any circumstances that may enliven opportunities for abuse.

7.5.2 The Role of Education, Careful Preparation and Ongoing Communication

Key informants explicitly recognised the need for further education for both older adults and professionals regarding APP, including the legal status of each instrument:

> I think we have a long way to come. While I think in principle Advance Care Planning documentation is fantastic, and I'm a huge advocate for it, there needs to be more around education, on both the clinician and the public side, around some of the legal nuances to it. (Key Informant 10, Nurse: End of Life)

The careful preparation of APP instruments was a key factor that improved key informants' confidence in their future use:

> [F]or them to be used in that way [successfully in future], they need to be developed ahead of time. And the people who are most likely to dispute them, actually, need to know what's in them and have those discussions. If they don't, then I don't know if they help very much. (Key Informant 27, Psychiatrist)

> I think there's so many things that influence the likelihood of these completed documents, or instruments, being able to affect future care. Obviously, one element would be the quality of them. … Some documents that we can [implement], they're more specific. They're more clear when it comes to communicating the person's preferences. (Key Informant 22, General Practitioner)

The need to engage in communication surrounding a person's documented wishes was explicitly discussed:

> I don't think a tool can ever replace good communication. … I like tools as a guide and suggestions, and, from a learning perspective, I think it's really good. But mediation, negotiation, good conversations that are balanced and inclusive and all of those things, is a different skill and not something that a tool will replace. (Key Informant 20, Nursing: Aged Care)

This perspective of APP instruments as 'tools' highlights a significant dilemma. While APP instruments, such as Advance Care Directives and Enduring Guardian appointments, are legally authoritative documents, health professionals may be perceiving them as 'guides' or 'suggestions' in the absence of clear education about APP instruments and their distinct purposes and powers. This may be a factor that influences why APP instruments can be disregarded when an older person becomes a patient in the healthcare system, especially if prepared instruments are not readily available at the point of care.

7.5.3 Challenges in Healthcare Settings

Generally, key informants working within health-related areas tended to express less confidence that completed instruments could be used successfully in future. This stands to reason, as it is generally clinicians who are involved in interpreting and implementing APP mechanisms at the point of care, often under extreme time pressure and in circumstances where appointed decision-makers are not readily identifiable due to conflict and contrasting opinions of family members:

> I am not really confident [in future use], to be honest. I am hopeful, but I know what is happening widely. I've seen the chaos, especially with the pandemic, the chaos in the emergency departments, and on geriatric wards. So many had a shortage of staff. So, so many clinicians are just pressed for time and don't have the opportunity to sit down and talk for very long. (Key Informant 21, Health Services Researcher)

Enhancing the factors influencing quality, such as education and communication, may in turn improve levels of confidence. As stated by the following key informant, it is essential that older adults are aware of the planning mechanisms they have in place, their distinct purposes, and when they begin to operate:

> So, the big problem is that a lot of people say, yes, I've got an Advance Care Plan, and they feel reasonably confident, but it's almost like having an insurance that doesn't actually work when you claim on it. And the processes to help people to get that step right are almost absent. (Key Informant 17, Intensive Care Specialist)

These 'processes' may include increased knowledge regarding the various APP instruments and more opportunities for collaboration between older people, their family, appointed decision-makers and professionals. Recommendations for improvement will be discussed further in Chapter 9.

7.6 Barriers to Successful Implementation of Completed APP Instruments

Key informants noted several barriers to the future use and implementation of APP instruments. The most frequently mentioned barrier was that prepared instruments are not followed in

practice,[27] usually because the document is unclear,[28] or wishes are overridden by family. There may also be confusion as to who a patient's decision-maker actually is,[29] and family conflict raises additional challenges.[30] Documents may not be accessible at the point of care,[31] meaning they are unable to be implemented. Finally, professional key informants discussed the potential for abuse of prepared instruments, undermining their ability to be implemented in the best interests of the older person.

7.6.1 Prepared Instruments are Not Followed

Barriers to implementation were mainly reported by key informants who worked in a health-related area of practice, given that they are the professional group who are most likely to experience the challenges of interpreting completed APP mechanisms. Key informants shared that it is often impossible to follow prepared instruments due to instructions not being clear, or the adoption of a 'tick-box' approach to preparing APP documents,[32] meaning plans are not tailored to specific circumstances:

> I guess what I'm trying to say is that vaguely worded Advance Care Directives around uncertain variable scenarios, it's going to be often difficult for them to be implemented. … [S]omething which is clearly written and if it is highly specific, they're more likely to be implemented. (Key Informant 22, General Practitioner)

> I think the Advance Care Plans I struggle with the most are the tick box ones, I suppose, because they don't really talk enough about the person from my perspective. (Key Informant 8, Emergency Clinician)

[27] Key Informant 1 (Lawyer); Key Informant 4 (Lawyer); Key Informant 6 (Lawyer); Key Informant 9 (Nurse – End of Life); Key Informant 10 (Nurse – End of Life); Key Informant 11 (Nurse – End of Life); Key Informant 12 (General Practitioner); Key Informant 14 (Intensive Care Clinician); Key Informant 18 (General Practitioner); Key Informant 25 (Nurse – Dementia Care); Key Informant 26 (Nurse – Emergency).
[28] Key Informant 1 (Lawyer); Key Informant 10 (Nurse – End of Life); Key Informant 16 (Palliative Care Clinician); Key Informant 19 (Senior Clinician); Key Informant 20 (Nurse – Aged Care); Key Informant 22 (General Practitioner).
[29] Key Informant 3 (Lawyer); Key Informant 8 (Emergency Clinician); Key Informant 9 (Nurse – End of Life); Key Informant 11 (Nurse – End of Life); Key Informant 16 (Palliative Care Clinician); Key Informant 17 (Intensive Care Clinician); Key Informant 18 (General Practitioner).
[30] Key Informant 2 (Lawyer); Key Informant 9 (Nurse – End of Life); Key Informant 10 (Nurse – End of Life); Key Informant 17 (Intensive Care Clinician); Key Informant 20 (Nurse – Aged Care); Key Informant 22 (General Practitioner).
[31] Key Informant 3 (Lawyer); Key Informant 8 (Emergency Clinician); Key Informant 10 (Nurse – End of Life); Key Informant 11 (Nurse – End of Life); Key Informant 25 (Nurse – Dementia Care); Key Informant 27 (Psychiatrist).
[32] Key Informant 8 (Emergency Clinician); Key Informant 10 (Nurse – End of Life); Key Informant 17 (Intensive Care Clinician); Key Informant 19 (Senior Clinician).

One participant shared very openly that in emergency scenarios, locating APP documents is not their first priority. Consequently, within the context of urgent care, plans, if prepared, are often not followed:

> Do you want me to be honest here? I usually ignore [an Advance Care Directive]. And I'll tell you why that is, it's that if you imagine the context of this very sick person with a low blood pressure. And now with our brilliant way of cleaning infections, the last thing we want to do is to say to the relatives, is this really what you want? Because it's so easily treated. So it's ignored by well-meaning health system doctors and nurses. … So it's not the first question on our lips. Where's the Advance Care Planning document? It's just not here. It's not one of our first priorities. So, to be quite honest, it's ignored for those reasons. (Key Informant 14, Intensive Care Clinician)

In contrast, legal key informants tended to focus on challenges arising from interpersonal relationships, rather than the difficulties of inquiring about and implementing APP instruments in emergency contexts:

> [Advance Care Directives are] a bit of a grey area as a legal document. Certainly, the health services will take note of it. If they find it in your record. But again, they have got their own indicator. And their interpretation of that feedback from maybe other members of your family, who have a different view, who may be Guardian or not. There's a delicate balancing act that goes on there. (Key Informant 4, Lawyer)

7.6.2 Confusion Regarding Decision-Maker and Family Conflict

Interpersonal factors present challenges for implementation, including confusion over who the authorised decision-maker is,[33] and family conflict that sometimes overrides the person's completed instruments.[34] The need to quickly and accurately identify a person's appointed decision-maker, who is authorised to make healthcare decisions, was acknowledged by informants working in health and law, with both professional perspectives highlighting time and work environment impacts as common barriers:

[33] Key Informant 3 (lawyer); Key Informant 8 (Emergency Clinician); Key Informant 9 (Nurse – End of Life); Key Informant 11 (Nurse – End of Life); Key Informant 16 (Palliative Care Clinician); Key Informant 17 (Intensive Care Clinician); Key Informant 18 (General Practitioner).
[34] Key Informant 2 (Lawyer); Key Informant 9 (Nurse – End of Life); Key Informant 10 (Nurse – End of Life); Key Informant 17 (Intensive Care Clinician); Key Informant 20 (Nurse – Aged Care); Key Informant 22 (General Practitioner).

> Who's the go to person in the family? Oh, we haven't had that discussion. We don't know who to talk to. Or, they could choose someone and they don't feel comfortable about it, and then there's probably some family dynamic issues there. Also there's sometimes family that don't want other family members to be involved. They're deemed to be excluded, and how do we deal with that? (Key Informant 16, Palliative Care Clinician)

> I think if we actually got our stuff together and actually find out who is their person responsible. In other words, who would be their voice if they can't speak? Because quite frankly, an Advanced Care Plan has no legal status.[35] An Advanced Care Directive? Now that's a different kettle of fish. But for an Advanced Care Plan, pardon me, it's meaningless. And quite frankly, when people come into an [emergency] department in a crisis, nobody looks. (Key Informant 11, Nursing: End of Life)

Further attention needs to be given to these appointments, especially as family structures change and personal circumstances may be different to traditional expectations:

> Well, in these days of de facto partners, blended marriages, married with a de facto, whatever, and kids from multiple relationships. Don't you think the hospital would love the roadmap as to who's who at the zoo? No matter whose contacts, these are the key people. (Key Informant 3, Lawyer)

7.6.3 Inconsistent Storage and Inaccessibility of Completed Instruments

Another reason why prepared documents may not be followed is their inaccessibility. The available literature indicates that one of the main barriers to implementation of completed instruments is that they may not be accessible when needed, or shared with relevant parties.[36]

Almost all older adults who completed an interview reported keeping copies of their APP documents at home in a safe locked box or filing cabinet. Nearly three-quarters of participants stated that copies of their documents were also stored at their solicitor's office. Three

[35] An Advance Care Plan refers to a plan that can be prepared by someone other than the older person, for example, a family member. Further, an Advance Care Plan is not legally enforceable and is only used to guide care decisions. An Advance Care Directive is prepared by the older person themselves, when they have capacity to do so, and is legally enforceable.

[36] Buck et al (n 15); Karen M Detering et al, 'Organisational and Advance Care Planning Program Characteristics Associated with Advance Care Directive Completion: A Prospective Multicentre Cross-Sectional Audit among Health and Residential Aged Care Services Caring for Older Australians' (2021) 21 *BMC Health Services Research* 700:1–12; R Sean Morrison, 'Advance Directives/Care Planning: Clear, Simple, and Wrong' (2020) 23(7) *Journal of Palliative Medicine* 878; Frances Batchelor et al, 'Facilitators and Barriers to Advance Care Planning Implementation in Australian Aged Care Settings: A Systematic Review and Thematic Analysis' (2019) 38(3) *Australasian Journal on Ageing* 173.

participants kept a copy on their computer, and one participant had stored a copy in a safety deposit box at their bank. Only six of the 16 participants who had appointed an Enduring Power of Attorney or Enduring Guardian had provided a copy of this document to their appointed decision-maker, and only two of the seven participants who had made an Advance Care Directive had provided a copy to family members. Five participants had shared their health-related documents with their doctor. One participant reported sharing their Enduring Power of Attorney appointment with their financial advisor. Only one participant detailed their plans for ensuring documents would follow them to hospital if they were to become unwell:

> I have a folder with all that sort of information in it. And I have that handy, like if I go away anywhere, I put that on the kitchen bench so that if they need it, it's there for them to see. Other than that, it's just kept handy in my bedroom on a little seat I have there, so it's obvious for somebody to find. (Participant 6)

This highlights a significant gap in the planning process. If planning instruments are not being shared with appointed decision-makers or healthcare providers, these individuals are placed in the extremely difficult position of not actually knowing what the older person's wishes and preferences are. This raises serious questions regarding the quality of future choices of those called upon to make decisions on behalf of the older person if they have never been provided a copy of the older person's planning instruments. In the absence of clear, collaborative communication, decisions made on behalf of the person may not align with the individual's wishes and preferences.

According to key informants working in healthcare settings, documents are rarely present with patients at the point of care:

> I'll refer to maybe a patient from the nursing home, or age care facility I should say, that they might have had an Advance Care Plan or some documentation. But then [the documents] don't seem to come to the emergency department. (Key Informant 10, Nurse: End of Life)

> If you move to hospital, then they're not available. If you move to residential care, they're mostly not going to be available. So, the reality is even though they can follow, mostly, for a variety of reasons, [they] don't. (Key Informant 27, Psychiatry)

One lawyer shared the advice they give to older clients to try and ensure the necessary documents accompany them to hospital:

> So it's another instruction I give people, once you've got your document [Advance Care Directive, Enduring Guardian, Enduring Power of Attorney], pack it next to your toothbrush. If you ever have to go to hospital … this tells them what they need to know. (Key Informant 3, Lawyer)

This highlights the evident lack of a standardised procedure that ensures documents, when created, can be located quickly and follow a person if they are admitted to hospital, or move into a residential care facility, especially in the event of an emergency.

7.6.4 Potential Abuse of Prepared Instruments

Concerns regarding the abuse or exploitation of older people were raised by almost all the key informants with a legal or law enforcement background.[37] While carefully prepared APP mechanisms can help to guard against elder abuse, there were also concerns raised that instruments can be deliberately prepared for the purpose of exploiting an older person.

Lawyers shared reflections on their professional experiences with elder abuse, noting that interpersonal relationships with children or carers are often at the core of any concerns: For example, one lawyer stated: '[R]arely is it a straightforward theft. It's abuse of trust' (Key Informant 1, Lawyer), and another shared: '[S]ometimes it's meant to happen. It's intended to be fraud and sometimes it's just sheer accident or laziness' (Key Informant 2, Lawyer). Others related:

> What we tend to find is, what I have concern, or concerns, actually, is where you find these private agencies [who are hired to provide care for an older person in their own home], where they have carers and they're actually … The family are actually left out of the Will for unforeseeable reasons. (Key Informant 5, Lawyer)

> On several occasions you will get a child or someone, let's just call them a proposed beneficiary, bring their elderly friend or bring their elderly mother, father in here … [t]o do a Will that would, of course, be in favour of them. That would be at a point when the elderly have no concept of what they're doing. (Key Informant 23, Lawyer)

[37] Key Informant 1 (Lawyer); Key Informant 2 (Lawyer); Key Informant 4 (Lawyer); Key Informant 5 (Lawyer); Key Informant 6 (Lawyer); Key Informant 7 (Lawyer); Key Informant 13 (Police); Key Informant 15 (Lawyer); Key Informant 23 (Lawyer); Key Informant 24 (Lawyer); Key Informant 28 (Lawyer).

The need to ensure older adults are living within a safe environment was explored by one key informant with extensive experience responding to, and working to prevent, elder abuse:

> Obviously the planning mechanism is just one component of a safe environment for an older person. But it's really clear that a big driving factor in abuse of older people is finance and money. Particular[ly] relating to relatives and family. And it's very clear that if a good instrument or regime is in place that the risks decline dramatically for the older person. (Key Informant 13, Police)

These statements demonstrate the multiple ways in which abuse can occur. There is an evident need for professionals to consider the wellbeing of the older person, including their social connections, as well as any vulnerability or heightened dependence they may be experiencing that necessitates further involvement of other individuals in their daily life and affairs. These social connections form a vital component of their wellbeing, but professionals must be cognisant of any potential opportunities for exploitation of the older person:

> I think it's a part, like other parts, which involve abuse of the document, abuse of the elder parent, because it's mainly this vertical relationship. … [I]t is common in my practice that we see either a sibling who comes in and says, 'my brother has been ripping my mum off for a couple of years. I only just glanced at her bank statement the other day and there used to be $500,000 and now there's only $200,000. Oh, and by the way, my brother drives around in a Mercedes now'. Those are the kinds of background facts that we like to hear because then that sounds like it won't be hard to convince either a tribunal or a court that there are suspicious circumstances, and therefore, this case merits inquiry. (Key Informant 28, Lawyer)

Another key informant working as a legal practitioner offered the following reflection on the potential for abuse within APP, highlighting that relational autonomy can present both benefits and risks for older people:

> Well, look, any system can be abused. I think we have to start from that premise. And that goes back to establishing that the person involved is actually operating on their own independent will. Given that they're operating with advices or with assistance, and trying to establish whether those people supporting them or assisting them are actually independent. And acting in, well, while I don't like the phrase, the person's best interests. Or at least that they can have a subsidiary interest in the person doing certain things, which would put them in a conflict of interest. (Key Informant 3, Lawyer)

Most healthcare practitioners reported no experience of APP instruments being used to facilitate the abuse of older people. This stands to reason, given that financial exploitation is one of the most common forms of elder abuse, and is more likely to fall within the scope of engagement of a lawyer. However, one key informant working in emergency medicine shared how elder abuse can be recognised when treating older patients:

> [I]t's not very common, and I don't think we think about it enough, that's an important part of it. And if you think about vulnerable people, sometimes the emergency department is the only place that they escape. But there's been a few cases, maybe not the instrument, but the circumstances. … So, I suppose, in hospital, the ones we see are around neglect and psychological [abuse], really. (Key Informant 8: Emergency Clinician)

Once again, this highlights the need for comprehensive consideration of an older person's wellbeing, including their social connections, and any potential opportunities for exploitation by those close to them. In accordance with Elder Law principles, the law should adopt a client-centric focus and be used to promote and improve the welfare of individuals as they age.[38] As one lawyer noted in an open text box in the survey, '[f]ailure to deal with these issues properly just creates more opportunity for elder abuse, and the act of obtaining instructions smokes out trouble makers and opportunists to some degree'. Indeed, a lack of careful consideration of individual circumstances, or completing APP in a rush, can lead to heightened risks in the future. Consequently, there is an apparent need for further education of healthcare practitioners regarding the circumstances in which elder abuse may arise, the different forms of abuse, and how to best create a safe environment for older adults who are admitted for treatment or emergency care.

7.7 Professional Strategies to Improve Quality

Key informants offered reflections on how the current approach to APP can be improved. Two main themes arose: (1) the need for further interprofessional collaboration,[39] and (2) integrating APP within usual care.[40]

[38] Gregory T Holtz, 'Understanding the Ethics of Empowerment: An Elder Law Lawyer's Challenge or Obligation' (2017) 38(1) *Northern Illinois University Law Review* 81, 85.
[39] Key Informant 3 (Lawyer); Key Informant 10 (Nurse – End of Life); Key Informant 14 (Intensive Care Clinician); Key Informant 22 (General Practitioner).
[40] Key Informant 9 (Nurse – End of Life); Key informant 18 (General Practitioner); Key Informant 19 (Senior Clinician); Key informant 21 (Health Services Researcher).

This interprofessional and integrated approach, with active and explicit consideration of an older person's wellbeing, autonomy, vulnerability and support community, has significant benefits. One key informant described how this process would work, ensuring the older adult is at the centre of all planning conversations and interactions:

> [Y]ou've got to start with who the person is. … First of all, medicine and law needs to get together with society and try and establish a way of defining who the person is, what are their core attitudes and beliefs? Because out of that will come what their wishes are in regard to … not just health, but also law and living circumstances and quality of life. … And those professionals, including legal ones, might want to drill down a bit and say, this is a high priority in your life. What if so and so and so? Yes, but the person is dictating the terms of the interrelationship between the health and legal professional. (Key Informant 14, Intensive Care Specialist)

Such an approach can help all cohorts – older adults, legal practitioners and healthcare professionals – to recognise the significance of planning ahead for the rest of life, not just the end of life. By providing frequent and ongoing opportunities to discuss an older person's preferences, goals and wishes for the future, these conversations will become more commonplace, rather than being a daunting discussion that only focuses on plans for the last weeks or days of life. The benefits of normalising this process were explicitly recognised by the one key informant:

> We see ageing and death as defeat, when in fact it is just part of the cycle of life. It's a normal part of the cycle of life. And so, preparing for death is in fact normal. Or it should be. And I don't know what it is about our society that there's denial, and we see death as failure, when in fact it's not. (Key Informant 18, General Practitioner)

The adoption of a more collaborative approach to APP at the outset is strongly promoted in the literature.[41] Older people should be encouraged to discuss wishes with those close to them, including family, friends and appointed decision-makers. Discussions with health and legal

[41] Helena Rodi et al, 'Exploring Advance Care Planning Awareness, Experiences, and Preferences of People with Cancer and Support People: An Australian Online Cross-Sectional Study' (2021) 29(7) *Supportive Care in Cancer* 3677; Karen M Detering et al, 'Prevalence of Advance Care Planning Documentation and Self-Reported Uptake in Older Australians with a Cancer Diagnosis' (2021) 12(2) *Journal of Geriatric Oncology* 274.

professionals should also occur, particularly given that doctors who are required to enact APP are reportedly often left out of health-related planning.[42]

To achieve this, a collaborative approach, with early involvement of trusted people and legal and medical professionals, should be integrated into usual care.[43] Community education initiatives and planning consultations should place more emphasis on the role of ongoing communication with all relevant parties in achieving quality APP, as well as clear strategies for storing prepared documents so they are readily available when needed. When encouraging the sharing of documents with trusted family, friends, decision-makers and health professionals,[44] it is important for a professional to explain to the older person why sharing is beneficial. While such conversations can be uncomfortable, sharing prepared instruments can make it more likely they will be available when needed, thereby increasing the chance that wishes and preferences can be followed in future.

7.8 Conclusion

This chapter explores key findings from my research that expand understanding of professional and personal approaches to planning, with a focus on the quality of completed instruments and challenges for implementation. Significantly, the present study has drawn together older people and professional key informants from legal and health backgrounds, exploring their shared and diverging perspectives on the later stages of the APP process, which have received far less attention in the existing literature. These results provide a new data set from which other researchers can investigate attitudes towards high quality APP and difficulties with implementing completed instruments in future. They also identify potential areas for improvement, which will be explored further in the final chapter of this thesis.

[42] Nadia Moore et al, 'Doctors' Perspectives on Adhering to Advance Care Directives When Making Medical Decisions for Patients: An Australian Interview Study' (2019) 9 *BMJ Open* e032638:1-11.
[43] Ibid.
[44] Buck et al (n 15).

8 DISCUSSION

8.1 INTRODUCTION

This chapter critically reflects on the findings of my research, exploring where conclusions align with, or diverge from, the conceptual framework within my chosen theoretical lens. This discussion provides an important link between my findings and the existing literature, demonstrating how my work contributes new data and unique insights relating to Advance Personal Planning (APP). Engagement in this intellectual discussion has informed my development of recommendations as to how existing APP processes can be improved and suggestions regarding areas for future research, which are presented in the following and final chapter of this thesis.

Vulnerability encourages recognition of declining health, lack of social support, and potential for the exploitation of older adults. Autonomy takes into account the need to ensure planning is authentic to an older person's wishes and considers the role of their support community in supporting future decision-making. In their interviews, older adults reported various factors that prompted them to engage with APP, including their health, personal relationships and access to services. These factors enliven a deeper understanding of vulnerability that goes beyond the confined focus of psychological wellbeing that is promoted by Therapeutic Jurisprudence. Older adults who want to be prepared for the future, thus exercising control over their current and future decision-making, are realising the central components of empowerment, these being participation, power and control. However, a deliberate decision

not to engage with APP can also be empowering, where an older adult has recognised a planning mechanism is not suited to their purposes in light of their individual circumstances.

8.2 Overview of Theoretical Perspectives and Conceptual Framework

As detailed in Chapter 4, my research integrates Preventive Law[1] and Therapeutic Jurisprudence,[2] recognised as theralaw, within the broader field of Elder Law.[3] The adoption of theralaw has allowed for a comprehensive examination of how the law can be used to support people as they age,[4] taking account of their personal wishes, goals, values and preferences in the context of their overall wellbeing,[5] and proactively planning to prevent future conflict.[6] Implementation of this informed approach would allow for greater care to ensure the wishes of older adults are understood and respected as they age,[7] and the adoption of an explicit client-centric focus that accounts for their individual needs.[8]

The conceptualisation of vulnerability in my thesis recognises that it is possible for people to become more dependent as they age if they experience declining health, fluctuating capacity or increased periods of isolation.[9] However, periods of heightened dependency should not be considered permanent, and should not automatically render a person incapable of making their

[1] Bruce J Winick, 'The Expanding Scope of Preventive Law Therapeutic Jurisprudence Symposium' (2002) 3 *Florida Coastal Law Journal* 189; Dennis P Stolle, 'Professional Responsibility in Elder Law: A Synthesis of Preventive Law and Therapeutic Jurisprudence' (1996) 14(4) *Behavioral Sciences & the Law* 459; Louis M Brown, 'The Law Office – A Preventive Law Laboratory' (1956) 104(7) *University of Pennsylvania Law Review* 940.
[2] Mark Glover, 'A Therapeutic Jurisprudential Framework of Estate Planning' (2011) 35 *Seattle University Law Review* 427; David B Wexler, 'From Theory to Practice and Back Again in Therapeutic Jurisprudence: Now Comes the Hard Part' (2011) 37(1) *Monash University Law Review* 33 ('From Theory to Practice and Back Again').
[3] Gregory T Holtz, 'Understanding the Ethics of Empowerment: An Elder Law Lawyer's Challenge or Obligation' (2017) 38(1) *Northern Illinois University Law Review* 81; AD Bogutz, 'Elder Law: A Personal Perspective' in Israel Doron (ed), *Theories on Law and Ageing: The Jurisprudence of Elder Law* (Springer, 2009) 1; I Doron, 'A Multi-Dimensional Model of Elder Law' in Israel Doron (ed), *Theories on Law and Ageing: The Jurisprudence of Elder Law* (Springer, 2009) 59.
[4] Holtz (n 3).
[5] Glover (n 2); Dennis P Stolle et al, 'Integrating Preventive Law and Therapeutic Jurisprudence: A Law and Psychology Based Approach to Lawyering' (1997) 34 *California Western Law Review* 15.
[6] Winick (n 1); Stolle (n 1).
[7] Bogutz (n 3).
[8] Richard L Kaplan, 'Elder Law as Proactive Planning and Informed Empowerment during Extended Life' (2010) 40(1) *Stetson Law Review* 15, 17.
[9] LA Frolik, 'Later Life Legal Planning' in Israel Doron (ed), *Theories on Law and Ageing: The Jurisprudence of Elder Law* (Springer, 2009) 11, 12.

own plans or recording their own wishes.[10] As such, I have operationalised vulnerability with the comprehension that, in the event an older person requires some support in one aspect of their lives, this does not mean they are entirely dependent in another area. Further, if they do require support with managing their affairs, as long as the older adult is able to understand the nature and effect of any APP instrument they are making, any perceived vulnerability can be accommodated in the planning process.[11] This is an especially important consideration when examining the role of professionals who support older adults to engage with APP, or those who are involved in the interpretation of completed planning instruments.

Autonomy emphasises the authenticity of an individual's wishes, taking account of whether any decisions are self-directed and represent the person's actual preferences.[12] This conceptualisation ensures any decisions are driven by the person's own judgement and free from the influence of other parties.[13] During my interviews with older people, this operationalisation of autonomy was kept front of mind, with an understanding that if the interviewee had chosen to engage with APP, their wishes represented their own choices and preferences. This was especially the case when people had deliberately declined to participate in a form of planning, usually because they did not feel they had someone they could trust to support their decision-making in future. In such instances, relational autonomy was a significant issue, necessitating consideration of 'the importance of relationships and the role of family carers'.[14] For the older people I interviewed, relationships were vitally important, whether they had a network of people they could call upon to support or make decisions in future,[15] or whether their circumstances meant there was no one to fulfil this role.

In my research, wellbeing has been conceptualised in a comprehensive way, taking account of contextual factors, personal relationships, and accessibility of available services and

[10] Martha Albertson Fineman, '"Elderly" as Vulnerable: Rethinking the Nature of Individual and Societal Responsibility' (2012) 20 *Elder Law Journal* 101.
[11] Lise Barry, '"He Was Wearing Street Clothes, Not Pyjamas": Common Mistakes in Lawyers' Assessment of Legal Capacity for Vulnerable Older Clients' (2018) 21(1) *Legal Ethics* 3, 10.
[12] Kathryn Abrams, 'From Autonomy to Agency: Feminist Perspectives on Self-Direction' (1999) 40 *William and Mary Law Review* 805, 807–808; Joel Feinberg, 'Autonomy' in John Christman (ed), *The Inner Citadel: Essays on Individual Autonomy* (Oxford University Press, 1989) 27, 30–43.
[13] Gerald Dworkin, 'The Concept of Autonomy' in John Christman (ed), *The Inner Citadel: Essays on Individual Autonomy* (Oxford University Press, 1989) 54, 61; Feinberg (n 12) 32.
[14] Gail Yapp et al, 'Planning for the Rest-of-Life, Not End-of-Life: Reframing Advance Care Planning for People with Dementia' in Gaynor Macdonald and Jane Mears (eds), *Dementia as Social Experience: Valuing Life and Care* (Routledge, 1st ed, 2018) 134, 147.
[15] Tamryn F Gray et al, 'The Decision Partner in Healthcare Decision-Making: A Concept Analysis' (2019) 92 *International Journal of Nursing Studies* 79, 80; Yapp et al (n 14) 147.

supports.[16] This can include consideration of housing stability, employment, geographic location, supportive relationships, access to health services, the availability of legal advice, and economic stability, which highlights the need to consider personal, financial, social and legal elements of wellbeing.[17] It is especially important to consider accessibility in relation to legal, health and financial services for older adults living in regional and rural areas. Access to services was a key theme that emerged from my interviews with older adults, as was support from other individuals in the community. This operationalisation of wellbeing expands on the traditional focus on psychological wellbeing within Therapeutic Jurisprudence. It promotes a holistic and multi-dimensional understanding of an older person's life, including their financial security, social connections, housing arrangements and lifestyle factors, in addition to their psychological wellbeing. This facilitates greater considerations of how APP can be tailored to an older adult's individual circumstances, allowing them to plan ahead effectively for the rest of their life.

Empowerment combines the key concepts of meaningful participation, decision-making power and control over your own affairs.[18] This conceptualisation has been well-suited to my research purposes, as I have investigated whether engaging with APP can lead to the empowerment of older adults in regional communities. This investigation also addressed the necessary elements of knowledge and awareness of available APP processes and instruments that can allow older adults to make informed decisions and take control. The preparation of high-quality instruments can ensure this control extends not only over their current circumstances, but also into the future, allowing for completed documents and appointed decision-makers to enact an older person's wishes at a time when they are not able to speak for themselves. However, empowerment is also supported by communication, and it was quite shocking to hear how few of the interviewed older adults had actually talked about their wishes with their family and appointed decision-makers. The absence of this communication undermines the ability of older adults to retain control over future decision-making, and to have their wishes acted upon. Further, the participation of appointed decision-makers and professionals who are included in

[16] Australian Institute of Health and Welfare, *Australia's Welfare 2019: Data Insights* (Australia's Welfare Series No 14. Catalogue No AUS 226, 2019) 2, 7 <https://www.aihw.gov.au/reports/australias-welfare/australias-welfare-2019-data-insights/data>.
[17] Ibid 2.
[18] Kaplan (n 8) 60; Zoë Oxaal and Sally Baden, *Gender and Empowerment: Definitions, Approaches and Implications for Policy* (BRIDGE Report No 40, Institute of Development Studies, January 1997) 7 <https://archive.ids.ac.uk/bridge/bridge-publications/reports/document/A23334.html>; Marilee Karl, 'Obstacles and Opportunities' in *Women and Empowerment: Participation and Decision-Making* (Zed Books Ltd, 1995) 14.

an older adult's support community can also be jeopardised, if they have not been provided the opportunity to take part in meaningful conversations regarding their roles in supporting decision-making in the future.

My research recognises that living in regional and rural areas can have a particular influence on, and frame the experiences of, older people due to geographic and sometimes social isolation, as well as the general decrease in accessibility of services.[19] It is also significant to note that despite potential similarities between regional and rural communities, they are not necessarily homogenous and variations between populations must be considered.[20] Some examples include people who have lived in a community for decades compared to individuals who have only recently relocated to the area, differences in socio-economic circumstances, any reduction in local services, and the potential over-representation of older adults in more rural communities.[21] In my interviews, older people mentioned the closure of local financial institutions, and the lack of continuity of healthcare due to a number of doctors visiting the community in lieu of a permanent healthcare practitioner. Key informants also recognised differences between their practice in regional areas compared with metropolitan contexts; they noted that older adults living in more rural areas have limited options with respect to accessing health and financial services but higher levels of community support.

8.3 Discussion of Research Findings

8.3.1 Vulnerability

When asked about factors that most often prompt older adults to engage in APP, lawyers who completed the online survey indicated that deteriorating health is the most common prompt. This finding is supported by existing research.[22] A decline in health may lead to additional support being required, which may in turn result in a period of heightened dependence, invoking the conception of vulnerability. Similarly, an agreed barrier among lawyers who participated in an interview was that the lack of a trusted person to appoint as a decision-maker

[19] Lisa Bourke et al, 'Understanding Rural and Remote Health: A Framework for Analysis in Australia' (2012) 18(3) *Health & Place* 496; MR McGrail et al, 'The Planning of Rural Health Research: Rurality and Rural Population Issues' (2005) 5(4) *Rural and Remote Health* 426:1–8, 2.
[20] McGrail et al (n 19) 3.
[21] Ibid; Australian Institute of Health and Welfare, *Older Australians* (Catalogue No AGE 87, 28 June 2023) <https://www.aihw.gov.au/reports/older-people/older-australians/contents/about>.
[22] Nola M Ries et al, 'How do Lawyers Assist their Clients with Advance Care Planning? Findings from a Cross-Sectional Survey of Lawyers in Alberta' (2018) 55(3) *Alberta Law Review* 683, 688–689 ('How do Lawyers Assist their Clients with Advance Care Planning?').

may prevent older adults from engaging with APP, which is also echoed in previous studies.[23] This lack of social support should be considered in the context of vulnerability, as it may make any future periods of heightened dependence more difficult to navigate.

Lawyers who responded to the survey agreed that APP mechanisms can be used to exploit older people by enforcing a relationship of control or dependence, thereby increasing a person's vulnerability. This theme of exploitation has been confirmed by other researchers.[24] The potential for exploitation was also raised by legal professionals who took part in an interview, who noted that this is especially concerning when an appointed decision-maker financially abuses an older person through their position as an Enduring Power of Attorney. Only one healthcare professional identified this issue with respect to potential instances of neglect, which falls outside of the focus in my research on APP instruments being used to facilitate abuse. This differing emphasis between professionals can be explained in relation to their different roles. For example, lawyers may speak directly with older adults about their planning wishes when they prepare a Will, allowing them to talk through other planning instruments and appointments that are available. However, doctors are more likely to see older patients further along in the process, when APP directions must be interpreted. This difference can also be explained in relation to each profession's area of focus, with lawyers directing their attention to avoiding problems, including financial abuse, while health professionals may be oriented towards solving the immediate medical issue for an older person and being alert to any indications of physical abuse or neglect.

Given the overt health context in which Advance Care Directives and Enduring Guardian appointments must be interpreted, this could mean fewer opportunities for health professionals to identify potential financial-based abuse. However, during my interviews, the healthcare key informant who discussed elder abuse noted their colleagues would be very aware of concerns relating to neglect or perhaps physical abuse. As such, further opportunities for interprofessional collaboration could help to bridge knowledge gaps for healthcare professionals regarding warning signs of financial abuse. Similarly, by sharing their

[23] Fineman (n 10).

[24] Lixia Qu et al, *National Elder Abuse Prevalence Study* (Final Report, Australian Institute of Family Studies, July 2021) 2 <https://aifs.gov.au/research/research-reports/national-elder-abuse-prevalence-study-final-report>; Nola M Ries, 'Enduring Powers of Attorney and Financial Exploitation of Older People: A Conceptual Analysis and Strategies for Prevention' (2022) 34(3) *Journal of Aging & Social Policy* 357, 360–361; Natalia Wuth, 'Enduring Powers of Attorney: With Limited Remedies – It's Time to Face the Facts' (2013) 7 *Elder Law Review* 1, 9–13.

experiences, those working with older adults in healthcare settings could help to inform their legal practitioner colleagues about any overt concerns that may alert them to neglect or physical abuse. This collaboration may help professionals to develop a holistic perspective of the older person's circumstances, including their key relationships and any potential opportunities for exploitation or abuse. Older adults who participated in an interview also expressed concerns that appointed decision-makers may not act in their best interests in the future, indicating that even where planning has occurred, there are still opportunities for vulnerability. These multifaceted approaches to vulnerability that emerge through my qualitative data enhances understandings of APP, while highlighting additional considerations that warrant further investigation.

8.3.2 Autonomy

Throughout my interviews with older people, talking about planning wishes with family or other members of an older person's support community invoked understanding of both autonomy, being the communication of decisions that are authentic to the person and directed by their own intentions,[25] and relational autonomy,[26] which further recognises the significant role other people can play when supporting older adults to make decisions or implement their completed plans.[27] Adopting this broader view of the concept facilitates a better understanding of the impact that engaging in APP, or choosing not to plan ahead, can have on a person's family, friends, appointed decision-makers, and professionals who may be involved in supporting decision-making or interpreting APP documents in the future. Older adults interviewed in this research considered that engaging in APP would make future choices easier for their family and appointed decision-makers, a theme that is confirmed in the existing literature,[28] and which highlights the significance of relational autonomy. This understanding also invoked the theoretical perspectives of theralaw, which propose that planning ahead can prevent conflicts from arising by better preparing others for potential decision-making roles, and can also give peace of mind to older adults who engage with advance planning.[29] However,

[25] Abrams (n 12); Feinberg (n 12) 30–43.
[26] Yapp et al (n 14) 147.
[27] Gray et al (n 15) 80.
[28] Irfana Musa et al, 'A Survey of Older Peoples' Attitudes towards Advance Care Planning' (2015) 44(3) *Age and Ageing* 371, 374.
[29] Stolle et al (n 5).

this proposition was challenged in my findings, given that so few of the older adults who I interviewed had actually taken the time to discuss their wishes with their friends and family.

The benefit of knowing that an older person's wishes and preferences are recorded was also evident in the findings from my interviews with older adults living in regional communities. Most participants stated they had engaged in APP because they wanted to be prepared for the future, highlighting self-direction in recording their own wishes. Further, this engagement was anticipated to benefit an older person's support community, including family, appointed decision-makers, and professionals who may be called upon to support or enact the person's wishes in future. Relational autonomy is enlivened here, as any plans that have been documented or discussed may help to inform and guide decisions, allowing for greater anticipation and consideration of the future involvement of other people.[30] Again, this was at odds with the experiences of older adults who were interviewed, as their plans had rarely been discussed with those close to them. Key informants who took part in an interview also referenced this concept, emphasising that a lack of discussion between older adults with the people around them, especially family and appointed decision-makers, is a barrier to high quality APP. This echoes findings from previous studies.[31]

Some lawyers who completed the online survey, and who had worked with older adults from First Nations or culturally and linguistically diverse populations, indicated concerns about the potential influence of family or people close to the person in instances where such people tried to insert their own wishes into the planning process. This is distinct from circumstances where a communal or family approach to decision-making has been adopted as a result of cultural preference. This could reveal a lack of understanding on the part of lawyers regarding the importance of relational autonomy to diverse communities, as the recognition of important personal relationships is likely to 'be more acceptable to those from culturally and linguistically diverse communities'[32] who adopt a less singular approach to decision-making.[33] If a family member were to substitute their own wishes for the actual preferences of the older person, such

[30] Jane B Baron, 'Fixed Intentions: Wills, Living Wills, and End-of-Life Decision Making' (2020) 87(2) *Tennessee Law Review* 375, 408–409; Yapp et al (n 14) 147.
[31] Kimberly Buck et al, 'Advance Care Directive Prevalence among Older Australians and Associations with Person-Level Predictors and Quality Indicators' (2021) 24(4) *Health Expectations* 1312; Heather Malcomson and Shannon Bisbee, 'Perspectives of Healthy Elders on Advance Care Planning' (2009) 21(1) *Journal of the American Academy of Nurse Practitioners* 18.
[32] Yapp et al (n 14) 147.
[33] Baron (n 30) 408–409.

action would go against the principles of authenticity and self-directedness that are understood to be present in autonomous decisions.[34]

8.3.3 Wellbeing

Lawyers who completed the online survey considered that older adults are prompted to engage with APP due to health factors and influences from their personal relationships, which are key features of an individual's wellbeing. Recognising the significance of health, personal and social factors highlights the interconnected elements of an individual's wellbeing, which is the foundation of considerations associated with Therapeutic Jurisprudence.[35] Similarly, some older participants also shared their concerns that even if they have engaged in APP, this does not prevent someone from having to make difficult decisions on their behalf in the future, especially with respect to end of life care where circumstances have not been addressed in prepared plans. This new insight emphasises the need for professionals to have continuing regard to the wellbeing of not only the older person who is engaging in APP, but also those in their support community who may be called upon to implement their plans in future.

Concurrently, wellbeing is relevant to barriers identified by lawyers in the survey, such as older adults not feeling ready to engage. This factor may incorporate personal circumstances, social engagement, inaccessibility of relevant services or lack of financial ability to engage in planning, which are all components of my comprehensive conceptualisation of wellbeing.[36] Similar barriers related to a person's wellbeing may be if an older person is experiencing personal conflict, or does not have a trusted person to appoint as a decision-maker.[37] However, engagement in planning may prevent disputes from occurring in the future, a key focus of Preventive Law, which could have the effect of preserving personal relationships and social connections, thus supporting an older person's wellbeing.[38] Interviews with key informants highlighted how a lack of consideration of an older adult's wellbeing by a professional working with that older person can be detrimental to the quality of any prepared APP instruments. If instruments are not personalised according to the older adult's individual circumstances,

[34] Abrams (n 12) 807–808; Feinberg (n 12) 31–32.
[35] Glover (n 2); Wexler, 'From Theory to Practice and Back Again' (n 2).
[36] Australian Institute of Health and Welfare (n 16) 2.
[37] Craig Sinclair et al, 'Professionals' Views and Experiences in Supporting Decision-Making Involvement for People Living with Dementia' (2021) 20(1) *Dementia* 84, 91 ('Professionals' Views and Experiences in Supporting Decision-Making Involvement'); Nadia Moore et al, 'Doctors' Perspectives on Adhering to Advance Care Directives When Making Medical Decisions for Patients: An Australian Interview Study' (2019) 9 *BMJ Open* e032638:1-11, 7.
[38] Australian Institute of Health and Welfare (n 16) 2, 7; Stolle (n 1).

including legal, health, social and personal factors, the ability to successfully implement their wishes in future may be drastically reduced in the event their recorded wishes do not relate to their specific circumstances or prepared plans were never tailored to account for these aspects of their wellbeing.[39]

As explored above, personal connections and family relationships have increased significance for individuals from First Nations and culturally and linguistically diverse communities.[40] The need to provide culturally safe access to services for diverse communities, including discussion of faith, spirituality and historical factors,[41] is also an area that requires further implementation in practice in the context of client wellbeing.

8.3.4 Empowerment

Empowerment was discussed by lawyers who completed the online survey, who noted that speaking with professionals is often a prompt for older adults to engage in APP. This indicates a level of control and meaningful participation, as the person is taking active steps to exercise control over their current and future decision-making power.[42] Older adults who completed an interview also recognised that receiving information relating to planning ahead or attending an education session was a prompt for them to do so, emphasising how the provision of information can lead to individuals exercising control and meaningfully participating in planning for the rest of life. Similarly, the self-identified desire of older adults to prevent future problems from arising represents the key elements of empowerment, as well as explicitly engaging our understanding of Preventive Law.[43]

[39] Buck et al (n 31); Austin Health, 'Improving the Quality and Safety of Advance Care Plans', *Advance Care Planning Australia* (Blog Post, 2021) <https://www.advancecareplanning.org.au/about-us/news-case-studies-and-blog/blog-improving-the-quality-and-safety-of-advance-care-plans>.
[40] Yapp et al (n 14) 147.
[41] Gloria T Anderson, 'Let's Talk about ACP Pilot Study: A Culturally-Responsive Approach to Advance Care Planning Education in African-American Communities' (2021) 17(4) *Journal of Social Work in End-of-Life & Palliative Care* 267; Emma Spencer and Eswaran Waran, 'Opening the Lines of Communication: Towards Shared Decision Making and Improved End-of-life Care in the Top End' (2020) 213(1) *The Medical Journal of Australia* 10; Eswaran Waran, Sharon Wallace and Jonathan Dodson-Jauncey, 'Failing to Plan is Planning to Fail: Advance Care Directives and the Aboriginal People of the Top End' (2017) 206(9) *The Medical Journal of Australia* 377.
[42] Kaplan (n 8); Jan Fook and Christine Morley, 'Empowerment: A Contextual Perspective' in Steven F Hick, Jan Fook and Richard Pozzuto (eds), *Social Work: A Critical Turn* (Thompson Educational Publishing, 2006) 67; Karl (n 18).
[43] Winick (n 1); Stolle et al (n 5); Soili Nysten-Haarala, 'Preventive Law – Some Theoretical and Practical Aspects', *National Center for Preventive Law* (Essay, 2000) <http://www.preventivelawyer.org/main/default.asp?pid=essays/nysten-haarla.htm>.

A deliberate decision not to plan ahead, or a personal belief that planning is not relevant, may also be an example of empowerment if the older person has considered their circumstances, has sufficient information to make an informed choice, and exercised their decision-making power and control over their affairs by choosing not to engage in APP, or recognising that some or all planning mechanisms are not suited to their purposes or interests.[44] As Kaplan explains, the essence of empowerment of older people is ensuring the 'person can exercise maximum control over his or her assets and autonomy',[45] which may include an explicit decision not to engage with APP. This was the case for at least two older adults who participated in an interview, providing a unique insight that challenges existing literature that only promotes the benefits of engaging with APP and does not explore the valid decisions of older adults who chose not to participate in planning ahead based on their own needs and circumstances.

Lawyers who completed the online survey believed a clear advantage of APP for older adults is that their wishes and preferences are known, demonstrating that they are taking control and participating in the process of planning ahead.[46] However, these lawyers also recognised a disadvantage of APP where an older person's engagement is inappropriately influenced by others,[47] which undermines the key elements of control, decision-making power and meaningful participation.[48] This highlights the vital role that lawyers play when assisting older people to engage with APP to ensure instruments guard against vulnerability or abuse, while preserving the wellbeing of clients. This engages the principles of theralaw, seeking to guard against future conflicts,[49] while increasing the positive effects of legal interactions and prioritising the wellbeing of individuals who choose to engage in the process.[50]

When asked about their experiences working with older clients from First Nations or culturally and linguistically diverse populations, lawyers who completed the online survey indicated some clients exhibit a lack of trust in service providers. Interviews with professional key

[44] Kaplan (n 8); Karl (n 18).
[45] Kaplan (n 8) 70.
[46] Buck et al (n 31); Elizabeth Weathers et al, 'Advance Care Planning: A Systematic Review of Randomised Controlled Trials Conducted with Older Adults' (2016) 91 *Maturitas* 101, 102; Karen M Detering et al, 'The Impact of Advance Care Planning on End of Life Care in Elderly Patients: Randomised Controlled Trial' (2010) 340 *BMJ* c1345:1-9, 5 ('The Impact of Advance Care Planning on End of Life Care').
[47] Qu et al (n 24) 2; Ries (n 24) 360–361; Wuth (n 24) 9–13.
[48] Oxaal and Baden (n 18); Karl (n 18).
[49] Winick (n 1); Stolle (n 1); Brown (n 1).
[50] Glover (n 2); Wexler, 'From Theory to Practice and Back Again' (n 2); Dennis P Stolle and David B Wexler, 'Therapeutic Jurisprudence and Preventive Law: A Combined Concentration to Invigorate the Everyday Practice of Law Essays' (1997) 39 *Arizona Law Review* 25.

informants also indicated language difficulties may be a barrier to engagement with APP. Both of these factors have been confirmed by other researchers.[51] These insights may indicate the goal of empowerment is not being achieved, and rather clients from diverse populations may be disempowered in APP processes due to a lack of power, control or meaningful participation.[52] As Oxaal states:

> Empowerment is demonstrated by the quality of people's participation in the decisions and processes affecting their lives. In theory, empowerment and participation should be different sides of the same coin. In practice, much of what passes for popular participation is not in any way empowering to the poorest and most disadvantaged people in society.[53]

This demonstrates further attention needs to be directed towards the quality of the participation of diverse communities when attempting to engage older adults in APP processes.

Older adults who took part in an interview noted their main reason for completing APP was wanting to be prepared, indicating control over their current and future decision-making power, which aligns with extant studies.[54] Interviews with key informants revealed that engagement in high quality APP has a greater chance of achieving the aims of empowerment compared with a 'tick-box' approach where a standard document is prepared with no customisation to the individual circumstances of the older adult. If an older adult has an understanding of the planning mechanisms and processes, has a trusted person to appoint to support future decision-making, starts planning early, adopts a collaborative approach, and engages in ongoing communication, they are more likely to be able to meaningfully participate in APP processes.[55] These insights from key informants further enliven our understanding of an ongoing, communicative and collaborative approach to APP that offers a more holistic perspective of

[51] Craig Sinclair et al, 'Association Between Region of Birth and Advance Care Planning Documentation Among Older Australian Migrant Communities: A Multicenter Audit Study' (2021) 76(1) *The Journals of Gerontology: Series B* 109, 111 ('Association Between Region of Birth and Advance Care Planning Documentation'); Laura Vearrier, 'Failure of the Current Advance Care Planning Paradigm: Advocating for a Communications-Based Approach' (2016) 28(4) *HEC Forum* 339, 347; Karen Detering et al, 'Feasibility and Acceptability of Advance Care Planning in Elderly Italian and Greek Speaking Patients as Compared to English-Speaking Patients: An Australian Cross-Sectional Study' (2015) 5(8) *BMJ Open* e008800:1-7, 4 ('Feasibility and Acceptability of Advance Care Planning in Elderly Italian and Greek Speaking Patients'); D Visala Rao, Jeni Warburton and Helen Bartlett, 'Health and Social Needs of Older Australians from Culturally and Linguistically Diverse Backgrounds: Issues and Implications' (2006) 25(4) *Australasian Journal on Ageing* 174, 175.
[52] Karl (n 18) 14.
[53] Oxaal and Baden (n 18) 7.
[54] Fook and Morley (n 42) 67; Karl (n 18).
[55] Kaplan (n 8); Fook and Morley (n 42).

the lives and priorities of older adults, while taking into account the values of theralaw relating to the prevention of future conflict and preserving wellbeing.[56]

Interviews with key informants revealed that the quality of prepared APP instruments correlates with the extent to which older people are empowered in the process of planning ahead. Professionals indicated that completed plans often contain inconsistent instructions or have not been regularly reviewed, which is consistent with findings from existing literature.[57] This demonstrates how low-quality APP provides little value in the context of future implementation, and disempowers older adults in undermining their decision-making power, control and meaningful participation.[58] This concern was echoed by older adults who participated in an interview, who indicated they were fearful prepared plans may not be enacted in future. Ensuring APP is completed to the highest standard may alleviate some of these concerns. Key informants also shared that confusion over the identity of the authorised decision-maker and family conflict can often override instruments in practice, further indicating how poor-quality planning can undermine the prior steps an older adult has taken in attempting to exercise power and control over future decisions.[59]

8.3.5 Regional and Rural Communities

No significant difference in APP engagement was reported by professionals who had worked in both regional and metropolitan communities. They did identify that older adults in regional and rural areas were often more involved in their local community and able to access more social support, but metropolitan areas generally have more accessible services, especially in the context of healthcare. These findings were also aligned with previous studies.[60]

Some interviewed older adults referred to difficulties accessing health services, especially in communities where there was no full time General Practitioner. The ramifications of a lack of a regular healthcare provider has been recognised within previous studies.[61] Other older adults reported that accessing vital services had become more difficult over time and gave the example that their financial institution had closed their local branch, which is an issue that is gaining

[56] Stolle et al (n 5).
[57] Buck et al (n 31); Baron (n 30); Vearrier (n 51); Friedemann Nauck et al, 'To What Extent are the Wishes of a Signatory Reflected in their Advance Directive: A Qualitative Analysis' (2014) 15 *BMC Medical Ethics* 1.
[58] Oxaal and Baden (n 18); Karl (n 18).
[59] Oxaal and Baden (n 18); Karl (n 18).
[60] Bourke et al (n 19) 498–499; McGrail et al (n 19) 428.
[61] Bourke et al (n 19) 499–500; McGrail et al (n 19) 428.

media attention.[62] Two older adults referenced the concept of 'pension poverty' during their interview, noting how dire their economic circumstances were and that they feared having to pay to replace any of their possessions as they simply did not have the money to do so. Such material circumstances can influence older adults' perceptions of APP, who may believe they do not need to complete instruments such as a Will because they don't have property to leave anyone after their death. This clearly connects with my conceptualisation of wellbeing, taking account of personal and financial circumstances that undermine an older person's ability to live comfortably.

While older people referenced geographic isolation in their interviews, this did not appear to have a negative impact on their planning experiences. One lawyer noted that legal professionals working in regional and rural communities often provide services at low or no cost to better support older adults to engage in planning, which can be very difficult for practitioners to sustain. Another regional lawyer stated that organisations such as the NSW Trustee and Guardian have become very 'Sydney-centric', which makes it more difficult for older adults outside of metropolitan areas to access services relating to appointing future decision-makers or making a Will.[63]

8.4 The Need for Interprofessional Collaboration

While my interviews with key informants revealed some shared perspectives, there is an evident disconnect between legal and medical professions that is preventing best practice for APP. Informants revealed that it is currently unclear whose role it is to raise APP discussions, even among their individual professional groups, which has been recognised in previous studies.[64] It has also been acknowledged that the lack of interprofessional collaboration

[62] Jessica Black, 'Older Australians say they're Being Shut out as Money Moves Digital', *ABC News* (online, 28 February 2024) <https://www.abc.net.au/news/2024-02-29/cheques-personal-finance-banks-rent-money-cash/103354036>.
[63] Bourke et al (n 19); McGrail et al (n 19) 428.
[64] Suet Ying Ng and Eliza Lai-Yi Wong, 'The Role Complexities in Advance Care Planning for End-of-Life Care – Nursing Students' Perception of the Nursing Profession' (2021) 18(12) *International Journal of Environmental Research and Public Health* 6574:1–13; Josie Dixon and Martin Knapp, 'Whose Job? The Staffing of Advance Care Planning Support in Twelve International Healthcare Organizations: A Qualitative Interview Study' (2018) 17(1) *BMC Palliative Care* 78:1–16, 8–10; Sumytra Menon et al, 'Advance Care Planning in a Multicultural Family Centric Community: A Qualitative Study of Health Care Professionals', Patients', and Caregivers' Perspectives' (2018) 56(2) *Journal of Pain and Symptom Management* 213, 218; Ries et al, 'How do Lawyers Assist their Clients with Advance Care Planning?' (n 22) 695.

between these fields clearly disadvantages individuals who wish to complete high quality planning instruments.[65] As Ries et al explain:

> [W]orking within their professional silos, neither doctors nor lawyers are optimally effective in helping their clients with ACP [Advance Care Planning]. Uncertainties about the legal validity of advance directives and the authority of substitute decision-makers are barriers to doctors having ACP conversations with patients. Fears about liability for limiting care at the end of life are a further medico-legal obstacle. Lawyers also face challenges in helping their clients with ACP. A main criticism is that lawyers are too 'transactional', helping clients prepare ACP documents, but not promoting the ongoing communication that is vital to ensuring the client's wishes are known and respected.[66]

Further, individuals may be more likely to speak with a lawyer than their healthcare provider about their wishes for Advance Care Planning.[67] This was once again evident in my findings, given almost all of the older adults who I interviewed had consulted a lawyer when preparing their APP documents, whereas only a few had spoken with a healthcare professional. There is a lack of awareness within each profession of what other fields may contribute to create a holistic approach to APP, as:

> … [c]linicians were generally unaware of the extent to which community lawyers engage in ACP [Advance Care Planning] with clients, while lawyers were often surprised to learn that advance directives are considered just one, but not the ultimate, piece of information relevant to clinical decision-making at the bedside.[68]

[65] Grace W Orsatti, 'Attorneys as Healthcare Advocates: The Argument for Attorney-Prepared Advance Healthcare Directives' (2022) 50(1) *Journal of Law, Medicine & Ethics* 157, 158; Amy Waller et al, 'Increasing Advance Personal Planning: The Need for Action at the Community Level' (2018) 18(1) *BMC Public Health* 606:1–8; Nola M Ries et al, 'Doctors, Lawyers and Advance Care Planning: Time for Innovation to Work Together to Meet Client Needs' (2016) 12(2) *Healthcare Policy* 12 ('Doctors, Lawyers and Advance Care Planning'); Sarah Russell, 'Advance Care Planning: Whose Agenda is it Anyway?' (2014) 28(8) *Palliative Medicine* 997, 998.

[66] Ries et al, 'Doctors, Lawyers and Advance Care Planning' (n 65) 14. See also Waller et al (n 65); Ries et al, 'How do Lawyers Assist their Clients with Advance Care Planning?' (n 22) 695.

[67] Orsatti (n 65) 158; Sarah Hooper, Charles P Sabatino and Rebecca L Sudore, 'Improving Medical-Legal Advance Care Planning' (2020) 60(2) *Journal of Pain and Symptom Management* 487; Joshua A Rolnick et al, 'Patients' Perspectives on Approaches to Facilitate Completion of Advance Directives' (2019) 36(6) *American Journal of Hospice & Palliative Medicine* 526, 528–529; Ries et al, 'Doctors, Lawyers and Advance Care Planning' (n 65) 14; Vearrier (n 51) 348; Nauck et al (n 57) 3, 7.

[68] Hooper, Sabatino and Sudore (n 67) 492–493. See also Ben P White, Lindy Willmott and Eliana Close, 'Better Regulation of End-Of-Life Care: A Call For A Holistic Approach' (2022) 19 *Journal of Bioethical Inquiry* 683.

Further, clinicians consider Advance Care Planning to be their responsibility, while lawyers perceive any advance planning to be a legal exercise,[69] given that it involves acting on legal rights and preparing legal documents. Similarly, both professions take a distinct approach to APP, with lawyers considering it part of the estate planning process, while healthcare professionals are more focused on Advance Care Planning and accessibility of an individual's APP documents to determine their wishes and treatment preferences during a period of incapacity.[70]

Similarly, the lack of collaboration between professions could be fuelling a fear of litigation, as healthcare professionals are concerned about legal ramifications that may arise if 'innovative' approaches to APP are not successful, such as using less legalese within planning documents,[71] or acting against an older person's expressed wishes in their planning instruments.[72] However, this fear of litigation was not evident in my research, despite several key informant professionals offering frank admissions that expressed wishes are often disregarded in clinical settings. The impact of financial and structural differences between legal and health contexts are also significant, as socio-economic differences between clients and/or patients may affect their ability to engage, and maintain an ongoing relationship with, professional advisors.[73] Fragmentation within the healthcare system and a lack of continuity of care is also a significant difference when compared to legal environments,[74] where it is more

[69] Hooper, Sabatino and Sudore (n 67) 492–493.
[70] Ibid 493. See also Rolnick et al (n 67) 528–529.
[71] Hooper, Sabatino and Sudore (n 67) 494; Vearrier (n 51) 344; Joel J Rhee, Nicholas A Zwar and Lynn A Kemp, 'Why are Advance Care Planning Decisions Not Implemented? Insights from Interviews with Australian General Practitioners' (2013) 16(10) *Journal of Palliative Medicine* 1197, 1201; Louise Robinson et al, 'A Qualitative Study: Professionals' Experiences of Advance Care Planning in Dementia and Palliative Care, "A Good Idea in Theory but …"' (2013) 27(5) *Palliative Medicine* 401, 404.
[72] Robinson et al (n 71) 404.
[73] Julie L Masters, Lindsey E Wylie and Sarah B Hubner, 'End-of-Life Planning: Normalizing the Process' (2022) 34(4) *Journal of Aging & Social Policy* 641, 643; Sarah Nouri et al, 'Evaluation of Neighborhood Socioeconomic Characteristics and Advance Care Planning Among Older Adults' (2020) 3(12) *JAMA Network Open* e2029063:1-12, 9; Australian Healthcare Associates, *Exploratory Analysis of Barriers to Palliative Care* (Issues Report on Aboriginal and Torres Strait Islander Peoples, Department of Health, September 2019) 1 <https://www.health.gov.au/resources/publications/exploratory-analysis-of-barriers-to-palliative-care-issues-report-on-aboriginal-and-torres-strait-islander-peoples?language=en>; Karly B Smith, John S Humphreys and Murray GA Wilson, 'Addressing the Health Disadvantage of Rural Populations: How does Epidemiological Evidence Inform Rural Health Policies and Research?' (2008) 16(2) *Australian Journal of Rural Health* 56, 59.
[74] Orsatti (n 65) 158–159; Helen Close et al, 'Qualitative Investigation of Patient and Carer Experiences of Everyday Legal Needs towards End of Life' (2021) 20 *BMC Palliative Care* 47:1–13, 2; Hui Yun Chan, 'Video Advance Directives: A Turning Point for Advance Decision-Making? A Consideration of Their Roles and Implications for Law and Practice' (2020) 41 *Liverpool Law Review* 1, 8; Hillary D Lum, Rebecca L Sudore and David B Bekelman, 'Advance Care Planning in the Elderly' (2015) 99(2) *Medical Clinics of North America* 391, 399; Kritika Samsi and Jill Manthorpe, '"I Live for Today": A Qualitative Study Investigating Older People's Attitudes to Advance Planning' (2011) 19(1) *Health & Social Care in the Community* 52, 57.

likely that one professional assists a client for the duration of any APP processes.[75] While the benefits of interprofessional collaboration have been recognised across both fields,[76] Ries et al have offered a clear framework for how this association can actually be realised between legal and health practitioners: the use of common best practices to help their clients/patients; attendance and cooperation at combined professional development events; collaboration in community clinics that address Advance Care Planning; and medical-legal partnerships facilitating the integration of lawyers into healthcare settings and teams.[77]

8.5 Integration into Usual Care: A Routine Approach

Reframing APP as a routine, communicative, ongoing and interprofessional exercise between an individual and their friends, family and trusted decision-makers is a vital step in shifting our understanding of APP as a regular part of medical and legal practice.[78] For example, if patients raise their financial circumstances during a consultation with a health professional, this could lead to vital discussion about the significance of appointing an Enduring Power of Attorney and seeking legal advice to do so. If the same patient then visits a lawyer to formalise the appointment, the lawyer may suggest consultation with a financial planner to detail a complete picture of the client's assets and property and a plan for their future management. Similarly, lawyers may be asked questions relating to their client's health preferences to be included in forms of Advance Care Planning, which they are not fully equipped to answer. This should then lead to the involvement of the client's healthcare provider to better understand their personal

[75] Orsatti (n 65) 158–159; Hooper, Sabatino and Sudore (n 67) 494.

[76] Orsatti (n 65) 163–164; Hooper, Sabatino and Sudore (n 67) 494; Rolnick et al (n 67); Ries et al, 'How do Lawyers Assist their Clients with Advance Care Planning?' (n 22) 695; Russell (n 67) 998; Susan W Tolle and Virginia P Tilden, 'Changing End-of-Life Planning: The Oregon Experience' (2002) 5(2) *Journal of Palliative Medicine* 311, 316.

[77] Ries et al, 'Doctors, Lawyers and Advance Care Planning' (n 67) 15–17.

[78] Buck et al (n 31) 1323; Karen M Detering et al, 'Prevalence of Advance Care Planning Documentation and Self-Reported Uptake in Older Australians with a Cancer Diagnosis' (2021) 12(2) *Journal of Geriatric Oncology* 274, 274 ('Prevalence of Advance Care Planning Documentation and Self-Reported Uptake'); Masters, Wylie and Hubner (n 73) 655; Canadian Hospice Palliative Care Association, *Advance Care Planning in Canada: A Pan-Canadian Framework* (Report, January 2020) 2 <https://www.advancecareplanning.ca/wp-content/uploads/2020/06/ACP-Framework-EN-Updated.pdf>; Stephanie B Johnson et al, 'Patient Autonomy and Advance Care Planning: A Qualitative Study of Oncologist and Palliative Care Physicians' Perspectives' (2018) 26(2) *Supportive Care in Cancer* 565, 566; Ina Carola Otte et al, 'The Utility of Standardized Advance Directives: The General Practitioners' Perspective' (2016) 19(2) *Medicine, Health Care and Philosophy* 199, 200; Ian A Scott et al, 'Difficult but Necessary Conversations – The Case for Advance Care Planning' (2013) 199(10) *The Medical Journal of Australia* 662, 663–664; Tim Sharp et al, 'Do the Elderly Have a Voice? Advance Care Planning Discussions with Frail and Older Individuals: A Systematic Literature Review and Narrative Synthesis' (2013) 63(615) *British Journal of General Practice* e657, e659–e660; Deborah P Waldrop and Mary Ann Meeker, 'Communication and Advanced Care Planning in Palliative and End-of-Life Care' (2012) 60(6) *Nursing Outlook* 365, 368.

circumstances, care needs and how their wellbeing can be best preserved. As such, each step of the interprofessional collaboration within the APP process is guided by, and responding to, the specific needs and circumstances of the older person. This notion that it is everyone's responsibility was raised during my interviews with professional key informants.

Carter et al acknowledge that Advance Care Planning is 'increasingly being integrated into usual care for specific populations, including those with chronic disease, dementia, advanced age and frailty, and residents of aged care facilities'.[79] However, rates of uptake are still variable, even for people with life-limiting illnesses.[80] This increased integration is clearly associated with a paternalistic view of vulnerability, assuming that people with life-limiting illnesses will automatically require support from a decision-maker, rather than the conceptualisation of vulnerability as episodic periods of heightened dependency.[81] Further, it does not account for a specific key barrier that is preventing widespread integration, perceived by both older adults and healthcare professionals, which is uncertainty surrounding the law.[82] While it is important to support individuals to complete forms of Advance Care Planning and APP that can help protect their wishes and preferences in future as part of routine health and legal care, it is vital that they are given clear and accurate information, and sufficient time to make informed and valid decisions regarding their best interests.[83] Older people should be provided with the opportunity to take control of their own planning, and to fully participate in the process, while being guided by relevant professionals and their respective expertise.

8.6 Shifting Perspectives

Reframing the understanding of APP as planning for the rest of life, rather than end of life, may help to remove some of the barriers that are preventing the realisation of the benefits of APP.

[79] Rachel Z Carter et al, 'Advance Care Planning in Australia: What does the Law Say?' (2016) 40(4) *Australian Health Review* 405, 405. See also Moore et al (n 37) 10; Samsi and Manthorpe (n 74) 53.
[80] Joel J Rhee, Nicholas A Zwar and Lynn A Kemp, 'Uptake and Implementation of Advance Care Planning in Australia: Findings of Key Informant Interviews' (2012) 36(1) *Australian Health Review* 98.
[81] Martha Albertson Fineman, 'The Vulnerable Subject: Anchoring Equality in the Human Condition' (2008) 20(1) *Yale Journal of Law and Feminism* 1.
[82] John Chesterman and Lois Bedson, *Decision Time: Activating the Rights of Adults with Cognitive Disability* (Report, Office of the Public Advocate, 15 February 2021) 98 <https://apo.org.au/node/314188>; Ng and Wong (n 64); Dixon and Knapp (n 64) 86–88; Ries et al, 'How do Lawyers Assist their Clients with Advance Care Planning?' (n 22) 695; Carter et al (n 79) 405; Vearrier (n 51) 344; Robinson et al (n 71) 404.
[83] Waller et al (n 65) 2; Sarah Jeong et al, '"Planning Ahead" among Community-Dwelling Older People from Culturally and Linguistically Diverse Background: A Cross-Sectional Survey' (2015) 24 *Journal of Clinical Nursing* 244, 249; Adam D Schickedanz et al, 'A Clinical Framework for Improving the Advance Care Planning Process: Start with Patients' Self-Identified Barriers' (2009) 57(1) *Journal of the American Geriatrics Society* 31, 35.

The barriers that professionals and older people nominated in in this study are confirmed in the existing literature and include a reluctance to start conversations that concern the end of life,[84] a lack of recorded wishes with respect to healthcare,[85] and the absence of high-quality instruments that can prevent financial abuse.[86]

This shift in perspective also encourages an understanding that a person's preferences for the care they wish to receive, or how they would like their finances to be managed, may change over time and plans can be updated accordingly to reflect this.[87] Thus, individualised goals are not only prioritised, but can actually be realised in the future,[88] which fulfils the principles of theralaw. By shifting attention from the end of life to the rest of life, the focus of APP is broadened to consider ramifications of periods of incapacity rather than only death. These considerations may include 'the preparation of patients and surrogates for meaningful communication about values and goals for medical care',[89] or better preparing appointed decision-makers to both understand their role and feel supported when fulfilling their duties.[90]

[84] Anderson (n 41) 267–268; Frances Batchelor et al, 'Facilitators and Barriers to Advance Care Planning Implementation in Australian Aged Care Settings: A Systematic Review and Thematic Analysis' (2019) 38(3) *Australasian Journal on Ageing* 173, 176; Moore et al (n 37) 9; Pascoe Pleasence, Nigel J Balmer and Catrina Denvir, 'Why do I Need a Will Anyway? Assessing the Impact of a Public Legal Education Intervention Embedded in a Longitudinal Survey' (2019) 18(2) *Social Policy and Society* 187, 189; Yapp et al (n 14) 135–136; Nola M Ries, Briony Johnston and Shaun McCarthy, 'Legal Education and the Ageing Population: Building Student Knowledge and Skills through Experiential Learning in Collaboration with Community Organisations' (2016) 37 *Adelaide Law Review* 495, 500.

[85] Buck et al (n 31) 1312; Craig Sinclair et al, 'Advance Care Planning in Australia during the COVID-19 Outbreak: Now More Important than Ever' (2020) 50(8) *Internal Medicine Journal* 918, 919; Siobhan Calafiore, 'Advance Care Directives Frequently Written by Someone Other than the Patient', *Australian Doctor Group* (online, 27 December 2019) <https://www.ausdoc.com.au/news/advance-care-directives-frequently-written-someone-other-patient/>; Rolnick et al (n 67) 528–529; Jeong et al (n 83) 249; Billingsley Kaambwa et al, 'Costs and Advance Directives at the End of Life: A Case of the "Coaching Older Adults and Carers to Have Their Preferences Heard (COACH)" Trial' (2015) 15 *BMC Health Services Research* 545:1–12, 5–7; Ben White et al, 'Prevalence and Predictors of Advance Directives in Australia' (2014) 44(10) *Internal Medicine Journal* 975, 976–979.

[86] Ries (n 24) 363–367; Rodney Lewis, 'Addressing Elder Abuse in Australia: The Case for an Elder Justice Law' (2018) 148 *Precedent* 41, 41; Wuth (n 24) 1; Ellison et al (n 84) 310–312.

[87] Orsatti (n 65) 160; Julien Tran et al, 'Systematic Review and Content Analysis of Australian Health Care Substitute Decision Making Online Resources' (2021) 45(3) *Australian Health Review* 317; Australian Digital Health Agency, *National Guidelines: Using My Health Record to Store and Access Advance Care Planning and Goals of Care Documents* (Guidelines, March 2021) 42 <https://www.digitalhealth.gov.au/healthcare-providers/advance-care-planning>; R Sean Morrison, 'Advance Directives/Care Planning: Clear, Simple, and Wrong' (2020) 23(7) *Journal of Palliative Medicine* 878, 878.

[88] Orsatti (n 65) 157; Buck et al (n 31) 1323; Detering et al, 'Prevalence of Advance Care Planning Documentation and Self-Reported Uptake' (n 78); Masters, Wylie and Hubner (n 73); Helena Rodi et al, 'Exploring Advance Care Planning Awareness, Experiences, and Preferences of People with Cancer and Support People: An Australian Online Cross-Sectional Study' (2021) 29(7) *Supportive Care in Cancer* 3677; Marcus Sellars et al, 'Personal and Interpersonal Factors and their Associations with Advance Care Planning Documentation: A Cross-Sectional Survey of Older Adults in Australia' (2020) 59(6) *Journal of Pain and Symptom Management* 1212.

[89] Hooper, Sabatino and Sudore (n 67) 489.

[90] Orsatti (n 65) 157–160; Sonja McIlfatrick et al, '"It's Almost Superstition: If I Don't Think about It, It Won't Happen". Public Knowledge and Attitudes towards Advance Care Planning: A Sequential Mixed Methods Study'

With respect to the importance of financial planning for the rest of life, it is vital that individuals understand that a decision-maker who is appointed as an Enduring Power of Attorney can act on an individual's behalf immediately, unless the appointment specifies otherwise, and continue doing so even if the person goes on to experience a period of incapacity.[91] The longevity of this role may help to ensure individuals are able to continue living a quality life for the rest of their life, as support can commence straight away, rather than waiting until a person cannot make decisions for themselves or is nearing the end of life.

As stated by the Australian Government Department of Health, this shift in focus from end of life to planning for future care, which may involve periods where individuals 'are unable to make informed decisions for themselves in the moment, such as during chronic illness, a sudden injury, cognitive decline, periods of acute mental illnesses or other times when their competency levels are fluctuating',[92] is a more normalised and less intimidating approach. The background paper on Advance Care Planning in Australia prepared for the recent Royal Commission into Aged Care Quality and Safety[93] has brilliantly described this changing focus:

> Conversations around end-of-life issues can be confronting, and issues outside of medical care can be even more important for some people (for example, where a person will live if their condition deteriorates). Discussing how a person wants to live, not how they want to die, can make the conversation easier. Instead of narrowly focusing on medical interventions, it may be better to have a broader conversation about a person's values and what is important to them in life. An appropriate person to initiate and facilitate the conversation also seems to be important. Ideally, advance care planning is a flexible, iterative and ongoing discussion involving regular review. It is important for family to be involved in advance care planning discussion, but … this should not be to the detriment of the participation of the focal person.[94]

(2021) 35(7) *Palliative Medicine* 1356, 1356; Tran et al (n 87); Marcus Sellars et al, 'Public Knowledge, Preferences and Experiences about Medical Substitute Decision-Making: A National Cross-Sectional Survey' [2021] *BMJ Supportive & Palliative Care* (advance):1-21; Batchelor et al (n 84) 173; Moore et al (n 37) 10; Ries (n 24); Detering et al, 'The Impact of Advance Care Planning on End of Life Care' (n 46) 4–5.

[91] Chesterman and Bedson (n 82) 104.

[92] Department of Health, *National Framework for Advance Care Planning Documents* (Report, May 2021) 6 <https://www.health.gov.au/resources/publications/national-framework-for-advance-care-planning-documents?language=en>.

[93] Royal Commission into Aged Care Quality and Safety, *Advance Care Planning in Australia* (Background Paper 5, Commonwealth of Australia, 2019) <https://agedcare.royalcommission.gov.au/publications/Documents/background-paper-5.pdf>.

[94] Ibid 8.

Burt et al encourage the use of a three-dimensional typology with respect to planning, which includes perspective, scope and network.[95] These elements support a holistic perspective of planning that can be applied at any stage of life, not only for end of life care. 'Perspective' should include both individual and professional viewpoints,[96] working in collaboration to achieve the best possible result for recording wishes, preferences and goals for both healthcare and financial matters.[97] While a focus on the rest of life inevitably directs attention towards healthcare and medical decision-making, individuals are more likely to engage with forms of Advance Care Planning and APP with lawyers, or their spouses or children, rather than healthcare practitioners.[98] In their qualitative study of end of life planning for community dwelling older adults aged 65 and over, Kahana et al found that almost three quarters of the physicians of the adults who had made an Advance Care Directive were not aware of their recorded end of life wishes.[99] By working together, professionals can produce a result that is best for the individual client/patient. While lawyers have detailed knowledge of the law and how it operates within the context of APP, healthcare professionals can correctly interpret medical language within documents, and can discuss treatment options and care preferences with individuals to ensure their preferences are desired but also achievable in the circumstances of their condition.[100]

'Scope' should acknowledge not only individual behaviours, but also their personal and financial goals and values,[101] which are subject to change throughout an individual's life.

[95] Jenni Burt et al, 'Care Plans and Care Planning in Long-Term Conditions: A Conceptual Model' (2014) 15(4) *Primary Health Care Research & Development* 342, 346.
[96] Ibid.
[97] Orsatti (n 65) 164; Meredith Blake, Olivia Nicole Doray and Craig Sinclair, 'Advance Care Planning for People with Dementia in Western Australia: An Examination of the Fit Between the Law and Practice' (2018) 25(2) *Psychiatry, Psychology and Law* 197, 210–211; Daren Heyland, 'How can We get Lawyers to Change the Way they do Advance Medical Care Planning with their Clients? A Physician's Reflections', *Slaw* (Blog Post, 25 September 2019) <http://www.slaw.ca/2019/09/25/how-can-we-get-lawyers-to-change-the-way-they-do-advance-medical-care-planning-with-their-clients-a-physicians-reflections/>; Rolnick et al (n 67); Ries et al, 'How do Lawyers Assist their Clients with Advance Care Planning?' (n 22) 695.
[98] Masters, Wylie and Hubner (n 73) 649–650; Hooper, Sabatino and Sudore (n 67) 489; Rolnick et al (n 67) 528–529; Otte et al (n 78) 204; Vearrier (n 51) 348; Nauck et al (n 57) 55, 59.
[99] Kahana et al (n 98) 1166. See also Amy Waller et al, 'Are Older and Seriously Ill Inpatients Planning Ahead for Future Medical Care?' (2019) 19 *BMC Geriatrics* 212:1–8, 5–6; Vearrier (n 51) 348.
[100] Meredith Blake, 'Protecting Older Persons from Life-Threatening and Fatal Abuse: Should Western Australian Criminal Law Do More?' (2019) 45(2) *University of Western Australia Law Review* 195, 210; Heyland (n 97); Yapp et al (n 14) 136; Ian J Hamilton, 'Advance Care Planning in General Practice: Promoting Patient Autonomy and Shared Decision Making' (2017) 67(656) *British Journal of General Practice* 104, 104; Susi Lund, Alison Richardson and Carl May, 'Barriers to Advance Care Planning at the End of Life: An Explanatory Systematic Review of Implementation Studies' (2015) 10(2) *PLOS ONE* e0116629:1-15, 2.
[101] Orsatti (n 65) 157–160; Buck et al (n 31) 1318; Batchelor et al (n 84) 176; Yapp et al (n 14) 140–147; Burt et al (n 95) 346; Malcomson and Bisbee (n 31).

Finally, a person's 'network' must be acknowledged, including the individual themselves, any professionals involved, and other members of an individual's community, including family, friends and appointed decision-makers.[102] Adopting this typology allows for greater recognition of the various factors that contribute to an individual's wellbeing, including psychosocial and socio-demographic issues.[103] It promotes self-management,[104] which is a key component of autonomy,[105] and encourages further attention to any vulnerability a person may be experiencing at that point in time, ultimately allowing for greater participation and control over the planning process by an individual,[106] leading to empowerment.

8.7 The Significance of Reframing Advance Personal Planning for Older Adults

Integrating APP as part of usual health and legal care is especially relevant for older adults. Kahana et al describe this approach as the 'proactivity model of successful aging'.[107] This model specifies consideration of: the context in which an individual lives, including their demographics; stressors that may be operating, such as chronic illness; behavioural adaptations, including preventively planning ahead; resources that an individual may possess, including financial circumstances, social supports and personal characteristics; and ultimately, the impact these factors may have on an individual's quality of life.[108] These influences are clearly linked

[102] Department of Health (n 92) 19; Sinclair et al, 'Professionals' Views and Experiences in Supporting Decision-Making Involvement' (n 37) 85; Royal Commission into Aged Care Quality and Safety (n 93) 8; Waller et al (n 99) 5–6; Tony Ryan, Karwan M Amen and Jane McKeown, 'The Advance Care Planning Experiences of People with Dementia, Family Caregivers and Professionals: A Synthesis of the Qualitative Literature' (2017) 6(4) *Annals of Palliative Medicine* 380, 386; Burt et al (n 95) 346; Hickman (n 84) 258–259.

[103] Laura I van Dyck et al, 'Understanding the Role of Knowledge in Advance Care Planning Engagement' (2021) 62(4) *Journal of Pain and Symptom Management* 778, 783; Sinclair et al, 'Association Between Region of Birth and Advance Care Planning Documentation' (n 51) 111; Nouri et al (n 73) 2; Australian Healthcare Associates (n 73) 1; Vearrier (n 51) 347; Detering et al, 'Feasibility and Acceptability of Advance Care Planning in Elderly Italian and Greek Speaking Patients' (n 51) 4; Burt et al (n 95) 349; Smith, Humphreys and Wilson (n 73) 59; Rao, Warburton and Bartlett (n 51) 175.

[104] Royal Commission into Aged Care Quality and Safety (n 93) 1; Burt et al (n 95) 350; Jenny Newbould et al, 'Experiences of Care Planning in England: Interviews with Patients with Long Term Conditions' (2012) 13 *BMC Family Practice* 71:1–9, 2.

[105] Close et al (n 74) 2; Kerstin Knight, '50 Years of Advance Care Planning: What do we Call Success?' (2021) 39(1) *Monash Bioethics Review* 28; Sinclair et al, 'Association Between Region of Birth and Advance Care Planning Documentation' (n 52) 117–118; C Haining, L Nolte and KM Detering, *Australian Advance Care Planning Laws: Can we Improve Consistency?* (Report, Advance Care Planning Australia, Austin Health, 2019) 4; Moore et al (n 38) 1–2; Royal Commission into Aged Care Quality and Safety (n 93) 1.

[106] Maria T Carney et al, 'Impact of a Community Health Conversation upon Advance Care Planning Attitudes and Preparation Intentions' (2021) 42(1) *Gerontology & Geriatrics Education* 82, 84–87; Yapp et al (n 14) 138–139; Vearrier (n 51) 340.

[107] Eva Kahana, Boaz Kahana and Jeong Eun Lee, 'Proactive Approaches to Successful Aging: One Clear Path through the Forest.' (2014) 60(5) *Gerontology* 466, 468.

[108] Ibid 467.

to the overarching principles of theralaw and my conceptualisation of wellbeing, which includes supportive social relationships and ease of access to health services, financial institutions, and legal advice.[109] These are vital factors that should be considered throughout an individual's entire life, not simply at the end of their life. Stressors, both cumulative and recent, account for challenges that may be experienced by individuals as they age.[110] Quality of life outcomes encourage consideration of an individual's wellbeing, as understood in line with Therapeutic Jurisprudence – personal, social, legal and financial factors included – as well as psychological wellbeing and life satisfaction.[111] Proactive behavioural adaptations are clearly aligned with Preventive Law, as 'planning for the future in late life' is considered a preventive adaptation.[112]

Kahana et al's conceptualisation of preventive adaptations clearly encompasses planning for the rest of life, not the end of life. They prompt older individuals to not only anticipate future healthcare and supports that may be needed, but also proactively take 'forward-looking action that may be in anticipation of new activities, social engagements or environmental options', which has been shown to 'diminish the adverse effects of chronic illness and social losses on the psychological wellbeing of older adults'.[113] This is how planning for the rest of life should be framed; it should not be merely concerned with financial management and future preferences for treatment, but should consider personal activities, social engagements and ultimately, the preservation of wellbeing.[114] These forms of proactive planning have positive affects for ageing individuals when considering how they wish to live the rest of their lives, not merely how they wish to shape the end of their life.[115] These plans can extend to where a person will reside, how they will pay for their home and how they ultimately wish to continue

[109] Australian Institute of Health and Welfare (n 16) 2.
[110] Jamie Bryant et al, 'Advance Care Planning Participation by People with Dementia: A Cross-Sectional Survey and Medical Record Audit' (2022) 12 *BMJ Supportive & Palliative Care* e464; Sinclair et al, 'Professionals' Views and Experiences in Supporting Decision-Making Involvement' (n 37) 85; Amanda Pereira-Salgado, Patrick Mader and Leanne M Boyd, 'Advance Care Planning, Culture and Religion: An Environmental Scan of Australian-Based Online Resources' (2018) 42(2) *Australian Health Review* 152, 160; Paul A Gardiner et al, 'Financial Capacity in Older Adults: A Growing Concern for Clinicians' (2015) 202(2) *The Medical Journal of Australia* 82, 84–85; Jeong et al (n 83); Kahana, Kahana and Lee (n 107) 468; Rao, Warburton and Bartlett (n 51) 177.
[111] Kahana, Kahana and Lee (n 107) 469.
[112] Ibid 471.
[113] Ibid.
[114] Ibid 470–471.
[115] Bryant et al (n 110); Eva Kahana, Jessica Kelley-Moore and Boaz Kahana, 'Proactive Aging: A Longitudinal Study of Stress, Resources, Agency, and Well-Being in Late Life' (2012) 16(4) *Aging & Mental Health* 438, 440.

living.[116] Such preventative steps help to encourage a more holistic view of an individual's life as they age, rather than focusing only on their final years.[117] This planning has also been shown to improve quality of life, with benefit 'derived from making positive, forward-looking discretionary plans for the future'.[118] This ensures older individuals are empowered to exercise maximum control over the rest of their life, upholding their autonomy and ability to self-manage their affairs.[119]

8.8 Conclusion

The findings from my research reveal new insights from the perspective of older adults, lawyers and key informant professionals. Adopting this holistic examination of APP processes has affirmed points from the existing literature, while also filling gaps within the evidence base. The conceptualisation of key terms from a perspective of theralaw within the field of Elder Law has produced a greater understanding of how APP can be used to uphold an older person's wellbeing, safeguard their autonomy, protect against vulnerability, and ultimately realise empowerment through meaningful participation, power and control. This discussion has also revealed the need for, and benefits of, increased interprofessional collaboration, and integrating APP within usual practice for legal and healthcare professionals.

Ultimately, there needs to be a shift in focus from planning for the end of life to the rest of life. While understanding APP as planning for the rest of life has clear links to both Preventive Law and Therapeutic Jurisprudence, through its proactive focus and concern with wellbeing, respectively, we must acknowledge the overarching context of Elder Law. As the focus of Elder Law is client-centric,[120] it is vital to understand, respect and uphold the wishes and foreground the voice of older adults at every stage of APP.[121] We must acknowledge not only how the law impacts individuals as they age,[122] such as through estate planning, but also how the law can play a more effective role in their experiences throughout the rest of life. This could include

[116] Sandra Timmermann, 'Planning for the Rest of Your Life: A New Perspective' (2001) 55(2) *Journal of Financial Service Professionals* 28, 28.
[117] Kahana, Kelley-Moore and Kahana (n 115).
[118] Ibid 448.
[119] Close et al (n 74) 2; Sinclair et al, 'Association Between Region of Birth and Advance Care Planning Documentation' (n 51) 117–118; Moore et al (n 37) 1–2; Yapp et al (n 14) 138–140; Kaplan (n 8) 70.
[120] Kaplan (n 8).
[121] Israel Doron, '25 Years of Elder Law: An Integrative and Historical Account of the Field of Law and Aging' (2019) 21(1) *Theoretical Inquiries in Law* 1; Bogutz (n 3).
[122] Nina A Kohn, 'A Framework for Theoretical Inquiry into Law and Aging' (2019) 21(1) *Theoretical Inquiries in Law* 187.

undertaking regular legal check-ups[123] and being on the lookout for ongoing legal and psycholegal soft spots,[124] instead of approaching forms of planning as one-off experiences. In the next and final chapter, this understanding of APP, through the lens of theralaw, will inform recommendations for improvements to existing APP process. Final conclusions will be offered, including areas for future research.

[123] Winick (n 1); Stolle et al (n 5); David B Wexler, 'Beyond Analogy: Preventive Law as Preventive Medicine', *National Center for Preventive Law* (Essay, 2000) <http://www.preventivelawyer.org/main/default.asp?pid=essays/wexler.htm> ('*Beyond Analogy*').
[124] Winick (n 1); Wexler, 'Beyond Analogy' (n 123).

9 RECOMMENDATIONS AND CONCLUSIONS

9.1 INTRODUCTION

My research has produced original insights, utilising a unique combined cohort approach, to understand older adults', lawyers' and key informant professionals' perspectives of, and experiences with, APP, with a particular focus on rural and regional areas. Barriers have been examined at three distinct stages: barriers to engaging with APP; barriers concerning factors affecting the quality of completed APP documents; and barriers to future use or implementation. Findings have been analysed thematically, with points of convergence and divergence highlighted within and across participant groups. This study has filled a previous gap in the existing literature, offering an alternative approach to the traditional, siloed perspective that has insisted on maintaining the divide between legal and health professionals. Further, integrating the perspectives of older adults within the discussion of professional viewpoints has allowed for a holistic, multifaceted examination of APP processes, leading to a thorough understanding of existing barriers.

As highlighted in the previous chapter, my findings have revealed a clear need for increased interprofessional collaboration, the integration of APP within routine practice, and reframing APP as planning for the rest of life, not simply the end of life. These key discussion points inform the following recommendations, at individual, professional, and structural levels. Finally, the limitations of my study will be addressed, along with areas for future research that can expand upon my initial findings and conclusions.

9.2 Recommendations for Improvement of APP Processes

Key themes that emerged from the qualitative analysis of my interviews that relate to opportunities for improvement centre on education, shifting attitudes, interprofessional collaboration, technological improvements and legislative reform. These will be examined in the following section, according to recommendations at the micro, meso and macro levels for individuals, professions and society, respectively.

9.2.1 Micro Level Recommendations for Older People and Professionals

9.2.1.1 Increased communication

Across my interviews with older adults, lawyers and professional key informants, the importance of communication consistently arose in connection with improving the quality of prepared APP instruments and the ability to use them effectively in future. By encouraging increased communication with members of their support community, including family members, appointed decision-makers and relevant professionals, older adults can feel more confident that their wishes for the future are known, understood and can be successfully implemented.[1] Further, speaking with healthcare professionals, especially for older adults living with a particular condition or chronic illness, can provide a clearer understanding of the disease trajectory, and can ensure recorded wishes are appropriate and able to be followed in future.[2] This form of communication should also be encouraged by lawyers who are involved in preparing healthcare instruments, ensuring any wishes with respect to future care or management are realistic in the context of particular diagnoses, allowing an older person's expectations to be discussed effectively.[3] Engaging legal professionals in the preparation of APP instruments, and talking through the various mechanisms that are available when planning

[1] Department of Health, *National Framework for Advance Care Planning Documents* (Report, May 2021) 19 <https://www.health.gov.au/resources/publications/national-framework-for-advance-care-planning-documents?language=en>; Helena Rodi et al, 'Exploring Advance Care Planning Awareness, Experiences, and Preferences of People with Cancer and Support People: An Australian Online Cross-Sectional Study' (2021) 29(7) *Supportive Care in Cancer* 3677, 3677; Jane B Baron, 'Fixed Intentions: Wills, Living Wills, and End-of-Life Decision Making' (2020) 87(2) *Tennessee Law Review* 375; Nadia Moore et al, 'Doctors' Perspectives on Adhering to Advance Care Directives When Making Medical Decisions for Patients: An Australian Interview Study' (2019) 9 *BMJ Open* e032638:1-11, 10.

[2] Karen M Detering et al, 'Prevalence of Advance Care Planning Documentation and Self-Reported Uptake in Older Australians with a Cancer Diagnosis' (2021) 12(2) *Journal of Geriatric Oncology* 274, 276; Sonja McIlfatrick et al, '"It's Almost Superstition: If I Don't Think about It, It Won't Happen". Public Knowledge and Attitudes towards Advance Care Planning: A Sequential Mixed Methods Study' (2021) 35(7) *Palliative Medicine* 1356, 1360; Moore et al (n 1).

[3] Grace W Orsatti, 'Attorneys as Healthcare Advocates: The Argument for Attorney-Prepared Advance Healthcare Directives' (2022) 50(1) *Journal of Law, Medicine & Ethics* 157.

ahead, ensures older adults are aware of, and understand, the full range of APP instruments available, and how and when they operate in future.

In my research, communication was cited by both legal and health professionals as a key factor in enhancing the quality of APP instruments, and ensuring people who have been appointed as decision-makers understand what the older person wants and that they are able to carry this out in future. This communicative approach to APP across both personal and professional groups is more likely to achieve the goals of Preventive Law and Therapeutic Jurisprudence, working to actively prevent disputes from arising in the future by engaging in planning and ongoing communication,[4] and focusing on the wellbeing of all involved in the process.[5] It realises the collaborative potential of both legal and healthcare planning, ensuring the older person is an active and informed participant in their own decision-making. In turn, this gives effect to the principles of autonomy and empowerment, including authenticity, self-direction, power and control. Frequent and transparent communication will also help to prepare for what should occur during any instances of vulnerability or periods of heightened dependence that an older person could experience in the future. Finally, better and earlier communication may also reduce risks of the older person being exploited, or discordant decisions being made on their behalf, during any periods of heightened dependency.

9.2.1.2 Improved education

Another evident theme that emerged from my research is the need for additional education for older adults and professionals. Education for older adults within the community regarding the range of APP mechanisms, the purpose of separate instruments, when they begin to operate, and the advantages of engaging with them may enhance the uptake and quality of planning instruments.[6] Increased knowledge and awareness regarding APP may help to support further

[4] Bruce J Winick, 'The Expanding Scope of Preventive Law Therapeutic Jurisprudence Symposium' (2002) 3 *Florida Coastal Law Journal* 189; Dennis P Stolle, 'Professional Responsibility in Elder Law: A Synthesis of Preventive Law and Therapeutic Jurisprudence' (1996) 14(4) *Behavioral Sciences & the Law* 459, 468.

[5] Mark Glover, 'A Therapeutic Jurisprudential Framework of Estate Planning' (2011) 35 *Seattle University Law Review* 427, 427; MB Kapp, 'A Therapeutic Approach' in Israel Doron (ed), *Theories on Law and Ageing: The Jurisprudence of Elder Law* (Springer, 2009) 31, 31; Dennis P Stolle and David B Wexler, 'Therapeutic Jurisprudence and Preventive Law: A Combined Concentration to Invigorate the Everyday Practice of Law Essays' (1997) 39 *Arizona Law Review* 25, 25.

[6] Kimberly Buck et al, 'Advance Care Directive Prevalence among Older Australians and Associations with Person-Level Predictors and Quality Indicators' (2021) 24(4) *Health Expectations* 1312; Frances Batchelor et al, 'Facilitators and Barriers to Advance Care Planning Implementation in Australian Aged Care Settings: A Systematic Review and Thematic Analysis' (2019) 38(3) *Australasian Journal on Ageing* 173; Austin Health, 'Improving the Quality and Safety of Advance Care Plans', *Advance Care Planning Australia* (Blog Post, 2021) <https://www.advancecareplanning.org.au/about-us/news-case-studies-and-blog/blog-improving-the-quality-and-safety-of-advance-care-plans>.

communication of decisions by older adults with members of their support community, including family, appointed decision-makers, and relevant professionals, and achieve the goal of a person-centred approach to APP.[7] Such a strategy may help to overcome self-reported beliefs that APP may be irrelevant or too confronting to think about,[8] especially if planning ahead is reframed as planning ahead for the rest of life, not simply the end of life. Education initiatives should be developed in conjunction with older adults, ensuring any information delivered and resources provided are explicitly addressing their questions and concerns relating to APP.

Education for professionals also carries benefits; it can provide high level knowledge about the available instruments, what their purpose is, and when they begin to operate. Some resources are available that seek to educate health professionals about the legal status of Advance Care Planning processes.[9] However, further initiatives should focus on providing guidance for clinicians on recognising authorised decision-makers appointed under an Enduring Power of Attorney or Enduring Guardian, the circumstances in which planning mechanisms have effect, and the distinct purposes of the various planning instruments. Education for health professionals is particularly important; they are more likely to have frequent contact and repeated opportunities to build a relationship with older patients when compared with how often older adults are visiting lawyers.[10] Similarly, this opportunity for regular communication with a health professional may reveal certain psycholegal soft spots connected to a person's wellbeing,[11] such as difficult interpersonal relationships or social isolation, which, similar to legal issues, may also have a significant impact on the wellbeing of adults as they age.

Education around physical, mental, financial and social factors that may impact older adults could help professionals to more easily recognise common legal problems, such as lack of a

[7] Batchelor et al (n 6); Rebecca L Sudore et al, 'Engagement in Multiple Steps of the Advance Care Planning Process: A Descriptive Study of Diverse Older Adults' (2008) 56(6) *Journal of the American Geriatrics Society* 1006.
[8] Julie L Masters, Lindsey E Wylie and Sarah B Hubner, 'End-of-Life Planning: Normalizing the Process' (2022) 34(4) *Journal of Aging & Social Policy* 641; McIlfatrick et al (n 2); Batchelor et al (n 6); Moore et al (n 1).
[9] Australian Centre for Health Law Research, *How to do Advance Care Planning: A Quick Guide for Health Professionals* (Report, Queensland University of Technology, 2021) <https://end-of-life.qut.edu.au/__data/assets/pdf_file/0016/1040209/How-to-do-Advance-Care-Planning.pdf>; Australian Centre for Health Law Research, 'Our Publications', *Queensland University of Technology* (Web Page) <https://research.qut.edu.au/achlr/our-research/our-publications/>.
[10] Orsatti (n 3); R Sean Morrison, Diane E Meier and Robert M Arnold, 'What's Wrong with Advance Care Planning?' (2021) 326(16) *JAMA* 1575.
[11] David B Wexler, 'From Theory to Practice and Back Again in Therapeutic Jurisprudence: Now Comes the Hard Part' (2011) 37(1) *Monash University Law Review* 33; Winick (n 4) 195.

trusted decision-maker, the utility and operation of specific APP instruments, such as an Enduring Guardian, and where patients could turn for further advice.[12] Legal professionals could also receive education regarding the implementation and interpretation of Advance Care Planning mechanisms in practice, including Enduring Guardian appointments and Advance Care Directives. In my interviews with professional key informants, the need to use clear and relevant medical language in planning instruments was discussed as a factor that would assist future implementation, as healthcare planning documents that are too broad or vague may be disregarded in clinical settings, thus undermining their use. Education initiatives could be delivered online, as the provision of information regarding planning ahead,[13] health[14] and other legal topics[15] has been demonstrated to improve confidence and readiness to engage with relevant processes.

9.2.2 Meso Level Recommendations Across Professions

9.2.2.1 Integration into usual care

The need to incorporate APP within usual care was a frequent recommendation made by key informants. For example, key informants suggested that General Practitioners could raise APP conversations with older patients annually during health assessments, or more regularly depending on any recent diagnoses or changes in their health. Similarly, lawyers could raise APP with their clients who have not yet prepared relevant instruments, or send an annual reminder to older clients encouraging them to self-review any prepared instruments and ensure any appointed decision-makers are still available and willing to carry out the role in accordance with the older person's wishes. By integrating APP into usual practice in both legal and health fields, planning conversations will become more commonplace, providing older adults and patients with frequent and accessible opportunities to discuss their planning wishes and

[12] Dennis P Stolle et al, 'Integrating Preventive Law and Therapeutic Jurisprudence: A Law and Psychology Based Approach to Lawyering' (1997) 34 *California Western Law Review* 15, 42–43.
[13] Nola M Ries, Briony Johnston and Shaun McCarthy, 'Legal Education and the Ageing Population: Building Student Knowledge and Skills through Experiential Learning in Collaboration with Community Organisations' (2016) 37 *Adelaide Law Review* 495.
[14] Marleen Prins et al, 'Use and Impact of the Alzheimer Experience: A Free Online Media Production to Raise Public Awareness and Enhance Knowledge and Understanding of Dementia' (2020) 24(6) *Aging & Mental Health* 985; Blanka Klimova et al, 'E-Learning as Valuable Caregivers' Support for People with Dementia – A Systematic Review' (2019) 19 *BMC Health Services Research* 781:1–7.
[15] Hugh M McDonald, Suzie Forell and Zhigang Wei, 'Uptake of Legal Self-Help Resources: What Works, for Whom and for What?' (2019) 30 *Justice Issues* 1.

preferences, which may assist in breaking down barriers such as not wanting to talk about their future, or not knowing how to plan ahead.[16]

If APP is part of everyone's role, something that was emphasised by both legal and health professionals in my interviews, it reduces the uncertainty that professionals have reported regarding whose role it should be to introduce planning discussions.[17] Further, it provides more opportunities for older people to engage in frequent, ongoing conversations, which can be especially difficult if they are seeing multiple health professionals for a variety of conditions, resulting in fragmented quality of care and lack of oversight regarding the progress of any planning discussions.[18] This ongoing, communicative approach to APP again enlivens the benefits of Preventive Law and Therapeutic Jurisprudence by proactively guarding against future conflicts through frequent and thorough consideration of an older person's financial, legal, health and personal wellbeing. Applying theralaw through the lens of Elder Law ensures older adults are valued and equal collaborators in APP processes.

9.2.2.2 Further interprofessional collaboration

Key informants frequently discussed the need to combine the professional experiences of lawyers and health professionals to ensure best practice is not only envisioned, but realised, for older clients and patients.[19] Interprofessional collaboration is especially important given that doctors and other health professionals are often excluded from, or not aware of, a patient's health-based planning.[20] Health Justice Partnerships[21] are a prime example of how such interprofessional collaboration can be realised in practice. Such partnerships are facilitated through lawyers being present on-site at medical facilities, allowing them to respond efficiently

[16] Orsatti (n 3); Buck et al (n 6) 1323; Detering et al (n 2) 274; Masters, Wylie and Hubner (n 8).
[17] Josie Dixon and Martin Knapp, 'Whose Job? The Staffing of Advance Care Planning Support in Twelve International Healthcare Organizations: A Qualitative Interview Study' (2018) 17(1) *BMC Palliative Care* 78:1–16.
[18] Hui Yun Chan, 'Video Advance Directives: A Turning Point for Advance Decision-Making? A Consideration of Their Roles and Implications for Law and Practice' (2020) 41 *Liverpool Law Review* 1, 8; Hillary D Lum, Rebecca L Sudore and David B Bekelman, 'Advance Care Planning in the Elderly' (2015) 99(2) *Medical Clinics of North America* 391, 399; Kritika Samsi and Jill Manthorpe, '"I Live for Today": A Qualitative Study Investigating Older People's Attitudes to Advance Planning' (2011) 19(1) *Health & Social Care in the Community* 52, 57.
[19] Orsatti (n 3).
[20] Laura Vearrier, 'Failure of the Current Advance Care Planning Paradigm: Advocating for a Communications-Based Approach' (2016) 28(4) *HEC Forum* 339, 348; Friedemann Nauck et al, 'To what Extent are the Wishes of a Signatory Reflected in Their Advance Directive: A Qualitative Analysis' (2014) 15 *BMC Medical Ethics* 1, 1.
[21] Health Justice Australia, 'Health Justice Partnership' https://healthjustice.org.au/health-justice-partnership/.

to any problems a person may be experiencing and breaking down barriers to accessing legal services.[22]

As stated above, this best practice would essentially involve comprehensive education of health and legal professionals, promoting an understanding of the range of available instruments, how they can be used to prevent disputes, and any relevant interpersonal factors. For example, health and legal professionals should inquire about an older person's family and support community, allowing for an understanding of their social connections and facilitating awareness of any potential opportunities for exploitation of the older person. Improved collaboration will help eliminate potential uncertainty among healthcare professionals regarding the purpose, operation and limitations of key instruments, as well as the scope of authority of appointed decision-makers. In turn, lawyers can feel more confident with respect to the medical context and policy factors that could enhance their approaches to assisting older adults to engage with appointing an Enduring Guardian or supporting them to complete Advance Care Directives, and knowing when personalised medical advice is necessary for their documented plans to be enacted in future.

Establishing an ongoing plan for consultation and review of prepared documents would also increase opportunities for therapeutic interactions, and enhance the lawyer-client or doctor-patient relationship.[23] Preventive Law has a dual purpose of lowering both the chance and associated costs of future conflicts, while encouraging clients to engage in forms of advance planning, which in turn have therapeutic benefits.[24] Interdisciplinary collaborations have thus far been lacking in the field of Elder Law[25] due to the siloed nature of both the health and legal professions.[26] The adoption of a holistic approach to services required by an older person may go beyond the skillset of the individual lawyer,[27] highlighting the need to both consider and allow for the input of other professionals. The rise of online seminars, especially following the

[22] Health Justice Australia, 'The Evidence Supporting Health Justice Partnership' (2018) 1, 2.
[23] Stolle et al (n 12) 26–27; Stolle (n 4) 461.
[24] Stolle (n 4) 461.
[25] Orsatti (n 3) 164; Israel Doron, '25 Years of Elder Law: An Integrative and Historical Account of the Field of Law and Aging' (2019) 21(1) *Theoretical Inquiries in Law* 1, 8.
[26] Nola M Ries et al, 'How do Lawyers Assist their Clients with Advance Care Planning? Findings from a Cross-Sectional Survey of Lawyers in Alberta' (2018) 55(3) *Alberta Law Review* 683, 695; Amy Waller et al, 'Increasing Advance Personal Planning: The Need for Action at the Community Level' (2018) 18(1) *BMC Public Health* 606:1–8, 2; Nola M Ries et al, 'Doctors, Lawyers and Advance Care Planning: Time for Innovation to Work Together to Meet Client Needs' (2016) 12(2) *Healthcare Policy* 12, 14.
[27] Thomas D Barton, *Preventive Law and Problem Solving: Lawyering for the Future* (Vandeplas Publishing, 2009); LA Frolik, 'Later Life Legal Planning' in Israel Doron (ed), *Theories on Law and Ageing: The Jurisprudence of Elder Law* (Springer, 2009) 11, 29.

COVID-19 pandemic, may go some way to connecting these disparate professions to fully realise the benefits of APP.

Interprofessional collaboration would facilitate a more holistic approach to APP, which takes greater account of the older person's wellbeing,[28] support community and personal circumstances,[29] from an informed and knowledgeable position of the types of protective instruments, and where people can go for more information if needed. Further, the combined professional expertise of both law and health practitioners, along with social workers and financial planners, would allow for the ideal circumstances in which theralaw could operate,[30] being the integration of Preventive Law and Therapeutic Jurisprudence. Professional groups can work together to guard against future problems for older adults through communication and proactive planning,[31] while ensuring their financial, legal, health and social wellbeing is prioritised as much as possible.[32]

9.2.2.3 International example

The 2019 *Pan-Canadian Framework on Advance Care Planning* provides a clear map for integrating Advance Care Planning within usual care, and expanding interprofessional perspectives of Advance Care Planning, which can readily be expanded to the broader process of APP.[33] The Framework encourages four connected tasks. Firstly, the partnership network is expanded by encouraging greater collaboration across professions, such as health, law, financial and social services,[34] to enhance person-centred planning processes with the older person.[35] This task is essential to achieving the principles of theralaw within the field of Elder

[28] Stolle and Wexler (n 5) 25; Glover (n 5) 427.
[29] Stolle et al (n 12) 42–43.
[30] Jill Z Barclift, 'Preventive Law: A Strategy for Internal Corporate Lawyers to Advise Managers of their Ethical Obligations' (2008) 33 *Journal of the Legal Profession* 31, 36.
[31] Winick (n 4) 189; Stolle (n 4) 468.
[32] Stolle and Wexler (n 5) 25; David B Wexler, 'Beyond Analogy: Preventive Law as Preventive Medicine', *National Center for Preventive Law* (Essay, 2000) <http://www.preventivelawyer.org/main/default.asp?pid=essays/wexler.htm>.
[33] Canadian Hospice Palliative Care Association, *Advance Care Planning in Canada: A Pan-Canadian Framework* (Report, January 2020) 3 <https://www.advancecareplanning.ca/wp-content/uploads/2020/06/ACP-Framework-EN-Updated.pdf>.
[34] Sarah Donnelly et al, 'Assisted Decision-Making and Interprofessional Collaboration in the Care of Older People: A Qualitative Study Exploring Perceptions of Barriers and Facilitators in the Acute Hospital Setting' (2021) 35(6) *Journal of Interprofessional Care* 852, 852; Suzanne Rainsford et al, 'Strengthening Advance Care Planning in Rural Residential Aged Care through Multidisciplinary Educational Case Conferences: A Hybrid Implementation-Effectiveness Study' (2021) 29(4) *Progress in Palliative Care* 199, 200; Masters, Wylie and Hubner (n 8) 656; Sarah Hooper, Charles P Sabatino and Rebecca L Sudore, 'Improving Medical-Legal Advance Care Planning' (2020) 60(2) *Journal of Pain and Symptom Management* 487, 491; Vearrier (n 20) 349.
[35] Canadian Hospice Palliative Care Association (n 31) 13–16.

Law, prioritising the autonomy and empowerment of older adults who are seeking to engage with APP. Secondly, support systems are built by first acknowledging and then removing barriers.[36] Such support systems could include family members, supported decision-makers and relevant professionals who are aware of, and can help to, implement an older person's wishes in future. This involvement of multiple stakeholders in the APP process will help increase awareness of an older person's preferences, as well as improving accountability to ensure those wishes are realised in the future. Thirdly, education is provided for all stakeholders in the process, framing planning ahead as part of life, rather than reserved for end of life considerations.[37] Training is also provided to professionals to ensure planning can be conducted in culturally safe environments for people from diverse backgrounds.[38] This is especially important for older adults from culturally and linguistically diverse communities, those of First Nations heritage, and older adults who identify as part of the LGBTQI+ community. Finally, impact is measured as a result of implementing these tasks to track both uptake and quality of planning mechanisms.[39] When considering the benefits of involving further professions in APP processes, Johnson et al specifically examine the role of social workers in assisting with proactive planning,[40] which is an area for further research.

9.2.3 Macro Level Recommendations for Structural Change

9.2.3.1 Legislative reform and national register

Legislative reform[41] through the introduction of a national register for enduring appointments,[42] was discussed by professional key informants in the context of recommendations to improve current approaches to APP. The use of a unified instrument for

[36] Ibid 17–21.
[37] Ibid 22–27.
[38] Emma Spencer and Eswaran Waran, 'Opening the Lines of Communication: Towards Shared Decision Making and Improved End-of-life Care in the Top End' (2020) 213(1) *The Medical Journal of Australia* 10, 10; Eswaran Waran, Sharon Wallace and Jonathan Dodson-Jauncey, 'Failing to Plan is Planning to Fail: Advance Care Directives and the Aboriginal People of the Top End' (2017) 206(9) *The Medical Journal of Australia* 377, 377; Susan W Tolle and Virginia P Tilden, 'Changing End-of-Life Planning: The Oregon Experience' (2002) 5(2) *Journal of Palliative Medicine* 311, 314–315.
[39] Canadian Hospice Palliative Care Association (n 31) 28–29. See also Donnelly et al (n 32) 583; Joel J Rhee, Nicholas A Zwar and Lynn A Kemp, 'Why are Advance Care Planning Decisions Not Implemented? Insights from Interviews with Australian General Practitioners' (2013) 16(10) *Journal of Palliative Medicine* 1197, 1202.
[40] Kimberly J Johnson et al, 'Social Work should be More Proactive in Addressing the Need to Plan for End of Life' (2016) 41(4) *Health & Social Work* 271, 271.
[41] Law Council of Australia, *National Register of Enduring Powers of Attorney* (Report, 8 July 2021) <https://lawcouncil.au/resources/submissions/national-register-of-enduring-powers-of-attorney>.
[42] Council of Attorneys-General (Australia) and Attorney-General's Department, *National Plan to Respond to the Abuse of Older Australians (Elder Abuse) 2019-2023* (Report, 8 July 2019) <https://www.ag.gov.au/rights-and-protections/publications/national-plan-respond-abuse-older-australians-elder-abuse-2019-2023>.

enduring appointments, as recommended by the NSW Law Reform Commission's review of the *Guardianship Act*,[43] was supported, as was the creation of a national register so that more certainty could be provided regarding the authority, currency and possible revocations of decision-making power.[44] Such a register would require significant resources and the development of a technological platform to function appropriately, necessitating coordination between governments, organisations and experienced developers to ensure the stability and security of all stored data.

Legislative reform was also recommended by key informants with a view to creating a more consistent and national approach to APP so that jurisdictional differences are not as confusing.[45] However, the current reform of the federal *Aged Care Act* may lead to further complexity and additional conflicts with state and territory legislative schemes.[46] In the absence of a unified instrument or consistent national approach to enduring appointments, professionals must be highly cognisant of the various schemes that are operating and ensure their older clients are fully informed about their options for supported decision-making.

Finally, one legal professional emphasised the need to overhaul the jurisdiction of courts and tribunals so that people requiring a determination on a matter concerned with APP, such as whether a person has decision-making capacity, can access justice in a less expensive and more efficient manner. These recommendations would require broad support and substantial funding, yet the benefits of implementing consistent statutory approaches and a central repository for documents are significant.

9.2.3.2 Cultural shifts

More broadly, cultural shifts around death, dying, receiving care, and normalising discussions regarding planning for the rest of life would be a positive, albeit ambitious, societal change.[47] As levels of death literacy are low in the community,[48] professionals can assist with encouraging a shift in perspective with respect to normalising the process of receiving care and

[43] New South Wales Law Reform Commission, *Review of the Guardianship Act 1987* (Report No 145, May 2018) 96 <https://lawreform.nsw.gov.au/completed-projects/recent/guardianship/report-145.html>.
[44] Council of Attorneys-General (Australia) and Attorney-General's Department (n 40).
[45] Law Council of Australia (n 39) 19.
[46] 'About the New Aged Care Act', *Department of Health and Aged Care* (Web Page, 6 February 2024) <https://www.health.gov.au/our-work/aged-care-act/about>.
[47] Masters, Wylie and Hubner (n 8); McIlfatrick et al (n 2).
[48] McIlfatrick et al (n 2).

preparing for the future, including considerations of end of life care.[49] Consulting older people directly to learn about how they would like to be cared for in future, what kind of treatment they would prefer, and how they envision living during their remaining decades is a good starting point that would inform such a cultural shift. This approach was championed by several of the key informants interviewed in this study, highlighting the need to normalise these essential considerations and conversations.

We can again draw inspiration from the Pan-Canadian Framework, where Advance Care Planning is interpreted as 'life planning'.[50] This form of planning includes wishes, goals and preferences relating to healthcare, but also an individual's finances and considerations regarding their assets and estate.[51] This holistic approach to planning for the rest of life shows the range of areas in which plans can be made, along with how a person's wishes in relation to each area may change at various stages throughout life,[52] which again emphasises the need to foreground the voice and experiences of older people at every stage of planning. Framing APP from this perspective is readily aligned with the principles of Preventive Law and Therapeutic Jurisprudence, prompting us to consider the types of issues that could arise for older adults in future, taking account of their personal, financial, social and health circumstances. When viewed through the lens of Elder Law, planning for the rest of life encourages an understanding of how conflicts and disputes can be prevented for the older person, while prioritising every facet of their wellbeing and accounting for their specific needs and values. This could include how they would like their finances to be managed, which social connections they would like to maintain, and any treatment they would be comfortable, or uncomfortable, receiving in future.

Planning must be understood as an ongoing, communicative process as opposed to a single event that is focused only on end of life wishes.[53] This planning is founded upon 'meaningful

[49] Masters, Wylie and Hubner (n 8).
[50] Canadian Hospice Palliative Care Association (n 31) 4.
[51] Ibid.
[52] Kerstin Knight, '50 Years of Advance Care Planning: What do we Call Success?' (2021) 39(1) *Monash Bioethics Review* 28; C Haining, L Nolte and KM Detering, *Australian Advance Care Planning Laws: Can We Improve Consistency?* (Report, Advance Care Planning Australia, Austin Health, 2019) 36; Charles P Sabatino, 'Advance Care Planning Tools That Educate, Engage, and Empower' (2014) 24(3) *Public Policy & Aging Report* 107, 107; Susan E Hickman et al, 'Hope for the Future: Achieving the Original Intent of Advance Directives' (2005) 35(6) *The Hastings Center Report* S26, S30.
[53] Haining, Nolte and Detering (n 50) 32; Jenny Newbould et al, 'Experiences of Care Planning in England: Interviews with Patients with Long Term Conditions' (2012) 13 *BMC Family Practice* 71:1–9, 7; Sudore et al (n 7) 1006; Susan E Hickman, 'Improving Communication Near the End of Life' (2002) 46(2) *American Behavioral Scientist* 252, 256.

conversations' over the course of life,[54] invoking our understanding of meaningful participation as a key component of empowerment. As Aitken states:

> Advance Care Planning is an essential part of a life well lived and planned. Like financial and estate planning, it begins long before someone is faced with a crisis or life-limiting illness, and continues throughout their lives. Normalizing ACP [Advance Care Planning] will help people feel more comfortable and confident talking about their values, wishes, and preferences for care.[55]

This normalised approach can be readily extended to all forms of APP, not simply those related to healthcare.[56] As such, APP is an essential part of living well, preparing to protect your financial, personal and legal wellbeing, in addition to your health, in future. It provides older people with the opportunity to consider future conflicts and proactively guard against them, encouraging them to share their wishes and preferences with trusted individuals, including family, appointed decision-makers and professional advisors.

9.2.3.3 Technological improvements

In my research, health professionals also mentioned the need for technological improvements to ensure computer-based systems are able to communicate with each other efficiently and effectively. If government and health organisations can work together to make the existing technology accessible and unified, professionals can ensure they are relying upon the most up-to-date records for patients, including recorded wishes relating to treatment and healthcare. Further, this would ensure the efficient recording and retrieval of vital information regarding allergies, medications and any chronic illnesses that the patient may be living with. In Australia, updates to the My Health Record platform[57] would also improve both clinician and patient confidence that APP mechanisms could be shared securely and easily accessed when needed.[58]

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[54] Canadian Hospice Palliative Care Association (n 31) 8; John Chesterman and Lois Bedson, *Decision Time: Activating the Rights of Adults with Cognitive Disability* (Report, Office of the Public Advocate, 15 February 2021) 113 <https://apo.org.au/node/314188>.

[55] Canadian Hospice Palliative Care Association (n 31) 9.

[56] Department of Health (n 1) 6.

[57] Advance Care Planning Australia, 'The Importance of Storing your Patients' Advance Care Planning Documents in My Health Record', *Advance Care Planning Australia* (online, 21 March 2022) <https://www.advancecareplanning.org.au/about-us/news/the-importance-of-storing-your-patients-advance-care-planning-documents-in-my-health-record>.

[58] Ibid; Australian Digital Health Agency, *National Guidelines: Using My Health Record to Store and Access Advance Care Planning and Goals of Care Documents* (Guidelines, March 2021) <https://www.digitalhealth.gov.au/healthcare-providers/advance-care-planning>; Royal Australian College of General Practitioners, *Planning and Recording My Future Healthcare Wishes: Advance Care Planning and My Health Record* (Report, 2021)

While clinicians are currently able to access an older adult's My Health Record, if it has been uploaded, existing programs require further integration to ensure all relevant information is available in an efficient and reliable manner.

9.2.3.4 Funding

Funding is required to support high-quality APP, allowing professionals more time to incorporate APP within usual care[59] and promote innovative services models, such as medical-legal partnerships.[60] Funding is also essential to support APP for priority populations, including people who face multiple barriers to accessing legal and health-related care.[61] By directing more focus to the various aspects of APP, including uptake, quality and successful implementation, we can develop a more informed view of current processes and considered approaches to improvement strategies.[62] This would also allow input of professionals from a wide range of disciplines, including social work[63] and finance,[64] in addition to lawyers and healthcare professionals, promoting an interprofessional perspective that could be accommodated in future processes.

9.3 AREAS FOR FUTURE RESEARCH

While this study is the first of its kind to adopt a mixed method, combined cohort examination of experiences with APP by older adults in regional NSW, several gaps still exist in our current knowledge. As noted in Chapter 5, older adults who participated in the study were already

<https://www.racgp.org.au/FSDEDEV/media/documents/Clinical%20Resources/My%20health%20record/ACP-MHR-Information-for-patients.pdf>; Royal Australian College of General Practitioners, *Advance Care Planning and My Health Record: Information for GPs* (Report, 2021) <https://www.racgp.org.au/FSDEDEV/media/documents/Clinical%20Resources/My%20health%20record/ACP-MHR-Information-for-GPs.pdf>.

[59] Bronwyn Hemsley et al, 'An Integrative Review of Stakeholder Views on Advance Care Directives (ACD): Barriers and Facilitators to Initiation, Documentation, Storage, and Implementation' (2019) 102(6) *Patient Education and Counseling* 1067.

[60] Lauren A Gard et al, 'Interprofessional Education in Medical-Legal Partnerships (MLPs) to Address Social Determinants of Health' (2021) 32(4) *Journal of Health Care for the Poor and Underserved* 1720.

[61] Buck et al (n 6); Austin Health (n 6).

[62] Batchelor et al (n 6); Colleen Cartwright et al, 'Medical Practitioners' Knowledge and Self-Reported Practices of Substitute Decision Making and Implementation of Advance Care Plans' (2014) 44(3) *Internal Medicine Journal* 234; Joel J Rhee, Nicholas A Zwar and Lynn A Kemp, 'Uptake and Implementation of Advance Care Planning in Australia: Findings of Key Informant Interviews' (2012) 36(1) *Australian Health Review* 98.

[63] Johnson et al (n 38).

[64] Australian Guardianship and Administration Council, *You Decide Who Decides: Making an Enduring Power for Financial Decisions* (Report, Victorian Office of the Public Advocate, October 2019) <https://www.agac.org.au/assets/documents/Other-Publications/You-Decide-Who-Decides.pdf>; Paul A Gardiner et al, 'Financial Capacity in Older Adults: A Growing Concern for Clinicians' (2015) 202(2) *The Medical Journal of Australia* 82.

aware of APP and were also highly educated. There was an overrepresentation from one region of NSW. Only two participants identified as First Nations, and the views of culturally and linguistically diverse older adults were absent from the data.

Some studies have demonstrated that literacy, religion and race are risk factors for low rates of Advance Care Planning,[65] and planning ahead is generally much lower among individuals who are not from Anglo Celtic backgrounds.[66] However, we do not know the reasons why this is the case, as these factors have not been explored in detail. While my research was not designed to closely examine the uptake of APP among specific groups, including First Nations Peoples and individuals from culturally and linguistically diverse backgrounds, these disparities must be noted and explored in future research.

Further research should also examine the experiences with, and perspectives of, APP for older adults who identify as part of the LGBTIQ+ community, and those living with a disability. Similarly, studies on a broader scale should include individuals who have not engaged in APP, or only in few forms, to provide greater insights regarding barriers to engagement and reasons why some older people decide not to engage with APP. Another beneficial area of future research would be longitudinal studies relating to the completion and future use of APP. Such

[65] Gloria T Anderson, 'Let's Talk about ACP Pilot Study: A Culturally-Responsive Approach to Advance Care Planning Education in African-American Communities' (2021) 17(4) *Journal of Social Work in End-of-Life & Palliative Care* 267, 268; Craig Sinclair et al, 'Association Between Region of Birth and Advance Care Planning Documentation Among Older Australian Migrant Communities: A Multicenter Audit Study' (2021) 76(1) *The Journals of Gerontology: Series B* 109, 116; Laura Panozzo et al, 'Communication of Advance Care Planning Decisions: A Retrospective Cohort Study of Documents in General Practice' (2020) 19 *BMC Palliative Care* 108:1–7, 6; Australian Healthcare Associates, *Exploratory Analysis of Barriers to Palliative Care* (Issues Report on Aboriginal and Torres Strait Islander Peoples, Department of Health, September 2019) <https://www.health.gov.au/resources/publications/exploratory-analysis-of-barriers-to-palliative-care-issues-report-on-aboriginal-and-torres-strait-islander-peoples?language=en>; Vearrier (n 20) 348–349; Pascoe Pleasence, Nigel J Balmer and Catrina Denvir, 'A Simple Public Legal Education Experiment' in *How People Understand and Interact with the Law* (PPSR, 2015) 170, 172–174; Katherine R Waite et al, 'Literacy and Race as Risk Factors for Low Rates of Advance Directives in Older Adults' (2013) 61(3) *Journal of the American Geriatrics Society* 403; Austin Health, *Respecting Patient Choices: Advance Care Planning with Aboriginals and Torres Strait Islanders* (Report, 2006) 6 <https://www.acrrm.org.au/docs/default-source/all-files/aboriginal_torres_strait_islander_advance_care_planning.pdf?sfvrsn=7d61dcc5_2>; D Visala Rao, Jeni Warburton and Helen Bartlett, 'Health and Social Needs of Older Australians from Culturally and Linguistically Diverse Backgrounds: Issues and Implications' (2006) 25(4) *Australasian Journal on Ageing* 174, 175.

[66] Anderson (n 63); Sinclair et al (n 63); Amanda Pereira-Salgado, Patrick Mader and Leanne M Boyd, 'Advance Care Planning, Culture and Religion: An Environmental Scan of Australian-Based Online Resources' (2018) 42(2) *Australian Health Review* 152; Karen Detering et al, 'Feasibility and Acceptability of Advance Care Planning in Elderly Italian and Greek Speaking Patients as Compared to English-Speaking Patients: An Australian Cross-Sectional Study' (2015) 5(8) *BMJ Open* e008800:1-7; Sarah Jeong et al, '"Planning Ahead" among Community-Dwelling Older People from Culturally and Linguistically Diverse Background: A Cross-Sectional Survey' (2015) 24 *Journal of Clinical Nursing* 244, 244, 249–250; Pleasence, Balmer and Denvir (n 63) 172–174; Kimberly S Johnson, Maragatha Kuchibhatla and James A Tulsky, 'What Explains Racial Differences in the Use of Advance Directives and Attitudes Toward Hospice Care?' (2008) 56(10) *Journal of the American Geriatrics Society* 1953.

longitudinal research would allow for consideration of whether higher quality instruments result in better outcomes for, and fewer instances of abuse or exploitation of, older people who have engaged in APP

The sample size of the online survey of lawyers was low, which was a significant limitation. Their views were not representative of lawyers working in medium to large organisations, those with fewer than 10 years of practice experience, or lawyers who were younger than 45 years of age. A comprehensive and more representative survey of lawyers across Australia, rather than only those working in NSW, would be beneficial to highlight similarities and differences between the perspectives of lawyers working in different jurisdictions with regard to APP. While over half of the lawyers surveyed reported working with clients from First Nations or culturally and linguistically diverse backgrounds, only four of the 31 participants reported having used resources that promoted culturally appropriate practice. This indicates the critical need for further research relating to how accessible resources can be created, and effectively promoted to lawyers, to ensure the advantages of APP are being realised for diverse groups in a meaningful and culturally appropriate manner.

Finally, the interviews with professional key informants, while insightful, may not be generalisable to other jurisdictions due to the focus on NSW. An examination of expert views from across Australia would be beneficial, allowing for a comparison of professional experiences and insights regarding barriers to engagement, factors affecting the quality of completed instruments, and any difficulties regarding their future implementation from both an interprofessional and national perspective.

9.4 CONCLUSION

This thesis provides insight regarding APP in regional and rural NSW, and has allowed for a deeper understanding of the attitudes, experiences and perspectives of older adults and professionals working in relevant fields of law and health. Findings from my research provide new data relating to factors that affect the quality of APP instruments, as well as vital information regarding barriers to engagement and future implementation of planning documents. My findings confirm themes from the existing literature, while offering new data that can inform baselines for further research. Contributions from older adults and professional key informants have informed recommendations relating to opportunities for improvement, highlighting steps that can be taken at individual, professional and structural levels. Limitations

associated with my research have also been addressed, driving suggestions for areas of future research.

My research provides original contributions to knowledge, including how the theoretical perspectives of Preventive Law and Therapeutic Jurisprudence can be applied within the context of Elder Law to produce a more holistic understanding of APP. This theoretical consideration allows for a greater understanding of key concepts, including autonomy, vulnerability, wellbeing and empowerment. Further, it underscores how APP can produce positive outcomes for older adults, including safeguarding their future wishes relating to their health, finances, personal matters and legal affairs, and preventing disputes or conflicts from arising at a later point in time.

APPENDIX A
INTERVIEW GUIDE FOR OLDER PEOPLE

Interview Guide:
Your Experiences with Advance Personal Planning

INTRODUCTION

Note to the Human Research Ethics Committee: The 'Verbal Consent Script' V1, 24.05.2021 will be completed here in place of this introductory text following feedback received in the pre-review of my application.

DEFINITION OF APP

As you know, this project is focused on Advance Personal Planning.

Advance Personal Planning is the process of thinking about and sharing your values and wishes for your future medical care, financial management, living arrangements and other personal matters. Advance Personal Planning can help other people know your wishes in case you get seriously ill or injured and cannot make or communicate decisions yourself. Advance Personal Planning can include making a Will, appointing a financial power of attorney and making other documents.

Do you have any questions before we begin?

a. If yes, answer questions
b. If no, continue.

ASPECTS OF Advance Personal Planning:

We will start with a few questions that focus on your experiences with Advance Personal Planning.

1. **I would like to learn more about any aspects of Advance Personal Planning you may have completed. Have you:**

- ❑ Made a Will, which is a written document that states your instructions about the distribution of your assets after death

- ❑ Appointed an Enduring Power of Attorney, a person who is legally appointed to make financial decisions and manage your money and property on your behalf if you're not able to do this yourself

- ❑ Appointed an Enduring Guardian, a person who is legally appointed to make health and medical decisions on your behalf if you're not able to do this yourself

- ❑ Made an Advance Care Directive, which is a legal document about your wishes, preferences and instructions for future living arrangements, personal matters, health care and end of life care

  Interviewer Note: Question options below will depend on responses to initial screening question. I will first go through documents they have made, before turning to documents they haven't made.

  a. You mentioned you have a Will:

  i. Why did you decide to make a Will?

  ii. How did you go about making your Will? (*Prompts:* see a solicitor, talk to other people, look up information about making a Will?)

  iii. Did you have discussions with those around you about your wishes? (*Prompts:* lawyer, family members, friends)

  1. How did these discussions go?
  2. How comfortable were you having these discussions?
  3. Did your feelings change depending on the person you were speaking with?
  4. Did you feel you got the information you needed from a lawyer to understand your legal rights and the importance of having a Will?
  5. Did you have enough time to talk about what you wanted to include in your Will?

  iv. Did you find it difficult or easy to make your Will? Was there any way in which the process could be improved?

  v. Approximately how long ago did you make your Will?

  vi. Have you ever changed your Will? If so, what prompted this?

  vii. Where is your Will stored? This can just be a general response. (*Prompts:* in my home, with my solicitor, in a safety deposit box)

  viii. Have you shared your Will with anyone, or told people where it can be found? (*Prompts:* lawyer, executor, others close to you)

  b. You mentioned you have appointed an Enduring Power of Attorney:

  i. Why did you decide to appoint a financial attorney?

  ii. How did you decide who to appoint as your financial attorney?

  iii. What is your relationship to your financial attorney? This can just be a general response, and you don't have to tell me the name of the person. (*Prompts:* adult child, friend)

iv. How did you go about appointing your financial attorney? (*Prompts:* spoke with a financial planner, spoke with a lawyer, talked to family members, talked to other people who might be involved in making financial decisions for them if they are very ill, looked up information)

v. Did you find it difficult or easy to appoint your financial attorney? Was there any way in which the process could be improved?

vi. Approximately how long ago did you appoint your financial attorney?

vii. Have you ever made changes to your Enduring Power of Attorney appointment? If so, what prompted this? (*Prompts:* person is no longer available)

viii. Where is your Enduring Power of Attorney document stored? This can just be a general response. (*Prompts:* i.e. in my home, with my lawyer, in a safety deposit box)

ix. Have you shared your Enduring Power of Attorney document with anyone, or told people where it can be found? (*Prompts:* financial planner, lawyer, appointed decision-maker, others close to you)

Being a financial attorney is an important role, because it involves making financial decisions for someone when they are very unwell and not able to make their own choices.

x. What kinds of conversations have you had with your financial attorney about how you want your money spent/property managed?

    1. Have you put any limits on your financial attorney's role?
    2. If you had help from a lawyer to prepare the Enduring Power of Attorney document, did they provide any information that would help your financial attorney to understand their role?
    3. How confident do you feel about your financial attorney making decisions for you about your money and/or property?

xi. What kinds of discussions have you had with those around you about who you wanted to appoint as your financial attorney? (*Prompts:* lawyer, family members, friends)

    1. How did these discussions go?
    2. How comfortable were you having these discussions?
    3. Did your feelings change depending on the person you were speaking with?
    4. Did you feel you got the information you needed from a lawyer to understand your legal rights and the importance of appointing a financial attorney?
    5. Did you have enough time to talk about what you wanted to include in your Enduring Power of Attorney document?

xii. Have you had experiences where your financial attorney has had to act on your behalf? For example, you've been very ill and they had to manage your bank accounts, money, etc? If yes, how did that go?

    1. How do you think your financial attorney managed? Were you happy or unhappy with decisions they made on your behalf?

c. You mentioned you have appointed an Enduring Guardian:

i. Why did you decide to appoint a health guardian?

ii. How did you decide who to appoint as your health guardian?

iii. What is your relationship to your health guardian? This can just be a general response, and you don't have to tell me the name of the person. (*Prompts:* adult child, friend)

iv. How did you go about appointing your health guardian? (*Prompts:* spoke with a doctor, spoke with a lawyer, talked to family members, talked to other people who might be involved in making decisions for them if they are very ill, looked up information)

v. Did you find it difficult or easy to appoint your health guardian? Was there any way in which the process could be improved?

vi. Approximately how long ago did you appoint your health guardian?

vii. Have you ever made changes to your Enduring Guardian appointment? If so, what prompted this? (*Prompts:* person is no longer available)

viii. Where is your Enduring Guardian document stored? This can just be a general response. (*Prompts:* i.e. in my home, with my doctor, in a safety deposit box)

ix. Have you shared your Enduring Guardian document with anyone, or told people where it can be found? (*Prompts:* doctor, lawyer, appointed decision-maker, others close to you)

Being a health guardian is an important role, because it involves making medical decisions for someone when they are very unwell and not able to make their own choices.

x. What kinds of conversations have you had with your health guardian about your wishes for the kind of care you would want if you were very ill?
    1. Have you put any limits on your health guardian's role? For example, have you given very strict instructions regarding your future healthcare, or have you allowed your health guardian to use their own judgment?

2. If you had help from a lawyer to prepare the Enduring Guardian document, did they provide any information that would help your health guardian to understand their role?
3. How confident do you feel about your health guardian making decisions for you about your healthcare and personal circumstances?

xi. What kinds of discussions have you had with those around you about who you wanted to appoint as your health guardian? (*Prompts:* doctor, lawyer, family members, friends)

1. How did these discussions go?
2. How comfortable were you having these discussions?
3. Did your feelings change depending on the person you were speaking with?
4. Did you feel you got the information you needed from a doctor and/or lawyer to understand your legal rights and the importance of appointing a health guardian?
5. Did you have enough time to talk about what you wanted to include in your Enduring Guardian document?

xii. Have you had experiences where your health guardian has had to act on your behalf? For example, if you've been very sick and they had to make decisions about your medical care? If yes, how did that go?

1. How do you think your health guardian managed? Were you happy or unhappy with decisions they made on your behalf?

d. You mentioned you have an Advance Care Directive:

i. Why did you decide to make an Advance Care Directive?

ii. How did you go about making your Advance Care Directive? (*Prompts:* spoke with a doctor, talked to family members, talked to other people who might be involved in making decisions for them if they are very ill, looked up information)

iii. Did you have discussions with those around you about your wishes for your future healthcare? (*Prompts:* doctor, lawyer, family members, friends)

1. How did these discussions go?
2. How comfortable were you having these discussions?
3. Did your feelings change depending on the person you were speaking with?
4. Did you feel you got the information you needed from a lawyer to understand your legal rights and the importance of having an Advance Care Directive?
5. Did you have enough time to talk about what you wanted to include in your Advance Care Directive?

iv. Did you find it difficult or easy to make your Advance Care Directive? Was there any way in which the process could be improved?

v. Approximately how long ago did you make your Advance Care Directive?

vi. Have you ever changed your Advance Care Directive? If so, what prompted this?

vii. Where is your Advance Care Directive stored? This can just be a general response. (*Prompts:* i.e. in my home, with my doctor, in a safety deposit box)

viii. Have you shared your Advance Care Directive with anyone, or told people where it can be found? (*Prompts:* doctor, appointed decision-maker, others close to you)

ix. How confident are you that your doctors and/or family members will follow the wishes and instructions you have included in your Advance Care Directive?

2. I would like to learn more about anything that has stopped you from engaging with Advance Personal Planning.

Interviewer Note: Question options below will depend on responses to initial screening question.

a. You mentioned you haven't made a Will:

i. Can you tell me a bit more about why you haven't made a Will? (*Prompts:* don't think it is needed, don't own property)

ii. Have you had any discussions with those around you about your wishes for what should happen to your property or assets following your death? (*Prompts:* lawyer, family members, friends)

1. How did these discussions go?
2. How comfortable were you when having these discussions?
3. Did your feelings change depending on who you were speaking with?
4. Did you feel you know enough about the kind of legal rights that are protected by having a Will?

iii. Would you feel more confident that your wishes will be followed if you were to make a Will? Or do you feel discussing your wishes is enough?

b. You mentioned you haven't appointed an Enduring Power of Attorney:

i. Can you tell me a bit more about why you haven't appointed a financial attorney? (*Prompts:* don't think it is needed, don't have a person they want to appoint in that role, not really sure what the role is for)

ii. Have you had any discussions with those around you about your wishes for how your money and/or property should be managed if you become very unwell and are unable to make these decisions for yourself? (*Prompts:* financial planner, lawyer, family members, friends)

1. How did these discussions go?
2. How comfortable were you when having these discussions?
3. Did your feelings change depending on who you were speaking with?
4. Did you feel you know enough about the kind of legal rights that are protected by appointing a financial attorney?

iii. Would you feel more confident that your wishes will be followed if you were to appoint a financial attorney? Or do you feel discussing your wishes is enough?

c. You mentioned you haven't appointed an Enduring Guardian:

i. Can you tell me a bit more about why you haven't appointed a health guardian? (*Prompts:* don't think it is needed, don't have a person they want to appoint in that role, not really sure what the role is for)

ii. Do you know who would legally be recognised as your medical decision-maker if you got very ill and couldn't make your own choices? (*Prompt*: 'Person Responsible' hierarchy under the *Guardianship Act* – Guardian; Spouse; Carer; Close Friend or Relative)

iii. Have you had any discussions with those around you about your wishes for your medical care if you become very unwell and are unable to make these decisions for yourself? (*Prompts:* doctor, lawyer, family members, friends)

1. How did these discussions go?
2. How comfortable were you when having these discussions?
3. Did your feelings change depending on who you were speaking with?
4. Did you feel you know enough about the kind of legal rights that are protected by appointing a health guardian?

iv. Would you feel more confident that your wishes will be followed if you were to appoint a health guardian? Or do you feel discussing your wishes is enough?

d. You mentioned you haven't made an Advance Care Directive:

i. Can you tell me a bit more about why you haven't made an Advance Care Directive? (*Prompts:* don't think it is needed, have talked about my wishes with others)

ii. Have you had any discussions with those around you about your preferences for future healthcare if you become very unwell and are unable to make these decisions for yourself? (*Prompts:* doctor, healthcare team, family members, family)

1. How did these discussions go?
2. How comfortable were you when having these discussions?
3. Did your feelings change depending on who you were speaking with?
4. Did you feel you know enough about the kind of legal rights that are protected by making an Advance Care Directive?

iii. Would you feel more confident that your wishes will be followed if you were to make an Advance Care Directive? Or do you feel discussing your wishes is enough?

3. **Have you personally had an experience being a decision-maker for someone else? This could be as a financial attorney, where you have made decisions regarding someone's money or property, or as a health guardian, where you have made decisions regarding someone's healthcare and personal circumstances.**

    a. If yes, what were the circumstances?

    b. How did it go? Did you understand what your roles and responsibilities were?

    c. Is there anything you think would have been helpful to know prior to being called on as a decision-maker?

    d. If you have appointed a financial attorney and/or a health guardian, did your experience as a decision-maker influence your own choice about who you want to appoint?

4. **Have you used any resources that helped you understand more about Advance Personal Planning? For example, have you looked at websites, been given brochures, read books, etc.?**

    a. If yes, what were they?

5. **Did the COVID-19 pandemic make you think about completing Advance Personal Planning or reviewing your Advance Personal Planning documents and appointments?**

    a. If yes, can you tell me a bit more about that?

BENEFITS AND RISKS:

Now that we have reflected on your experiences of Advance Personal Planning, I would like to talk more generally about your thoughts on the main benefits or potential risks of engaging in Advance Personal Planning.

6. **If you were speaking with someone who was thinking about doing Advance Personal Planning:**

    a. What kinds of benefits would you discuss with them?

    b. What kinds of risks do you think they should be aware of?

    c. Do you think people are more likely to get what they want by doing Advance Personal Planning?

Benefit Prompts:
- Preferences and wishes are known;
- Instruments can be used to guide future decisions and minimise uncertainty
- Helps to prevent legal disputes arising in future.

Risk Prompts:
- Instructions given when a person is healthy may not accurately represent their wishes at a time when they are unwell
- Advance Personal Planning instruments may not be reviewed or updated
- Participation of older person may be inappropriately influenced by others
- Sufficient consideration is not given to the person's wellbeing, including legal, social, personal and financial factors
- Advance Personal Planning may facilitate opportunities for abuse or exploitation.

DEMOGRAPHICS AND CONCLUSION:

I have a few demographic questions for you before we end the interview.

7. **What is your age? (an age range is acceptable i.e. 65-70 years)**

8. **What is your gender? (female, male, non-binary, identify with no particular gender, prefer not to say)**

9. **Do you identify as an Aboriginal or Torres Strait Islander Person?**

❑ Yes
❑ No

10. **What is the highest level of education you have completed?**

❑ Primary School (Year 6)
❑ High School (Year 7-12)
❑ Trade or vocational education (e.g. TAFE)
❑ University degree
❑ Other (please specify)

11. **Were you born in Australia?**

❑ Yes
❑ No (please specify)

12. In which region of NSW do you currently live?

- ❑ Central Coast
- ❑ Central West & Orana
- ❑ Far West
- ❑ Hunter
- ❑ Illawarra-Shoalhaven
- ❑ New England & North West
- ❑ North coast
- ❑ Riverina Murray
- ❑ South East & Tablelands
- ❑ Other (please specify)

13. Before we wrap up, is there anything else you would like to add?

14. Would you like to receive a copy of the interview transcript so that you can clarify any points, correct any factual errors, or add brief examples that you have thought of since our interview?

a. If yes, confirm contact details.
b. If no, continue.

15. Would you like to receive a brief summary of the results of this study? I anticipate the summary will be available by late 2021.

a. If yes, confirm contact details.
b. If no, continue.

Thank you very much for your time. If you have any questions about this project, please feel free to contact me. You will find my details on the information sheet I sent you.

Thank you again, and goodbye.

END OF INTERVIEW

APPENDIX B
OLDER PERSON
PARTICIPANT INFORMATION STATEMENT

PARTICIPANT INFORMATION SHEET

ETH21-5989 – YOUR PERSPECTIVES AND EXPERIENCES OF ADVANCE PERSONAL PLANNING

WHO IS CONDUCTING THIS RESEARCH?

My name is Briony Johnston, and I am a PhD candidate in the Faculty of Law at the University of Technology Sydney. My Principal Supervisor is Professor Nola Ries, who can be contacted via email on Nola.Ries@uts.edu.au. You can also contact me by phone [redacted] or by email Briony.Johnston@student.uts.edu.au.

WHAT IS THE RESEARCH ABOUT?

The purpose of this research is to explore your perceptions and experiences of Advance Personal Planning. Advance Personal Planning is the process of thinking about and sharing your values and wishes for your future medical care, financial management, living arrangements and other personal matters. Advance Personal Planning can help other people know your wishes in case you get seriously ill or injured and cannot make or communicate decisions yourself. Advance Personal Planning may include making documents such as a Will or Advance Care Directive or appointing decision-makers such as an Enduring Guardian or an Enduring Power of Attorney.

The interview will ask you about your experiences with Advance Personal Planning, including:

- If you have completed any aspects of Advance Personal Planning;
- If anything helped you, or stopped you from, engaging with Advance Personal Planning;
- If you have spoken with those close to you about your wishes;
- If you have spoken with professionals, such as a lawyer or healthcare provider, about your wishes; and
- What you think are the benefits and/or disadvantages of Advance Personal Planning.

The interview will not ask you about any specific wishes or instructions you may have discussed with those close to you, or anything you have specifically included in legal documents.

WHY HAVE I BEEN INVITED?

You have been invited to participate because you previously completed a survey, 'Taking action: Supporting older adults to do advance personal planning'. At the end of that survey, you indicated you may be willing to take part in an interview with me. I am now getting in touch with everyone who provided their contact details.

Before you decide to participate in this research study, please confirm that you are able to complete an interview in English, that you are aged 65 years or over, or 50 years or over for Indigenous people, and that you live in a regional community in NSW.

FUNDING

My candidature is supported by the Australian Research Council Discovery Project Grant 'Taking Action: Increasing Advance Personal Planning by Community-Dwelling Older Adults'. The Australian Research Council, as a funder, does not have a role in my sub-studies, nor do they have any commercial interests in my outcomes.

WHAT DOES MY PARTICIPATION INVOLVE?

If you decide to participate, I will invite you to take part in one interview via telephone. The interview may take up to 60 minutes of your time and will occur on a day and at a time that is convenient for you. You are welcome to have a support person with you during the interview or any other form of support that would help you. With your permission, I would like to audio-record our conversation so that a transcript can be prepared of our discussion for analysis. You will have the opportunity to review the transcript of your interview. You can choose not to answer any questions if you prefer not to, and you can pause and/or stop the interview at any time. You can also receive a brief summary of the results of my study if you are interested.

ARE THERE ANY RISKS/INCONVENIENCE?

Yes, there are some risks/inconvenience. If you agree to complete an interview, there is an inconvenience of taking the time to participate, which I estimate will be up to 60 minutes.

While no risks are anticipated, it is possible that involvement in this study may cause you to reflect on experiences relating to issues involved in Advance Personal Planning, such as end-of-life care, preparation for death and management of finances. I will not ask for any personal details about your wishes or instructions that you may have discussed with those close to you or included in any legal documents.

The interview will discuss the process of planning for the rest of your life, including your health care preferences, financial decisions and the distribution of property following the end of life. If this conversation raises any concerns for you, I will be able to provide information such as the Senior Rights Service (**1800 424 079**) and the Older People's Mental Health Services (**1800 011 511**).

By completing the interview, you will have the opportunity to share your views and experiences. This will improve knowledge of how people approach Advance Personal Planning.

DO I HAVE TO TAKE PART IN THIS RESEARCH PROJECT?

Participation in this study is voluntary. It is completely up to you whether or not you decide to take part. If you do decide to take part, you can change your mind and stop the interview at any time. You can also choose not to answer any questions if you prefer not to.

WHAT IF I WITHDRAW FROM THIS RESEARCH PROJECT?

If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason by simply stopping the interview. If you withdraw from the study, I might ask you if it is okay to use the information you shared with me up to that point, but I will not include any identifying information about you. If you are not comfortable with this, any responses noted and/or audio-recorded during the interview will be destroyed.

WHAT WILL HAPPEN TO INFORMATION ABOUT ME?

By providing verbal consent, you consent to the research team collecting and using personal information about you for the research project. All this information will be treated confidentially.

Consent will be requested to audio-record the interview so a transcript can be prepared. The transcript will be de-identified, so I will be using a code to identify you to protect your privacy. Your name or any identifying information you may have provided will be removed from the transcript. Both the audio-recordings and transcripts will be stored securely. Only myself and my supervisors will be able to view the data for the purpose of analysis. Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law. Data will be stored for a minimum period of five years from the date of completion of the research project, in line with the UTS Guidelines for the Management of Research Data. Following this period, all data will be archived according to UTS processes for archiving records.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums, including journal articles, conference presentations, electronic publications or reports, as well as in my thesis. In any publication and/or presentation, information will be provided in such a way that you cannot be identified. I will protect your privacy at all times as no personal details will be disclosed or included in any form of discussion or publication.

In accordance with relevant Australian and/or NSW Privacy laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

The results of this research may also be shared through open access (public) scientific databases, including internet databases. This will enable other researchers to use the data to investigate other important research questions. Results shared in this way will always be de-identified by removing all personal information (e.g. name, address, date of birth etc.).

WHAT IF I HAVE CONCERNS OR A COMPLAINT?

If you have concerns about the research that you think I or my supervisor can help you with, please feel free to contact me by email Briony.Johnston@student.uts.edu.au or by phone [redacted].

You will be given a copy of this form to keep.

NOTE:
This study has been approved in line with the University of Technology Sydney Human Research Ethics Committee [UTS HREC] guidelines. If you have any concerns or complaints about any aspect of the conduct of this research, please contact the Ethics Secretariat on ph.: +61 2 9514 2478 or email: Research.Ethics@uts.edu.au and quote the UTS HREC reference number [ETH21-5989]. Any matter raised will be treated confidentially, investigated and you will be informed of the outcome.

APPENDIX C
SURVEY INSTRUMENT FOR LAWYERS

Your Experiences with Assisting Older People with Advance Personal Planning

This survey will take about 20 minutes to complete.

This survey will explore a range of issues, including:
- Your professional experience with advising older people on APP
- Advantages and disadvantages of APP for older people
- Capacity
- The impact of COVID-19 on APP for older people
- Demographics

If you have any questions about this survey, please email Ms Briony Johnston: Briony.Johnston@student.uts.edu.au

Any information you provide will remain private and confidential.

Thank you for taking the time to complete this survey.

Note to the Ethics Committee: Please note this is a word document version of the survey that will be programmed online in REDCap. The subscript numbers next to each response option are included for coding purposes only and will not be visible to participants when completing the survey online.

Section A: Your Professional Experience with Advising Older People on Advance Personal Planning

Advance Personal Planning **(APP)** is a communication process that involves contemplation, discussion, preparation and revision of instruments relating to a person's future property, health, living, and financial arrangements in anticipation of future incapacity or death.

APP may involve one or more of: writing a **Will**; completing an **Advance Care Directive (ACD)**; or appointing an **Enduring Guardian (EG)** or **Enduring Power of Attorney (EPA)**.

1. In your current professional role, do you assist older people with APP?

For this survey, ***older people*** refers to those aged 65 years and older or, for Aboriginal people, those aged 50 years and older.

☐$_0$ No – Thank you for your response. Unfortunately, you are not eligible to complete the rest of the survey.
☐$_1$ Yes – Please continue to complete this survey.

2. What proportion of your practice involves APP work?

☐$_1$ Less than 25%
☐$_2$ 25-49%
☐$_3$ 50-74%
☐$_4$ More than 75%

In the questions that follow, please note the following guidance:
Rarely means around 20% of the time or less
Sometimes means less than 50% of the time
Often means more than 50% of the time
Usually means 80% of the time or more

3. In your experience, an older person is prompted to engage in APP when:

		Rarely	Sometimes	Often	Usually
A	A lawyer initiates APP conversations	☐$_1$	☐$_2$	☐$_3$	☐$_4$
B	S/he has received a medical diagnosis with life limiting implications and/or is experiencing deteriorating health	☐$_1$	☐$_2$	☐$_3$	☐$_4$
C	S/he has had a discussion about APP with their family or friend	☐$_1$	☐$_2$	☐$_3$	☐$_4$
D	A doctor or other healthcare provider recommends APP	☐$_1$	☐$_2$	☐$_3$	☐$_4$
E	S/he has had a discussion with a financial planner, banker or insurance advisor	☐$_1$	☐$_2$	☐$_3$	☐$_4$
F	A residential facility requires the older person to do APP	☐$_1$	☐$_2$	☐$_3$	☐$_4$
G	S/he has had experience as a carer or decision-maker for another person	☐$_1$	☐$_2$	☐$_3$	☐$_4$
H	There has been an illness or death of someone close to them	☐$_1$	☐$_2$	☐$_3$	☐$_4$
I	Other (please specify): _____	☐$_1$	☐$_2$	☐$_3$	☐$_4$

4. In your experience, what stops older people from engaging in APP?

		Rarely	Sometimes	Often	Usually
A	Not ready to engage in APP	☐$_1$	☐$_2$	☐$_3$	☐$_4$
B	Do not think APP is relevant or needed	☐$_1$	☐$_2$	☐$_3$	☐$_4$

C	They don't have someone they trust to appoint as an EG/EPA	☐1	☐2	☐3	☐4
D	Conflict among family or others close to the older person	☐1	☐2	☐3	☐4
E	Concern that APP instruments cannot be changed once made	☐1	☐2	☐3	☐4
F	APP is too time consuming	☐1	☐2	☐3	☐4
G	APP is too expensive	☐1	☐2	☐3	☐4

5. How often does the scope of your APP practice involve assisting older people with making or updating the following instruments?

		Rarely	**Sometimes**	**Often**	**Usually**
A	Will	☐1	☐2	☐3	☐4
B	ACD	☐1	☐2	☐3	☐4
C	EG	☐1	☐2	☐3	☐4
D	EPA	☐1	☐2	☐3	☐4
E	Other instrument (please specify): _____	☐1	☐2	☐3	☐4

6. How often do you encourage older people to speak about their wishes with:

		Rarely	**Sometimes**	**Often**	**Usually**
A	Their appointed decision-maker(s)	☐1	☐2	☐3	☐4
B	Other family members, carers or friends who are not an appointed decision-maker	☐1	☐2	☐3	☐4
C	Their family doctor or other healthcare provider	☐1	☐2	☐3	☐4
D	A financial advisor	☐1	☐2	☐3	☐4
E	Other (please specify): _____	☐1	☐2	☐3	☐4

7. Do you assist older people with drafting Advance Care Directives (ACDs)?

An ***Advance Care Directive (ACD)*** is a document that states a person's values and wishes for health care they would or would not want in the event of a serious or life-threatening illness or injury and they lack capacity to make care decisions.

☐0 No – Go to Question 8.
☐1 Yes – Go to Question 9.

8. What stops you from assisting older people with ACDs?

		Strongly Agree	**Agree**	**Unsure**	**Disagree**	**Strongly Disagree**
A	I do not see drafting ACDs as being part of a lawyer's role	☐1	☐2	☐3	☐4	☐5
B	Concern about upsetting the older person	☐1	☐2	☐3	☐4	☐5

C	Conversations are upsetting or uncomfortable for me	☐1	☐2	☐3	☐4	☐5
D	Differences between the older person and me in age, cultural, religious or other personal characteristics	☐1	☐2	☐3	☐4	☐5
E	Older people do not want to discuss their healthcare wishes with me	☐1	☐2	☐3	☐4	☐5
F	It is difficult to draft documents that can be applied in specific medical contexts	☐1	☐2	☐3	☐4	☐5
G	I do not know enough about the medical context of ACDs, including medical interventions and their implications for the older person	☐1	☐2	☐3	☐4	☐5
H	I do not know enough about health sector policies/practices	☐1	☐2	☐3	☐4	☐5
I	Other (please specify): _____	☐1	☐2	☐3	☐4	☐5

9. When assisting older people with drafting ACDs, have you experienced any of the following difficulties?

		Rarely	**Sometimes**	**Often**	**Usually**
A	Conversations are upsetting for the older person	☐1	☐2	☐3	☐4
B	Conversations are upsetting or uncomfortable for me	☐1	☐2	☐3	☐4
C	Differences between the older person and me in age, cultural, religious or other personal characteristics	☐1	☐2	☐3	☐4
D	Older people do not want to discuss their healthcare wishes with me	☐1	☐2	☐3	☐4
E	It is difficult to draft documents that can be applied in specific medical contexts	☐1	☐2	☐3	☐4
F	I do not know enough about the medical context of ACDs, including medical interventions and their implications for the older person	☐1	☐2	☐3	☐4
G	I do not know enough about health sector policies/practices	☐1	☐2	☐3	☐4
H	Other (please specify): _____	☐1	☐2	☐3	☐4

10. When assisting older people with drafting ACDs, is there a specific template or precedent you use?

☐$_0$ No – Go to Question 11.
☐$_1$ Yes – Please note the source of any templates, for example, specific public websites, developed in-house, etc.: _____
_____
_____
_____
_____

11. Do you have experience working with older people from Aboriginal populations?

Please note, the Australian Institute of Health and Welfare clarifies older Aboriginal populations typically refer to people aged 50 years and over.

☐$_0$ No – Go to Question 12.
☐$_1$ Yes – Go to Question 12 and then Question 13.

12. Do you have experience working with older people from culturally and linguistically diverse (CALD) populations?

Please note, NSW Health defines CALD as people who identify as having cultural or linguistic connections with their place of birth, ancestry or ethnic origin, religion, preferred language or language spoken at home.

☐$_0$ No
☐$_1$ Yes

13. When engaging older people from Aboriginal or CALD populations in APP, have you experienced any of the following?

		Rarely	Sometimes	Often	Usually
A	There is a lack of trust of the legal system or legal processes	☐$_1$	☐$_2$	☐$_3$	☐$_4$
B	There is a reluctance to discuss death or the end-of-life	☐$_1$	☐$_2$	☐$_3$	☐$_4$
C	I do not have sufficient understanding of significant cultural, historical or spiritual issues relating to the older person	☐$_1$	☐$_2$	☐$_3$	☐$_4$
D	There are language difficulties	☐$_1$	☐$_2$	☐$_3$	☐$_4$
E	Concerns about the influence or involvement of a family member or friend	☐$_1$	☐$_2$	☐$_3$	☐$_4$
F	Concerns about the information being communicated to the older person or me, if a family member or friend is translating/interpreting during a meeting with the older person	☐$_1$	☐$_2$	☐$_3$	☐$_4$

G	Other (please specify): _____	☐1	☐2	☐3	☐4

14. Have you used any resources that were specifically tailored to promote culturally appropriate practice?

☐0 No – Go to Question 15.
☐1 Yes – Please note the source of these resources: _____
_____
_____
_____
_____

15. If you have experience working with older people from Aboriginal or CALD populations, are there any further reflections you would like to include?

☐0 No – Go to Section B.
☐1 Yes – Please include any further reflections here: _____
_____
_____
_____
_____

Section B: Advantages and Disadvantages of Advance Personal Planning for Older People

16. To what extent do you think the following are advantages of APP for older people?

		Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree
A	APP ensures an older person's wishes and preferences are known	☐1	☐2	☐3	☐4	☐5
B	APP makes decisions easier for family, friends or appointed decision makers to act on the older person's behalf	☐1	☐2	☐3	☐4	☐5
C	An older person's wellbeing is prioritised when completing APP	☐1	☐2	☐3	☐4	☐5
D	Engagement with APP helps to prevent legal disputes or problems in future	☐1	☐2	☐3	☐4	☐5
E	Other (please specify): _____	☐1	☐2	☐3	☐4	☐5

17. To what extent do you think the following are risks or disadvantages of APP for older people?

		Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree
A	APP documents prepared when older people are healthy may not accurately represent their wishes at a time when they are unwell	☐1	☐2	☐3	☐4	☐5
B	APP documents and appointments are not reviewed or updated	☐1	☐2	☐3	☐4	☐5
C	The participation of older people in APP processes may be inappropriately influenced by others	☐1	☐2	☐3	☐4	☐5
D	APP documents and appointments could be misused to exploit or abuse older people	☐1	☐2	☐3	☐4	☐5
E	Other (please specify): _____	☐1	☐2	☐3	☐4	☐5

18. Reflecting on the survey, is there anything else you would like to add about your perceptions of, or experiences with, assisting older people with APP?

_____
_____
_____
_____

Section C: Capacity

In the questions that follow, please note the following guidance:
Rarely means around 20% of the time or less
Sometimes means less than 50% of the time
Often means more than 50% of the time
Usually means 80% of the time or more

19. How often do you have concerns about whether an older person has capacity to make APP instruments?

Rarely	Sometimes	Often	Usually
☐1	☐2	☐3	☐4

20. How often do the following factors prompt you to have capacity concerns about older people?

		Rarely	Sometimes	Often	Usually
A	The older person has a diagnosis of dementia or other neurocognitive condition	☐1	☐2	☐3	☐4
B	The person is of advanced age and considered ‘very old’ (i.e. 85 years or older)	☐1	☐2	☐3	☐4

C	The older person resides in an aged care facility	☐1	☐2	☐3	☐4
D	The older person has difficulty recalling or communicating information relevant to their legal affairs	☐1	☐2	☐3	☐4
E	The older person is accompanied by others (e.g. family, friends) who speak for the older person	☐1	☐2	☐3	☐4
F	Concern that others (e.g. family, friends) are unduly influencing the older person	☐1	☐2	☐3	☐4
G	Results of a cognitive test such as the Mini Mental State Examination (MMSE)	☐1	☐2	☐3	☐4
H	The older person's instructions do not appear to safeguard their interests	☐1	☐2	☐3	☐4
I	Other (please specify other factors that prompt you to have concerns about the capacity of older people): _____	☐1	☐2	☐3	☐4

21. Have you ever referred an older person for a capacity assessment by a health professional?

☐0 No – Go to Section D.
☐1 Yes – Go to Question 22.

22. Of the older people you assist with making APP instruments, what proportion have you referred to a health professional for capacity assessments? You may specify a proportion by selecting 'Other' or indicate one of the ranges provided.

Specify a proportion (e.g. 10%): _____

☐1 Less than 25%
☐2 25-49%
☐3 50-74%
☐4 More than 75%

23. To whom do you refer older people for capacity assessments? Please tick all that apply.

☐1 General Practitioner
☐2 Geriatrician
☐3 Geriatric Neuropsychology Specialist
☐4 Clinical Psychologist
☐5 Psychiatrist
☐6 Other (please specify): _____

24. Have you encountered any issues accessing appropriately qualified health professionals to conduct capacity assessments?

☐0 No
☐1 Yes (please specify): _____

Section D: The Impact of COVID-19 on Advance Personal Planning

25. Has the COVID-19 situation prompted inquiries to you or your organisation for legal information or advice about APP?

☐$_0$ No – Go to Question 28.
☐$_1$ Yes – Go to Question 26.
☐$_2$ Unsure – Go to Question 28.

26. If so, have these inquiries been from (please tick all that apply):

☐$_1$ Older people wanting to make or update APP documents
☐$_2$ Family members or friends making inquiries on behalf of an older person
☐$_3$ Healthcare practitioners or aged care facilities
☐$_4$ Other (please specify): _____

27. If you wish to elaborate on the nature and extent of inquiries you or your organisation have received, please do so here:

_____
_____
_____
_____
_____

28. Did you encounter any of the following barriers during the COVID-19 situation due to social distancing requirements?

		No	Yes
A	Older people were concerned about travelling to lawyer's premises	☐$_0$	☐$_1$
B	Lawyers not being able to visit older people in residential aged care facilities or other locations (e.g. home visits)	☐$_0$	☐$_1$
C	Difficulties with witness requirements	☐$_0$	☐$_1$
D	Other (please specify): _____	☐$_0$	☐$_1$

29. Did you use any of the following technological options to overcome these barriers?

		No	Yes
A	Phone consultations	☐$_0$	☐$_1$
B	Video consultations	☐$_0$	☐$_1$
C	Witnessing documents via audio-visual links	☐$_0$	☐$_1$
D	Other (please specify): _____	☐$_0$	☐$_1$

30. To what extent do you believe the COVID-19 situation created anxiety and stress for older people in your community with respect to APP?

Not at All	A Little	Some	A Lot	Don't Know / Not Sure
☐$_1$	☐$_2$	☐$_3$	☐$_4$	☐$_5$

31. To what extent do you agree or disagree with the following advantages of older people completing APP in a situation like COVID-19?

		Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree
A	Encourages older people to think about something they may have been putting off	☐1	☐2	☐3	☐4	☐5
B	Provides guidance for family, friends or appointed decision-makers in the event the older person becomes seriously ill	☐1	☐2	☐3	☐4	☐5
C	Other (please specify): _____	☐1	☐2	☐3	☐4	☐5

32. To what extent do you agree or disagree with the following disadvantages of older people completing APP in a situation like COVID-19?

		Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree
A	Potential for abuse, exploitation or manipulation if the preparation of documents has been motivated or instigated by others	☐1	☐2	☐3	☐4	☐5
B	The process may be rushed with less time for careful consideration	☐1	☐2	☐3	☐4	☐5
C	Other (please specify): _____	☐1	☐2	☐3	☐4	☐5

Section E: Demographics

33. How many years of APP practice experience do you have?

☐1 0-4 years
☐2 5-9 years
☐3 10 years or more

34. What is the size of the firm or organisation where you work?

☐1 Sole practice
☐2 Small organisation (2-9 lawyers)
☐3 Mid-size organisation (10-49 lawyers)
☐4 Large organisation (50 or more lawyers)

35. Please indicate the region of NSW in which you currently work:

☐1 Central Coast
☐2 Central West & Orana
☐3 Far West
☐4 Hunter
☐5 Illawarra-Shoalhaven
☐6 New England & North West
☐7 North Coast
☐8 Riverina Murray

☐9 South East & Tablelands ☐11 Sydney Metropolitan Area
☐10 Other (please specify): _____

36. What is your gender?

☐1 Male
☐2 Female
☐3 Prefer to self-describe (please specify): _____

37. What is your age?

☐1 24 or younger
☐2 25-34
☐3 35-44
☐4 45-54
☐5 55-64
☐6 65 and over
☐7 Prefer not to say

Section F: Further Contact

38. Would you be interested in receiving information regarding follow-up research? Additional studies may include a review of ACD templates used by lawyers or a telephone interview to discuss your APP experiences in more detail.

☐0 No – Thank you for taking the time to complete this survey. You will not receive information regarding further studies.
☐1 Yes – Thank you for your interest in receiving information regarding further studies. Please provide your contact details below.

Name: _____

Role / Workplace: _____

Contact Phone Number: _____

Email Address: _____

Preferred Method of Contact: _____

Thank you for completing this survey.

APPENDIX D
PARTICIPANT INFORMATION STATEMENT FOR ONLINE SURVEY

INFORMATION SHEET FOR ONLINE SURVEY

ETH20-5024 – YOUR EXPERIENCES WITH ASSISTING OLDER PEOPLE WITH ADVANCE PERSONAL PLANNING

Note to the Ethics Committee: This information sheet will display when participants click on the weblink to the online survey.

What is the research study about?
This survey explores the perceptions and experiences of regional lawyers with assisting older adults to complete Advance Personal Planning (APP).

APP may involve one or more of: writing a Will; completing an Advance Care Directive (ACD); or appointing an Enduring Guardian (EG) or Enduring Power of Attorney (EPA). The survey explores current processes and any barriers that may prevent older people in regional areas from fully engaging with planning ahead.

Who can participate in the survey?
You are eligible to complete the online survey if you are a lawyer with experience assisting older adults to complete APP in your professional role.

Who is conducting this research?
My name is Briony Johnston and I am a PhD candidate in the Faculty of Law at the University of Technology Sydney. My Principal Supervisor is Associate Professor Nola Ries, who can be contacted via email on Nola.Ries@uts.edu.au.

Do I have to take part in this research study?
Participation in this study is voluntary. It is completely up to you whether or not you decide to take part. The survey should take about 20 minutes of your time. You can change your mind at any time and stop completing the survey without consequences.

Are there any risks or benefits of participating?
There are no anticipated risks associated with participating in this research, except for the possible inconvenience of taking time to complete the survey.

By completing the survey, you will have the opportunity to share your views and experiences. This will improve knowledge of how lawyers work with older people in the area of APP.

What will happen to information about me?
Access to the online survey is via REDCap, which is an electronic platform. Submission of the online survey is an indication of your consent. By ~~clicking the following weblink [insert weblink],~~ agreeing to proceed with the survey, you consent to the research team collecting and using your survey responses for the research project.

All information will be treated confidentially. A code will be used to store answers to the survey in REDCap. Access to REDCap is protected by password and the data will only be available to myself and my supervisors. A copy of the data will be exported to Excel for the purpose of analysis, and this spreadsheet will also be password protected. Personal details will only be collected from participants who agree to receive information regarding additional research activities. If you do not agree to receive further information, no personal details will be obtained. If personal details are provided, these will be stored separately from your survey responses in a password protected document.

Your information will only be used for the purpose of this research project. Data will be stored for a minimum period of five years from the date of completion of the research project, in line with the UTS Guidelines for the Management of Research Data. Following this period, all data will be archived according to UTS processes for archiving records.

I plan to discuss and publish the results of this survey in journal articles, conference presentations, electronic publications or reports, as well as in my thesis. If you do provide personal details for the purpose of receiving information regarding further activities in my PhD research, these details will never be disclosed or included in any form of discussion or publication.

What if I have concerns or a complaint?
If you have concerns about the research that you think I or my supervisor can help you with, please feel free to contact me on Briony.Johnston@student.uts.edu.au.

If you would like to talk to someone who is not connected with the research, you may contact the Research Ethics Officer on 02 9514 9772 or Research.Ethics@uts.edu.au and quote this number ETH20-5024.

Thank you for taking the time to consider this invitation.

APPENDIX E
INTERVIEW GUIDE FOR KEY INFORMANT PROFESSIONALS

Interview Guide for Professionals:
Your Perspectives and Experiences on Assisting Older People with Advance Personal Planning

INTRODUCTION

Hello, this is Briony from the University of Technology Sydney. Thank you for your interest in the research project on professionals' perspectives and experiences of Advance Personal Planning for older adults.

NOTE TO THE HUMAN RESEARCH ETHICS COMMITTEE: I will read the 'Verbal Consent Script V1 28.01.2022' here and complete it over the phone or web conference with participants before proceeding with the interview.

DEFINITION OF KEY TERMS
As you know, this project is focused on Advance Personal Planning by older adults. I would like to define some key terms to make sure we have a common understanding.

First, **Advance Personal Planning** or **APP** allows people to plan ahead to prevent unwanted medical, financial and legal consequences from arising in future if they are no longer able to speak for themselves, due to either a loss of capacity or death. **APP** may involve one or more of: writing a Will; completing an Advance Care Directive (ACD); or appointing an Enduring Guardian (EG) or an Enduring Power of Attorney (EPA).

Second, **older adults** means anyone who is 65 years of age or older.

Do you have any questions before we begin?
a. If yes, answer questions
b. If no, continue.

INTERVIEW QUESTIONS

<u>Description of Role:</u>

1. Could you begin by describing your role, and the role of your organisation?

a. **Are there any particular aspects of your role / any particular focus within your organisation that helps to promote Advance Personal Planning?**

General Views on Advance Personal Planning:

2. **In your professional experience:**

    a. **What do you consider to be high-quality Advance Personal Planning?**

    b. **How confident are you that the completed Advance Personal Planning instruments can be used successfully in future and/or reduce disputes and problems?**

    c. **Do you have any concerns relating to, or experiences of, Advance Personal Planning mechanisms facilitating the abuse or exploitation of older people?**

3. **Do you have experience working in both regional and metropolitan areas? If so, have you noticed any differences within your professional experience depending on the context?**

Barriers, Benefits and Risks:

Now that we have reflected on your general views of Advance Personal Planning, I would like to discuss barriers to, and benefits or potential risks of, engaging older people in Advance Personal Planning in more detail.

4. **From your perspective, what are the barriers that most often arise for older adults when they are attempting to complete Advance Personal Planning? These may include person-centred, professional-centred, or structural barriers.**

Prompts:

- Person-centred barriers –
    - Lack of knowledge/awareness of APP
    - Lack of readiness to engage
    - Belief that APP is irrelevant or not needed
    - Preference for discussion rather than strict written records
    - Uncertainty regarding the future
    - Lack of support to make decisions

    - Concerns regarding time and/or expense of completing APP
    - Documents may not be current
    - Instructions may be vague / too specific / unhelpfully broad to be implemented
- Professional-centred barriers –
    - Belief that APP instruments (e.g. ACD) are not beneficial or can be too vague or ambiguous to be followed in practice
    - Inconsistency in templates used to prepare APP instruments, including ACDs
    - Not able to access prepared APP instruments at the time when they are needed
    - Time pressures
    - Lack of familiarity with medical aspects / legal aspects of APP documents
    - Concern about upsetting the older person
    - Differences between older person and professional in age / cultural / religious / personal characteristics
- Structural barriers –
    - Fragmented state of current recognition regarding separate instruments (i.e. EG and EPA under statute; ACD under common law)
    - Lack of a uniform scheme for enduring appointments
    - Lack of a uniform system for storing completed APP instruments
    - Lack of a uniform system for accessing completed APP instruments

5. In your experience, what do you think are the main benefits and potential risks of Advance Personal Planning?

Prompts:

- Benefits –
    - Preferences and wishes are known
    - Instruments can be used to guide future decisions and minimise uncertainty
    - Helps to prevent legal disputes arising in future
- Risk –
    - Instructions given when a person is healthy may not accurately represent their wishes at a time when they are unwell
    - APP instruments may not be reviewed or updated
    - Participation of older person may be inappropriately influenced by others
    - Sufficient consideration is not given to the person's wellbeing, including legal, social, personal and financial factors
    - APP may facilitate opportunities for abuse or exploitation

<u>Implementation of Advance Personal Planning Instruments:</u>

6. With respect to interpreting or implementing prepared Advance Personal Planning instruments, what are some of the challenges you have faced?

7. When communicating with family regarding a person's wishes and preferences, what are some of the challenges you have faced?

   a. **Do you implement any particular strategies or guidelines to make these interactions easier?**

8. **When communicating with appointed decision makers regarding a person's wishes and preferences, what are some of the challenges you have faced?**

   a. **Do you implement any particular strategies or guidelines to make these interactions easier?**

9. **Do you think older people are more likely to have their wishes met by completing Advance Personal Planning? Why or why not?**

10. **Advance Personal Planning has several preventive benefits in theory, including the prevention of legal and personal disputes through communication and planning, and encouraging people to engage in regular reviews of their wishes to proactively guard against future conflicts. Do you believe these benefits are realised in your professional experience?**

<u>Potential Areas for Improvement:</u>

Finally, I would like to hear more about your thoughts on potential areas for improvement.

11. **From your perspective, are there any opportunities for improvement within existing Advance Personal Planning processes?**

   a. **If so, can you nominate one area that is most in need of improvement?**

DEMOGRAPHICS AND CONCLUSION

I have a few demographic questions for you before we end the interview.

12. **Before we wrap up, is there anything else you would like to add?**

13. **How long have you worked in your current professional role?**

14. What is your age? (Please note, an age range is acceptable i.e. 40-45years)

15. What is your gender? (female, male, non-binary, identify with no particular gender, prefer not to say)

16. Do you have any colleagues or peers you could recommend who also have experience in this area and may be willing to speak with me?

a. If yes, confirm contact details.
b. If no, continue.

17. Would you like to receive a copy of the interview transcript to review our conversation?

a. If yes, confirm contact details.
b. If no, continue.

18. Would you like to receive a brief summary of the results of this study?

a. If yes, confirm contact details.
b. If no, continue.

Thank you very much for your time. If you have any questions about this project, please feel free to contact me. You will find my details on the information sheet I sent you. Thank you again, and goodbye.

APPENDIX F
PARTICIPANT INFORMATION SHEET FOR PROFESSIONALS

PARTICIPANT INFORMATION SHEET

ETH20-5024 – YOUR PERSPECTIVES AND EXPERIENCES ON ASSISTING OLDER PEOPLE WITH ADVANCE PERSONAL PLANNING

WHO IS CONDUCTING THIS RESEARCH?

My name is Briony Johnston and I am a PhD candidate in the Faculty of Law at the University of Technology Sydney. My Principal Supervisor is Associate Professor Nola Ries, who can be contacted via email on Nola.Ries@uts.edu.au.

WHAT IS THE RESEARCH ABOUT?

The purpose of this research is to explore the perceptions and experiences of professionals with assisting older adults to complete Advance Personal Planning, or interpreting completed Advance Personal Planning documents, or advocating for older people in this area. Advance Personal Planning may involve one or more of: writing a Will; completing an Advance Care Directive; or appointing an Enduring Guardian or Enduring Power of Attorney.

The interview explores current processes, any barriers that may prevent older people from fully engaging with planning ahead, difficulties with interpreting or enacting completed instruments, and areas for improvement from the perspective of professionals with expertise in this area. The interview will ask you about your experiences in the field of Advance Personal Planning, including:

- Factors that may prompt older people to discuss or complete Advance Personal Planning;
- What you consider to be high quality Advance Personal Planning;
- Your level of confidence that completed documents can be used successfully in future;
- Any concerns you may have regarding Advance Personal Planning mechanisms facilitating the abuse or exploitation of older people;
- The main barriers that most often arise for older adults when they are attempting to engage with Advance Personal Planning;
- The main benefits, and potential risks, of Advance Personal Planning for older people; and
- Opportunities for improvement within existing Advance Personal Planning processes.

WHY HAVE I BEEN INVITED?

You have been invited to participate because you have been identified as a professional with experience in the field of Advance Personal Planning, or have contact with older people through a health or advocacy organisation.

You are eligible to complete an interview if you are a professional with experience advocating for the rights of older adults, assisting older adults to complete APP, or interpreting completed Advance Personal Planning documents in your role.

FUNDING

My candidature is supported by the Australian Research Council Discovery Project Grant 'Taking Action: Increasing Advance Personal Planning by Community-Dwelling Older Adults'. The Australian Research Council, as a funder, does not have a role in my sub-studies, nor do they have any commercial interests in my outcomes.

WHAT DOES MY PARTICIPATION INVOLVE?

If you decide to participate, I will invite you to take part in one interview via telephone or web conference. The interview may take up to 45 minutes of your time and will occur on a day and at a time that is convenient for you.

With your permission, I would like to audio-record our conversation so that a transcript can be prepared of our discussion for analysis. You will have the opportunity to review the transcript of your interview. You can choose not to answer any questions if you prefer not to, and you can pause and/or stop the interview at any time. You will also have the opportunity to receive a brief summary of the results of my study if you are interested.

ARE THERE ANY RISKS/INCONVENIENCE?

There are no anticipated risks associated with participating in this research, except for the inconvenience of taking time to participate in the interview, which I estimate will be up to 45 minutes.

By completing the interview, you will have the opportunity to share your views and experiences. This will improve knowledge of how professionals work with older people in the area of Advance Personal Planning and how systems can be improved.

DO I HAVE TO TAKE PART IN THIS RESEARCH PROJECT?

Participation in this study is voluntary. It is completely up to you whether or not you decide to take part. If you do decide to take part, you can change your mind and stop the interview at any time. You can also choose not to answer any questions if you prefer not to.

WHAT IF I WITHDRAW FROM THIS RESEARCH PROJECT?

If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason by simply stopping the interview. If you withdraw from the study, I might ask you if it is okay to use the information you shared with me up to that point, but I will

not include any identifying information about you. If you are not comfortable with this, any responses noted and/or audio-recorded during the interview will be destroyed.

WHAT WILL HAPPEN TO INFORMATION ABOUT ME?

By providing verbal consent, you consent to the research team collecting and using personal information about you for the research project. All this information will be treated confidentially.

Consent will be requested to audio-record the interview so a transcript can be prepared of the conversation for analysis. The transcript will be de-identified, so I will be using a code to identify you to protect your privacy. Your name or any identifying information you may have provided will be removed from the transcript. Both the audio-recordings and transcripts will be stored securely. Only myself and my supervisors will be able to view the data for the purpose of coding and analysing the results. If personal details have been provided, they will never be disclosed or included in any form of discussion or publication.

Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law. Data will be stored for a minimum period of five years from the date of completion of the research project, in line with the UTS Guidelines for the Management of Research Data. Following this period, all data will be archived according to UTS processes for archiving records.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums, including journal articles, conference presentations, electronic publications or reports, as well as in my thesis. In any publication and/or presentation, information will be provided in such a way that you cannot be identified. I will protect your privacy at all times as no personal details will be disclosed or included in any form of discussion or publication.

In accordance with relevant Australian and/or NSW Privacy laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.
The results of this research may also be shared through open access (public) scientific databases, including internet databases. This will enable other researchers to use the data to investigate other important research questions. Results shared in this way will always be de-identified by removing all personal information (e.g. name, address, date of birth etc.).

WHAT IF I HAVE CONCERNS OR A COMPLAINT?

If you have concerns about the research that you think I or my supervisor can help you with, please feel free to contact me on Briony.Johnston@student.uts.edu.au.

You will be given a copy of this form to keep.

Thank you for taking the time to consider this invitation.

NOTE:
This study has been approved in line with the University of Technology Sydney Human Research Ethics Committee [UTS HREC] guidelines. If you have any concerns or complaints about any aspect of the conduct of this research, please contact the Ethics Secretariat on ph.: +61 2 9514 2478 or email: Research.Ethics@uts.edu.au and quote the UTS HREC reference number [ETH20-5024]. Any matter raised will be treated confidentially, investigated and you will be informed of the outcome.

APPENDIX G

PUBLICATION IN JOURNAL OF BIOETHICAL INQUIRY

Bioethical Inquiry
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ORIGINAL RESEARCH

A Revised Approach to Advance Personal Planning: The Role of Theory in Achieving "The Good Result"

Briony Johnston

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Abstract This article explores traditional views of advance care planning in the broader context of advance personal planning, which also accounts for legal and financial matters. Criticisms of existing processes are noted, while the significance of interprofessional collaboration is highlighted. Reframing the purpose of advance personal planning as planning for the rest of life, rather than the end-of-life, and adopting a more holistic perspective informed by theory may help individuals to view advance personal planning as a routine, preventative exercise that safeguards their autonomy and well-being. Both lawyers and healthcare providers have an important role to play in reframing the purpose of advance personal planning. This revised approach is underpinned by the unification of two separate theoretical lenses: Preventive Law Theory and Therapeutic Jurisprudence. This combination enhances our understanding of what it means for people to truly achieve "the good result" (Holtz 2017) when planning ahead for their future legal, financial, health, and personal interests. Preventive Law Theory encourages an ongoing, collaborative relationship between lawyers and their clients, or healthcare providers and their patients, while Therapeutic Jurisprudence ensures an ethical approach to advance personal planning that accounts for all aspects of the individual's well-being, including consideration of vulnerability, autonomy, and empowerment.

Keywords Advance personal planning · Lawyers · Healthcare providers · Theoretical perspectives · Preventive Law Theory · Therapeutic Jurisprudence

Introduction

Advance personal planning (APP) provides a means of protecting individuals' future legal, financial, health, and personal interests at a time when they can no longer speak for themselves (Waller et al. 2018). It is broader than advance care planning (ACP), which is confined to healthcare considerations only, and describes the process of a patient and their healthcare team discussing relevant options and potentially recording their preferences for treatment and goals of care (Sudore et al. 2017). This may produce a legal document known as an Advance Care Directive (ACD) or living will (Kimberly Buck et al. 2021; Baron 2019). APP is an umbrella term that encompasses planning ahead for health, legal, financial, and other personal matters so that wishes can be known and recorded ahead of a period of future incapacity or death (Waller et al. 2018). As opposed to being a distinct area of planning, APP simply refers to the full range of planning mechanisms that are available, such as: a Will, for disposing of property and assets

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following death; the appointment of an Enduring Power of Attorney, which authorizes another person to make decisions regarding an individual's finances and property if they were experiencing a period of incapacity; the appointment of an Enduring Guardian, which enables someone to make decisions in relation to the future health or personal care that may be provided in the event the person cannot make those decisions for themselves; and documenting an ACD, which sets out a person's wishes, values, and preferences for future medical treatment and personal matters, including end-of-life care.

Uptake of relevant instruments remains low and variable (Kimberly Buck et al. 2021; Sellars et al. 2021; Baron 2019). People are often hesitant to engage in APP, equating it with the end-of-life (Batchelor et al. 2019; Moore et al. 2019). The vast majority of existing literature has only focused on ACP processes, relating to the contemplation, discussion, and possible documentation of a person's wishes relating to future healthcare and medical treatment only (Buck et al. 2019; Sudore et al. 2017) rather than considering the full range of advance planning mechanisms that are available. Recent literature has also questioned the utility of ACP, and whether it can in fact achieve its objective of providing high-value, goal-concordant care (Morrison, Meier, and Arnold 2021; McMahan, Tellez, and Sudore 2021; Morrison 2020).

Reframing the purpose of APP as planning for the rest-of-life (Masters, Wylie, and Hubner 2021; Yapp et al. 2018) and adopting a more holistic perspective informed by interdisciplinary collaboration and the application of theory may help individuals to perceive APP as a routine, preventative exercise that safeguards a person's autonomy and well-being (Yapp et al. 2018; Brinkman-Stoppelenburg, Rietjens, and van der Heide 2014; Rhee, Zwar, and Kemp 2012). This revised approach is founded upon the unification of two separate theoretical perspectives: Preventive Law Theory; and Therapeutic Jurisprudence. The combination of Preventive Law Theory and Therapeutic Jurisprudence, termed "theralaw" (Barclift 2008, 36), enhances our understanding of what Holtz (2017) has termed "the good result." Preventive Law Theory encourages an ongoing, collaborative relationship between professionals and their individual clients or patients, while Therapeutic Jurisprudence ensures an ethical approach to APP that accounts for all aspects of an individual's well-being, including consideration of vulnerability, autonomy, and empowerment in the process of planning ahead.

Advance Personal Planning

APP is concerned with an individual's wishes, values, and preferences associated with their money, property, legal affairs, and medical care at a time in the future when they may be either too ill to speak for themselves or cannot communicate their decisions due to a decline in, or loss of, capacity (Sinclair et al. 2020; Detering et al. 2019; NSW Health 2018; Waller et al. 2018). APP may involve a series of acts, including thinking about preferences for the future, discussing these wishes with important parties including family, appointed decision-makers and professionals, and potentially taking the step of formally recording these intentions (Department of Health 2021; Sudore et al. 2017). Relevant instruments include: a Will; the creation of an ACD; an Enduring Power of Attorney appointment; and an Enduring Guardian appointment. APP has been described as empowering (Baron 2019; Ries et al. 2018; Yapp et al. 2018) and an important exercise in self-determination (Close et al. 2021; Sinclair et al. 2021; Moore et al. 2019) as it represents "a means of extending the autonomy of patients to stages in life where they have become incompetent" (Brinkman-Stoppelenburg, Rietjens, and van der Heide 2014, 1000). However, uptake of APP remains low and variable (Buck et al. 2021; Sellars et al. 2021; Baron 2019) and the final steps of maintenance or ongoing reflection are often overlooked (Buck et al. 2021; Baron 2019; Buck et al. 2019; Scott et al. 2013).

Criticisms of Current Processes

While discussions of APP are only now emerging in the available literature (Waller et al. 2018), the utility and success of ACP processes have recently been questioned (Orsatti 2022; Morrison, Meier, and Arnold 2021; McMahan, Tellez, and Sudore 2021; Morrison 2020). Morrison et al. argue that existing evidence reveals ACP "fails to improve end-of-life care" and the objectives of delivering goal-concordant care and improving quality of life for patients are not being met (Morrison, Meier, and Arnold 2021, 1575).

Similarly, appointed decision-makers are often unable to meet their obligations, as they are either not aware of the person's preferences (Morrison 2020, 878) or cannot enact their wishes in a meaningful way in complex clinical environments (Morrison, Meier, and Arnold 2021, 1575–1576). Similarly, even if an ACD has been prepared, it may not be accessible at the point of care, or instructions provided may be either too broad or too specific to be applied in the treatment context (Morrison, Meier, and Arnold 2021, 1576). Communication is another significant factor, as patients are often not talking about their wishes with their healthcare provider or other members of their support community, including family, carers, or appointed decision-makers (Morrison 2020, 878). From a professional perspective, clinicians may not have time to engage in planning conversations or may not feel adequately equipped to introduce the topic with their patients (Morrison 2020, 878).

The Need for Interdisciplinary Collaboration

The traditional approach towards ACP has prioritized communication and shared decision-making between healthcare practitioners and patients (Sudore et al. 2017; Rhee, Zwar, and Kemp 2012). However, evidence indicates people may be more inclined to speak about their healthcare wishes with lawyers as part of the broader exercise of planning for the future (Orsatti 2022, 157; Masters, Wylie, and Hubner 2021; Rolnick et al. 2019). Interestingly Rolnick et al. found that, of the eleven participants interviewed regarding their experience of creating an ACD, six had prepared the document in consultation with a lawyer as it was often incorporated as part of the estate planning process (Rolnick et al. 2019, 3–4). Even the four participants who completed their ACD through a health institution had not sought the involvement of health professionals when documenting their wishes. Participants reported that they appreciated lawyers' knowledge of, and attention to, legal details which gave them a sense of assurance that their wishes would be followed in future (Rolnick et al. 2019, 3–4). This gives people confidence that their plans for the rest-of-life are valid, and their future goals and preferences will be safeguarded.

Masters et al. also highlighted the role of lawyers in assisting individuals to complete APP (Masters, Wylie, and Hubner 2021). In normalizing discussions about future wishes, especially at a time when individuals are in good health, we need to recognize the vital role of lawyers in initiating these conversations. While respondents were most likely to speak with their spouse/partner or a family member about their end-of-life wishes, they were more likely to speak with a lawyer regarding APP than a healthcare professional (Masters, Wylie, and Hubner 2021, 12). This highlights a key area in which lawyers can play a continuing role in APP, ensuring plans are accurate and accommodate all aspects of an individual's welfare when planning for the rest-of-life.

This dichotomy creates tension, as lawyers are not perceived as having the requisite medical knowledge to prepare robust documents relating to future healthcare and treatment (Orsatti 2022, 157). However, Orsatti highlights the benefit of involving lawyers in ACP processes, as they are able to assist people to select "the healthcare agent best suited to the task of promoting the client's wishes," ensure preferences are shared widely among an individual's support community, including with their family, healthcare provider, and appointed decision-makers, and ensure ACP instruments "comply with applicable law to protect clients against the possibility of the documents being ineffective when needed most" (Orsatti 2022, 158). Given that lawyers may be assisting individuals with other planning instruments, including the preparation of a Will or the appointment of a decision-maker, they are likely to have a full overview of the person's circumstances, including who would be best placed to support them in future. Further, lawyers can provide resources for decision-makers that can help explain the purpose of their role, what they would be required to do, and when their powers would begin to operate.

While the benefits of including lawyers are clear, attention should also be directed to lawyers' attitudes towards engaging with people in these areas. Ries et al. conducted a survey of lawyers in Alberta and found the main barrier to assisting clients with ACP was the person's "lack of preparedness to engage in ACP" and that nearly all respondents "said they never or seldom find ACP discussions upsetting or uncomfortable" (Ries et al. 2018, 691). However, just under half of the respondents "revealed some degree of concern with their own lack of knowledge about the medical aspects of ACP and health sector policies and practices" (Ries et al. 2018, 691). This discussion highlights that, while lawyers can fulfil a vital role

in APP processes, including traditional ACP discussions, there is a need for enhanced interprofessional collaboration between the health and legal fields. In this way, people can be assisted to plan ahead holistically, benefiting from the expertise of both healthcare providers and legal practitioners, each bringing their unique insight to an individual's circumstances.

Now that we have identified the need for, and benefits of, interprofessional collaboration in a reframed approach to APP, the relevance of theory will be explored in more detail.

Preventive Law Theory

Preventive Law Theory was first articulated by Brown and Daure in the 1950s (Brown 1956) and developed further under Stolle in the 1990s (Stolle et al. 1997; Stolle and Wexler 1997; Stolle 1996). The introduction of "theralaw" (Barclift 2008, 36) also occurred at this time (Winick 2001). Essentially, Preventive Law Theory is a shift in focus from reacting retrospectively to a crisis and instead taking active steps to prevent it from occurring in the first place (Brown 1956; Goldblatt, Hardaway, and Scranton n.d.; Barton n.d.) through communication and planning (Winick 2001; Stolle 1996) rather than adopting a conflict-driven approach (Zirkel n.d.). These principles very much echo our existing, health-informed processes to ACP where communication and forward-planning are championed. It introduces the concept of "legal hygiene" (Zirkel n.d.) and the need for regular "legal checkups" (Winick 2001; Stolle et al. 1997; Brown n.d.; Wexler n.d.) which, similar to health checkups, are designed to provide a holistic view of the person's life, including their values, finances, concerns, and family structure (Stolle et al. 1997). The goal is to protect their interests and proactively guard against future legal conflicts (Stolle et al. 1997; Stolle 1996). Prevention and protection are key goals of APP, just as in ACP, and continue to apply when reframing our approach as planning for the rest-of-life. The goal is still to prevent future conflicts or issues arising in future, while ultimately protecting the person's wishes and preferences.

Preventive Law Theory ensures people are able to actively engage in the process and collaborate with their lawyer, something that is often missing in litigation (Barclift 2008). Lawyers work alongside clients, providing them with a deeper understanding of any particular issues that may arise in future (Barclift 2008; Stolle 1996), much like healthcare providers do when considering a particular diagnosis or disease trajectory. This early intervention helps to prevent legal risks from occurring or minimize their impact if they do eventuate (Barclift 2008). The preventive lawyer must understand the potential problem and devise appropriate solutions in connection with the person's whole environment, acknowledging their values and well-being (Barton 2009). Transparency is key, as the lawyer needs to be provided with all of the relevant facts and the individual must be made aware of the applicable law that will operate in order for Preventive Law Theory to be effective (Brown 1956). This collaborative approach between lawyers and clients provides a clear direction when planning for the rest-of-life. It is vital to understand not only what is important to a person now but what their wishes and preferences are for the rest-of-life. Armed with this information, lawyers can assist clients to plan ahead in a way that acknowledges and incorporates their wishes and protects their interests in a meaningful way.

While many lawyers are undoubtedly implementing aspects of Preventive Law Theory, there is a desire to make the approach more systematic (Stolle and Wexler 1997). APP has a significant preventive role in protecting individuals if they were to experience future periods of incapacity. To ensure this protective role is realized, APP instruments need to be carefully prepared to minimize the risk that any legal planning tools "can be abused and transformed from a preventive tool to a harmful one" (Doron and Gal 2007, 51). This careful preparation can be undertaken by a lawyer, in conjunction with a health professional, with a clear understanding of a person's goals and preferences when planning for the rest-of-life, preventing future issues, and guarding against opportunities for abuse or manipulation.

Therapeutic Jurisprudence

As Therapeutic Jurisprudence aims to humanize the law and make it a more positive experience for those involved (Wexler n.d.), it can improve our approach to APP. Therapeutic Jurisprudence is concerned with the effect the law can have on the psychological well-being of individuals (Stolle and Wexler

1997), prompting us to work to increase therapeutic, and decrease antitherapeutic, consequences of APP (Glover 2011; Kapp 2009). Therapeutic Jurisprudence also introduces the concept of "psycholegal soft spots" (Winick 2001; Wexler n.d.). While "legal soft spots" relate to circumstances that might lead to future legal conflicts for the person, a concept which is highly relevant to Preventive Law Theory, "psycholegal soft spots" are concerned with the individual's social connections and well-being, which should be taken into account when attempting to prevent conflict or considering which legal tools are best suited to the situation (Stolle et al. 1997). Our understanding of a person's well-being should acknowledge the related concepts of vulnerability, autonomy, and empowerment.

Vulnerability

Properly understood, vulnerability should be recognized as experiences "of chronic and episodic dependency across the lifecourse" (Fineman 2008, 11). Building on this understanding of vulnerability as periods of heighted dependency, our focus is directed to relationship-based and circumstantial elements that can make someone vulnerable (Hall 2009). It also individualizes the concept as it can manifest differently for every individual, if at all (Hall 2009). Vulnerability is highly contextual as opposed to comparative (Boni-Saenz 2019), meaning it should be considered at regular intervals throughout a person's life, as it forms an essential foundation for future planning.

Autonomy

The Australian Health Ministers' Advisory Council states autonomy "is generally understood as a person's ability to make self-determining choices and direct his or her own life" (Australian Health Ministers' Advisory Council 2011, 17) which emphasizes the concepts of self-direction and control. Further, Abrams connects these concepts with the values of authenticity and self-identity (Abrams 1999). Self-direction enables an individual to engage in decision-making that is free from external influences (Abrams 1999). Authenticity is paramount to autonomy, as it ensures an individual "is not merely the mouthpiece of other persons or forces. Rather, his tastes, opinions, ideals, goals, values, and preferences are all authentically *his*" (Feinberg 1989, 32). Similarly, self-identity enables an autonomous person to not be "exhaustively defined by his relations to any particular other" (Feinberg 1989, 31–32). Finally, autonomy can be understood "as a kind of competency … that makes it possible to act in a self-aware and self-directed fashion" (Abrams 1999, 814–15). This conceptualization can allow for a deeper understanding that, if an individual lacks the ability to self-manage a specific area of their lives, such as their financial affairs, they may still retain the capacity, and autonomy, to make decisions regarding their healthcare, or vice versa. This is vital for individuals when planning for the rest-of-life, in the event their competency may change over time.

Relational autonomy is also promoted by Gray et al. (Gray et al. 2019). While autonomy in health contexts has traditionally been recognized as "the capacity to make decisions independently" (Gray et al. 2019, 80) this fails to account for the participation of people close to the individual in the decision-making process (Baron 2019; Gray et al. 2019) and the potential reliance that may be placed upon them, for example, if required to make a decision with respect to the treatment of another in light of a serious diagnosis (Gray et al. 2019). However, familial relationships or caregiver responsibilities can also present "ethically challenging" circumstances with regard to autonomous decision-making (Tobin Tyler 2019, 3). This requires a careful balance, acknowledging the significant role carers or family may play in the individual's life while ensuring that the wishes being communicated are in fact those of the individual (Australian Guardianship and Administration Council 2019; Tobin Tyler 2019). Therefore, prioritizing a person-centred approach for healthcare or legal matters must take these considerations into account, particularly when planning for the rest-of-life.

Empowerment

Karl has defined empowerment as "a process of awareness and capacity building leading to greater participation, to greater decision-making power and control" (Karl 1995, 14). The knowledge of the full range of available APP mechanisms, not simply those associated with ACP, would enable individuals to make a wider range of decisions and take control of their current affairs, while also retaining control

through the relevant documents and appointments at a time when they may not be able to speak for themselves. Participation is key, but it must be meaningful, as "[e]mpowerment is demonstrated by the quality of people's participation in the decisions and processes affecting their lives" (Oxaal and Baden 1997, 7).

Within the health promotion context, Mason et al. highlight that empowerment is largely concerned with enabling individuals to recognize and utilize their personal power, with an acknowledgement of others who are involved in any relevant processes (Mason, Backer, and Georges 1991). This perspective allows individuals to take control over their future while also considering and respecting others who are involved, including family, trusted individuals, and appointed decision-makers. It provides greater opportunities for people to exercise control over their own lives and affairs, allowing them to express their wishes and retain their voice when future decisions must be made. Reframing APP as planning for the rest-of-life promotes the ongoing decision-making authority of individuals. Both lawyers and healthcare providers have a key role to play with respect to knowledge provision to ensure people have both a greater level of confidence with, and awareness of, the full range of available planning mechanisms.

"The Good Result"

Holtz' expression of "the good result" is essential to understanding how APP could be informed by a more ethical and holistic perspective (Holtz 2017). While lawyers may lack training relating to the traditional focus of Therapeutic Jurisprudence, being the psychological well-being of clients (Stolle et al. 1997), legal practitioners are readily able to collaborate with individuals and their care providers to consider what a "good result" would be in light of their personal circumstances. As such, "the good result" must encompass legal, financial, social, and personal well-being, including relevant health matters. A shift from the traditional legal transaction approach to a more communicative and collaborative process is vital, as "the good result" "is achieved through time, patience and perseverance … practitioners must be continually ready and willing to provide their clients insight and guidance as they make a variety of life-impacting decisions" (Holtz 2017, 86–87). Further, consistency and continued consideration of a person's subjective circumstances, rather than a one-off consultation, is needed to produce the best outcome for the individual (Holtz 2017), both currently and into the future. This informs our ethical understanding of the possibility of reframing APP as planning for the rest-of-life, as "the good result" may change depending on a person's stage of life. Lawyers and doctors, along with their clients and patients, must continue to work together over time, engaging in ongoing communication, collaboration, and reflection, to ensure their goals continue to be achieved.

Our understanding of vulnerability as flexible periods of heightened dependency is informed by the theoretical framework and our understanding of "the good result." Professionals can act to reduce opportunities for harm that may come from circumstances where an individual is relying on others for support or is otherwise dependent. This is overtly linked to Preventive Law Theory and the ability of lawyers to assist clients in protecting themselves. They may put mechanisms in place that will help prevent legal conflicts from arising in future or may offer protection for clients from people in their lives who may be actively placing them in a vulnerable position. Therapeutic Jurisprudence then comes into play as both health and legal practitioners will need to be mindful of the person's well-being, including legal, social, financial, and personal factors, when determining the best course of prevention or protection, both currently and when planning for the rest-of-life.

Autonomy, informed by authenticity, ensures decisions that people make are true to, and clearly represent, their values, wishes and preferences, and not those of their advisors or those close to them. Self-direction is also key to achieving "the good result," as decisions must be made according to the personal goals and values that are prioritized by an individual. Partial or limited autonomy also accounts for instances where, for example, a person may have competence in one area of their life, such as their healthcare, but may need assistance through APP mechanisms to manage their finances. The role and significance of personal relationships should also be recognized, as they are an important factor when considering the well-being of individuals, in line with Therapeutic Jurisprudence. Further, under Preventive Law Theory, relationships must be acknowledged when determining how best to help people guard against future conflicts or proposed risks.

With respect to empowerment and its connection to "the good result," Holtz draws on key aspects of planning for the rest-of-life in the following analysis:

> … [t]he lure of contemporary empowerment has encouraged individuals to 'avoid' probate, adopt alternate methods of wealth transfer, and 'secure' their own future. Once a 'spectator' in the estate and financial planning process, individuals are encouraged to manage their own destiny. (Holtz 2017, 83)

The concept of self-management is again emphasized and clearly promotes the principles of Preventive Law Theory outlined above. Holtz' conceptualization also highlights the significance of delegation, as people engaging in APP processes are able to anticipate and consider delegating future decision-making powers to trusted individuals (Holtz 2017). This echoes the earlier significance of control, as APP not only allows for current consideration of an individual's affairs but what they would like to happen in future and who they would like to act on their behalf. This ensures APP, as planning for the rest-of-life, achieves "the good result" not only during the planning process itself, but in the future as well.

A New Approach

APP would clearly benefit from a redirection under theralaw (Kapp 2009) with a focus on planning for the rest-of-life. Unifying the perspectives of Preventive Law Theory and Therapeutic Jurisprudence creates a more beneficial model than if either of them were adopted in isolation, as they strengthen one another when used together (Winick 2001; Stolle 1996). While the principles of Therapeutic Jurisprudence are significant, they can only be operationalized successfully by implementing Preventive Law Theory tools (Winick 2001; Stolle 1996) such as regular "legal checkups." Similarly, by adopting a practice that is grounded in Preventive Law Theory, professionals will find themselves able to respond more easily to therapeutic concerns (Stolle 1996) and actively understand and protect the well-being of their clients and patients. The combination of Preventive Law Theory and Therapeutic Jurisprudence enhances their individual flexibility, so they can be introduced across a greater range of professions. Therapeutic Jurisprudence also represents an important tool via which we can measure improvements to the quality of life of individuals (Kapp 2009) with particular reference to their well-being. Wexler highlights the interaction between the two, as Preventive Law Theory seeks to guard against "legal soft spots" and Therapeutic Jurisprudence helps identify any "psycholegal soft spots" that, while not recognized as significant legal issues, may nevertheless have a real impact on a person's well-being (Wexler n.d.). As Therapeutic Jurisprudence "is far from self-executing, and is in desperate need of a facilitating legal structure or context," (Stolle and Wexler 1997, 27) Preventive Law Theory provides the necessary foundation for Therapeutic Jurisprudence to be introduced and implemented with confidence. The practicality of Preventive Law Theory is thus supplemented by the ethical framework offered by Therapeutic Jurisprudence (Stolle and Wexler 1997; Wexler n.d.).

Within the context of APP, lawyers play an important role in assisting clients to control their own affairs and to put steps in place for their management in the event they are not able to act autonomously in future. Similarly, healthcare providers have vital insight with respect to the health of their patients, including any recent diagnosis or potential disease trajectories. Both professions must consider the person's well-being (Stolle 1996), including what is important to them and what they wish to prepare for or guard against in future. Lawyers must assist their clients to understand the range of legal protections available to them and demonstrate how APP can be used to record and protect the person's values, wishes, and future intentions when they are managing their affairs, in line with Preventive Law Theory. Similarly, healthcare providers can assist with this sharing of knowledge, and encourage patients to think about their preferences for future treatment.

Clearer links should be made to the therapeutic nature of APP and the vital role well-being plays in achieving "the good result." Professionals working in this area must actively engage with their clients' and patients' needs, values, and wishes across health, lifestyle, and social sectors, accounting for a broader and more ethical approach according to Therapeutic Jurisprudence. Using the example of ACDs, a document with which both professions are familiar, Ellison highlights the concepts of participation and control. An ACD allows an individual to "maintain

control over their medical treatment" and aims "to uphold principles of autonomy and self-determination for people with diminishing capacity" (Ellison et al. 2004, 156), as well as allowing for increased participation in future processes. Expanding the focus of autonomy provides a broader framework for appointed decision-makers when called upon to act on behalf of an individual, as they will have a greater understanding of the context in which the wishes were recorded (Yapp et al. 2018). This provides an ethical, holistic view of a person's life and their personal framework when planning for the rest-of-life.

Consideration of a wide range of barriers encourages a more comprehensive view of an individual's circumstances, which is very important when considering both their legal hygiene under Preventive Law Theory and their well-being in accordance with Therapeutic Jurisprudence. Therapeutic Jurisprudence has a clear goal within the field of APP to encourage a holistic assessment of the impact legal and planning processes can have on people and those around them, as any legal interactions can have consequences on the well-being of all involved (Kapp 2009). APP has both therapeutic and antitherapeutic effects. Positive consequences include personal freedom in creating plans and personal connection with, and support from, professionals during the process (Glover 2011) including lawyers and healthcare providers. However, negative consequences such as anxiety associated with mortality and the potential loss of capacity (Glover 2011), conflicts within families (Barry 2017), and concerns about the duration and cost of planning processes (Close et al. 2021; Sellars et al. 2019) must also be acknowledged.

With respect to empowerment, facilitating individual participation when planning for the rest-of-life may help to guard against legal conflicts or prevent adverse medical events from arising in future. Further, it may help to reduce antitherapeutic effects that a person may otherwise experience if they were not aware of the available legal protections and their purpose. The element of control is also satisfied with respect to APP generally. The process of planning for the rest-of-life allows people to not only record their wishes, values, and preferences, but also retain control over the direction of their remaining years. They are able to appoint people to whom they delegate decision-making responsibility and specify their preference for healthcare to guide future decisions at a period when they may be experiencing incapacity. The key role that lawyers and healthcare providers play in the promotion and completion of APP instruments can help safeguard individuals in circumstances where people close to them may be either pressuring them to make certain arrangements or exercising undue influence for their own personal motives (Lewis 2018; Holtz 2017). Adopting this holistic view of the person's life and well-being also links to Therapeutic Jurisprudence, as "the good result" for each individual needs to be informed by their personal circumstances and preferences.

Prioritizing communication enhances an individual's participation and continued involvement in managing their affairs (Department of Health 2021, 19; Rodi et al. 2021). Engaging in the process of APP can be empowering for individuals (Glover 2011; Kohn 2006) as long as they are provided with opportunities for meaningful participation (Purser and Sullivan 2019; Yapp et al. 2018, 138–39) and are fully informed about the available planning mechanisms and their intended purpose (Kapp 2009; Doron and Gal 2007). Preventive Law Theory helps subvert the power imbalances that can exist in lawyer–client relationships by encouraging collaboration and the client's active involvement (Barton n.d.), proceeding from a perspective of empowerment rather than vulnerability. Communication and participation are vital, as they preserve the person's autonomy and control over their own affairs (Kohn 2006) and have the potential to decrease antitherapeutic consequences that may otherwise arise. By adopting this new approach to APP, involving a holistic examination of a person's life and encouraging collaboration that accounts for any vulnerability, while upholding individual autonomy and promoting opportunities for empowerment, lawyers and healthcare providers are able to work with the individual to identify and achieve their "good result."

Beyond the initial creation of APP instruments, establishing an ongoing plan for consultation and review of prepared mechanisms also increases the opportunity for therapeutic interactions and enhances the relationship between professionals and their clients or patients (Stolle et al. 1997; Stolle 1996). These regular "legal checkups" are encouraged under Preventive Law Theory, as well as being a regular part of routine healthcare practice. This proactive approach has a dual purpose of lowering both the chance and associated

costs of future conflicts, while encouraging people to engage in all available forms of advance planning, which in turn produces therapeutic benefits (Stolle 1996). Interdisciplinary collaborations have been lacking in the field of APP despite the overt social aspects of legal interactions, including the mental well-being of clients (Stolle et al. 1997). The adoption of a holistic approach to APP goes beyond the skillset of the individual lawyer or healthcare provider (Orsatti 2022; Rolnick et al. 2019; Ries et al. 2018), highlighting the need to both consider and actively encourage collaboration between these professions (Heyland 2019; Johnson et al. 2016).

Conclusion

While APP provides an important means for individuals to plan ahead regarding their future legal, financial, personal, and health affairs, uptake is low and too often associated only with the end-of-life. By reframing our approach to APP as planning for the rest-of-life and applying the unified theoretical perspectives of Preventive Law Theory and Therapeutic Jurisprudence under "theralaw," we are paving the way for a new, interdisciplinary, ethical method of planning ahead that accounts not only for a person's wishes but focuses on preventing conflict and protecting their well-being. Lawyers and healthcare providers both have a key role to play in this new approach, and should encourage an ongoing, collaborative relationship with those who are choosing to plan ahead for the rest-of-life.

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APPENDIX H

PUBLICATION IN JOURNAL OF LAW AND MEDICINE

Key Informant Perspectives on Barriers to Advance Personal Planning: Results from a Qualitative Interview Study

Briony Johnston, Nola M Ries and Amy Waller*

Advance Care Planning (ACP) relates to the process of thinking about, discussing, and potentially documenting future wishes and preferences relating to personal and health matters. Existing literature has explored ACP from the perspective of health care professionals and older people. However, data exploring the broader process of Advance Personal Planning (APP), which also accounts for plans relating to legal and financial matters, are limited. This article reports on an interview study that explored barriers to APP engagement, factors influencing the quality and future use of instruments, and opportunities for improving APP processes for older adults from the perspectives of key informants working in the fields of law, health, and aged care. Data were coded in NVivo and analysed thematically. Opportunities for improvement include education, normalising conversations, integration into usual practice, and reform. Recommendations are made at professional, community, and structural levels, with the aim of improving APP outcomes for all involved.

Keywords: *advance personal planning; older people; key informant; barriers; recommendations; qualitative*

I. BACKGROUND

Advance Personal Planning (APP) describes the process of contemplating, discussing and recording an individual's wishes for future legal, financial, health and personal matters.[1] It may include the completion of several instruments: including a will to dispose of assets after death; the appointment of an enduring power of attorney (EPA) to make decisions regarding a person's property or finances if they are unable to take care of these matters without support in future; the appointment of an enduring representative for health-related matters (also referred to as an enduring guardian) who is authorised to assist with decisions relating to personal and health matters if a person is experiencing a period of incapacity; and the completion of an advance care directive (ACD) which records an individual's intentions regarding future health care, treatment, and lifestyle matters if they were not able to communicate these decisions at a later point in time. It is broader than traditional advance care planning (ACP) which relates to

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[1] A Waller et al, "Increasing Advance Personal Planning: The Need for Action at the Community Level" (2018) 18(1) BMC Public Health 1.

discussion and possible documentation of wishes, preferences, and goals relating to health matters. While the literature relating to ACP is established,[2] APP is still an emerging area of research.[3]

The perspectives of Australian health care professionals have been explored broadly in relation to certain aspects of ACP, including adhering to prepared ACDs,[4] and the relevance of ACP for professionals working in oncology, dementia, and palliative care.[5] The prevalence and quality of ACDs has been examined among certain population groups in Australia, including older adults,[6] people living with dementia,[7] and individuals receiving treatment for cancer.[8] Available studies also consider the experiences of people residing in aged care facilities and accessing health services in the community.[9] The highest prevalence of ACP documents in Australian communities was found among people residing in aged care facilities.[10] Factors associated with planning completion include: discussing the process with someone else;[11] being female;[12] older age;[13] the presence of two or more health conditions;[14] having children;[15] owning property;[16] receiving palliative care;[17] other self-protective behaviours, such as regular legal check-ups;[18] and Anglo Celtic heritage.[19]

[2] MT Carney et al, "Impact of a Community Health Conversation upon Advance Care Planning Attitudes and Preparation Intentions" (2021) 42(1) *Gerontology & Geriatrics Education* 82; M Sellars et al, "Personal and Interpersonal Factors and Their Associations With Advance Care Planning Documentation: A Cross-Sectional Survey of Older Adults in Australia" (2020) 59(6) *Journal of Pain and Symptom Management* 1212; F Batchelor et al, "Facilitators and Barriers to Advance Care Planning Implementation in Australian Aged Care Settings: A Systematic Review and Thematic Analysis" (2019) 38(3) *Australasian Journal on Ageing* 73.

[3] Waller et al, n 1.

[4] N Moore et al, "Doctors' Perspectives on Adhering to Advance Care Directives When Making Medical Decisions for Patients: An Australian Interview Study" (2019) 9(10) BMJ Open e032638.

[5] C Sinclair et al, "Professionals' Views and Experiences in Supporting Decision-Making Involvement for People Living with Dementia" (2021) 20(1) *Dementia* 84; L Robinson et al, "A Qualitative Study: Professionals' Experiences of Advance Care Planning in Dementia and Palliative Care, 'a Good Idea in Theory but …'" (2013) 27(5) *Palliative Medicine* 401.

[6] K Buck et al, "Advance Care Directive Prevalence among Older Australians and Associations with Person-Level Predictors and Quality Indicators" (2021) 24(4) *Health Expectations* 1312; Sellars et al, n 2; I Musa et al, "A Survey of Older Peoples' Attitudes towards Advance Care Planning" (2015) 44(3) *Age and Ageing* 371.

[7] J Bryant et al, "Inadequate Completion of Advance Care Directives by Individuals with Dementia: National Audit of Health and Aged Care Facilities" (2021) 12(e3) *BMJ Supportive & Palliative Care* e319; Sellars et al, n 2.

[8] KM Detering et al, "Prevalence of Advance Care Planning Documentation and Self-Reported Uptake in Older Australians with a Cancer Diagnosis" (2021) 12(2) *Journal of Geriatric Oncology* 274; H Rodi et al, "Exploring Advance Care Planning Awareness, Experiences, and Preferences of People with Cancer and Support People: An Australian Online Cross-Sectional Study" (2021) 29(7) *Supportive Care in Cancer* 3677.

[9] Batchelor et al, n 2; KM Detering et al, "Prevalence and Correlates of Advance Care Directives among Older Australians Accessing Health and Residential Aged Care Services: Multicentre Audit Study" (2019) 9(1) BMJ Open e025255.

[10] Buck et al, n 6.

[11] Sellars et al, n 2.

[12] Buck et al, n 6.

[13] Buck et al, n 6; C Tilse et al, "Making and Changing Wills: Prevalence, Predictors, and Triggers" (2016) 6(1) *SAGE Open* 1; MR Greenberg et al, "Risk-Reducing Legal Documents: Controlling Personal Health and Financial Resources" (2009) 29(11) *Risk Analysis* 1578.

[14] Buck et al, n 6.

[15] Tilse et al, n 13; Greenberg et al, n 13.

[16] Tilse et al, n 13; Greenberg et al, n 13.

[17] Buck et al, n 6; Robinson et al, n 5.

[18] Greenberg et al, n 13.

[19] S Jeong et al, "'Planning Ahead' among Community-Dwelling Older People from Culturally and Linguistically Diverse Background: A Cross-Sectional Survey" (2015) 24 *Journal of Clinical Nursing* 244.

Studies have demonstrated relevant barriers to engaging with advance planning, such as: a general lack of awareness and understanding of available instruments;[20] poor understanding of legal rights;[21] difficulty accessing information about planning, including translated materials for people belonging to culturally and linguistically diverse groups;[22] planning may be viewed as irrelevant or too confronting to think about;[23] cost;[24] and family conflict.[25] Additional barriers relating to the quality and future implementation of completed documents include: wishes expressed in plans may not be current;[26] end-of-life care may not align with the person's preferences;[27] documents may not be accessible when needed or shared with relevant parties;[28] and limited professional knowledge regarding the legal status of completed instruments.[29]

While professional perspectives have been explored in the literature, the experiences of health professionals[30] and lawyers[31] have generally been separated. Adopting this siloed approach reinforces the separation between the professions. However, both legal and health professionals should have familiarity

[20] C Sinclair et al, "Association Between Region of Birth and Advance Care Planning Documentation Among Older Australian Migrant Communities: A Multicenter Audit Study" (2021) 76(1) *The Journals of Gerontology: Series B* 109; JB Baron, *Fixed Intentions: Wills, Living Wills, and End-of-Life Decision Making* (Social Science Research Network, 2019); S Trarieux-Signol et al, "Advance Directives from Haematology Departments: The Patient's Freedom of Choice and Communication with Families. A Qualitative Analysis of 35 Written Documents" (2018) 17 BMC Palliative Care 1.

[21] H Close et al, "Qualitative Investigation of Patient and Carer Experiences of Everyday Legal Needs towards End of Life" (2021) 20(1) BMC Palliative Care 1; S Ellison et al, *The Legal Needs of Older People in NSW* (Law and Justice Foundation of New South Wales, 2004).

[22] M Sellars et al, "Public Knowledge, Preferences and Experiences about Medical Substitute Decision-Making: A National Cross-Sectional Survey" (2021) BMJ Supportive & Palliative Care 002619; C Sinclair et al, "A Public Health Approach to Promoting Advance Care Planning to Aboriginal People in Regional Communities" (2014) 22(1) *Australian Journal of Rural Health* 23; DV Rao et al, "Health and Social Needs of Older Australians from Culturally and Linguistically Diverse Backgrounds: Issues and Implications" (2006) 25(4) *Australasian Journal on Ageing* 174; Ellison et al, n 21.

[23] JL Masters et al, "End-of-Life Planning: Normalizing the Process" (2021) 34 *Journal of Aging & Social Policy* 1; S McIlfatrick et al, "'It's Almost Superstition: If I Don't Think about It, It Won't Happen'. Public Knowledge and Attitudes towards Advance Care Planning: A Sequential Mixed Methods Study" (2021) 35(7) *Palliative Medicine* 1356; Batchelor et al, n 2; Moore et al, n 4; IA Scott et al, "Difficult but Necessary Conversations – the Case for Advance Care Planning" (2013) 199(10) *Medical Journal of Australia* 662.

[24] Close et al, n 21; S Thompson et al, "Passing on Wisdom: Exploring the End-of-Life Wishes of Aboriginal People from the Midwest of Western Australia" (2019) 19(4) *Rural and Remote Health* 1; Robinson et al, n 5.

[25] KM Detering et al, "Organisational and Advance Care Planning Program Characteristics Associated with Advance Care Directive Completion: A Prospective Multicentre Cross-Sectional Audit among Health and Residential Aged Care Services Caring for Older Australians" (2021) 21(1) BMC Health Services Research 1; J Tran et al, "Systematic Review and Content Analysis of Australian Health Care Substitute Decision Making Online Resources" (2021) 45(3) *Australian Health Review* 317; Ellison et al, n 21.

[26] Tran et al, n 25; HY Chan, "Video Advance Directives: A Turning Point for Advance Decision-Making? A Consideration of Their Roles and Implications for Law and Practice" (2020) 41(1) *Liverpool Law Review* 1; RS Morrison, "Advance Directives/Care Planning: Clear, Simple, and Wrong" (2020) 23(7) *Journal of Palliative Medicine* 878; F Nauck et al, "To What Extent Are the Wishes of a Signatory Reflected in Their Advance Directive: A Qualitative Analysis" (2014) 15 BMC Medical Ethics 1.

[27] Morrison, n 26; JA Rolnick et al, "Patients' Perspectives on Approaches to Facilitate Completion of Advance Directives" (2019) 36(6) *American Journal of Hospice & Palliative Medicine* 526; Nauck et al, n 26; Scott et al, n 23.

[28] Buck et al, n 6; Detering et al, n 8; Morrison, n 26; Batchelor et al, n 2.

[29] C Cartwright et al, "Medical Practitioners' Knowledge and Self-Reported Practices of Substitute Decision Making and Implementation of Advance Care Plans" (2014) 44(3) *Internal Medicine Journal* 234; KJ Purser and T Rosenfeld, "Evaluation of Legal Capacity by Doctors and Lawyers: The Need for Collaborative Assessment" (2014) 201(8) *Medical Journal of Australia* 483.

[30] Carney et al, n 2; SY Ng and EL Wong, "The Role Complexities in Advance Care Planning for End-of-Life Care – Nursing Students' Perception of the Nursing Profession" (2021) 18(12) *International Journal of Environmental Research and Public Health* 1; Sinclair et al, n 5.

[31] B Hemsley et al, "An Integrative Review of Stakeholder Views on Advance Care Directives (ACD): Barriers and Facilitators to Initiation, Documentation, Storage, and Implementation" (2019) 102(6) *Patient Education and Counseling* 1067; NM Ries et al, "How Do Lawyers Assist Their Clients with Advance Care Planning? Findings From a Cross-Sectional Survey of Lawyers in Alberta" (2018) 55(3) *Alberta Law Review* 683; E Helmes et al, "Australian Lawyers' Views on Competency Issues in Older Adults" (2004) 22(6) *Behavioral Sciences & The Law* 823.

with and knowledge of the full suite of available APP instruments and appointments.[32] This familiarity across professions would mean that, in the course of communicating with clients and patients, both lawyers and doctors would be enlivened to any potential legal or personal issues that a person may be experiencing. In the case of health professionals, they could then have the confidence to assess when it may be suitable to share information with their patient about APP that could help safeguard their patient's interests and preferences. The combination of knowledge and experience of both lawyers and health professionals through a key informant approach will allow us to understand similarities and points of distinction better, bridging the gap between the fields and ultimately providing a more holistic approach to planning processes.[33] By actively encouraging more opportunities for APP discussions across both legal and medical contexts, it will allow the incorporation of insights from both professional groups, which are essential to creating APP documents that are not only meaningful to the person, but can be successfully implemented in future. This interdisciplinary approach would support patient- and client-centred services that adopt a more complete understanding of the person's wishes, values, and preferences. Further, this will allow deeper insights regarding how current systems operate and opportunities for improvement from a diverse range of perspectives.

The aim of this study was to examine the perceptions of professionals who have contact with older adults in relation to APP issues, including lawyers advising clients on making documents, health professionals who interpret completed instruments when people are ill and lack capacity, and police who respond to elder abuse where circumstances may involve the misuse or absence of APP instruments. They were asked to discuss barriers to engaging in APP and implementing planning instruments in practice; factors influencing the quality of APP; confidence in the future use of completed instruments; and potential improvements to systems and processes.

II. Method

A. Study Design

This study adopted a qualitative descriptive design.[34] This method allowed for the exploration of perspectives of key informants in an area that is currently under-researched to provide new data and insights regarding the experiences of legal and health professionals with APP for older people.

B. Ethics

The research discussed in this article was approved by the Human Research Ethics Committee of the University of Technology Sydney (ETH20-5024 and ETH21-6622).

C. Participants

Participants were eligible to complete an interview if they had experience advocating for the rights of older adults, assisting older adults to engage with APP processes and/or complete relevant instruments, or interpreting completed APP documents in their professional role. Specific disciplines were targeted, including law, health, aged care, and advocacy organisations. Participants had to be able to complete an interview via telephone or web-conference in English. The final sample of key informants included professionals from a range of backgrounds, including law and law enforcement (eg succession planning and elder law professionals), health (eg doctors, nurses, specialists), and research (eg end-of-life planning, health services research).

[32] GW Orsatti, "Attorneys as Healthcare Advocates: The Argument for Attorney-Prepared Advance Healthcare Directives" (2022) 50(1) *Journal of Law, Medicine & Ethics* 157; Rolnick et al, n 27; Ries et al, n 31; Waller et al, n 1; S Russell, "Advance Care Planning: Whose Agenda Is It Anyway?" (2014) 28(8) *Palliative Medicine* 997.

[33] Orsatti, n 32; Ries et al, n 31.

[34] C Bradshaw et al, "Employing a Qualitative Description Approach in Health Care Research" (2017) 4 *Global Qualitative Nursing Research* 1; M Sandelowski, "Whatever Happened to Qualitative Description?" (2000) 23 *Research in Nursing & Health* 334.

D. Recruitment

Twenty-eight (28) key informants were recruited via two methods.[35] Lawyers who took part in a previous online survey gave consent to further contact for future studies on APP. Relevant organisations and/or experts were also identified via study investigators' networks and organisational websites. An invitation email with a detailed information sheet was sent to relevant participants. Depending on responses, the lead author provided further information about involvement or scheduled dates for interviews. Key informants were also given the opportunity to suggest other suitable individuals via snowball sampling.[36] Adopting the information power model outlined by Malterud et al,[37] it was anticipated a sample size of 20–30 participants would be appropriate to meet the aims of the study. Malterud et al cite five key elements for consideration: the breadth of the study aim; the specificity of the sample involved; whether an established theory is being adopted and applied; the quality of the dialogue; and the type of analysis strategy adopted.[38] Given the focused topic of the study, namely, professional experiences relating to APP with older people, the high level of expertise of selected participants, and the completion of in-depth individual interviews with all participants, an adequate sample size was reached at 28 participants across all professional areas.

E. Data Collection

Semi-structured interviews were conducted by the lead author with participants via telephone or web-conference between October 2020 and June 2022. Participants provided verbal consent and all interviews were audio-recorded. Part I of the interview guide asked participants to describe their professional role, especially aspects related to the promotion, completion, or implementation of APP. Part II of the interview guide explored general views of APP, including what they consider to be high quality APP, confidence in the future use of completed instruments, and any concerns relating to APP instruments facilitating elder abuse or the exploitation of older people. Part III of the interview guide discussed perceived barriers, benefits, and risks of APP for older people, including person-centred, professional-centred, and structural barriers. Part IV of the interview guide asked key informants about their experience with interpreting or implementing prepared APP instruments and any challenges they have faced. Part V of the interview guide asked about opportunities for improvement within existing APP processes. Finally, Part VI contained demographic questions such as how long they have worked in their professional role, age, gender, and any referrals for snowball sampling. Participants were also asked if they would like to receive a copy of the interview transcript to review the discussion and provide feedback, as well as a summary of the findings once the project was completed.

F. Data Analysis

Interviews were transcribed verbatim. Transcripts were coded in NVivo according to discrete phenomena relating to participants' experiences, including perceived: quality of APP; confidence in planning instruments; barriers to engagement, quality, and future use; advantages and disadvantages of planning ahead; and improvements in current processes. The lead author was the sole coder for the dataset. While multiple coders are encouraged, the process of utilising a single coder was appropriate in these circumstances, given the study was part of the lead author's PhD and in light of the qualitative descriptive approach that was adopted.[39] Further, the semi-structured interview guide was organised into

[35] MQ Patton, "Expert Sampling" in BB Frey (ed), *The SAGE Encyclopedia of Educational Research, Measurement, and Evaluation* (SAGE Publications Inc, 2018) 648–649; JA Parsons, "Key Informant" in P Lavrakas (ed), *Encyclopedia of Survey Research Methods* (SAGE Publications Inc, 2011) 406–408.

[36] T Crouse and PA Lowe, "Snowball Sampling" in BB Frey (ed), *The SAGE Encyclopedia of Educational Research, Measurement, and Evaluation* (SAGE Publications Inc, 2018) 1532.

[37] K Malterud et al, "Sample Size in Qualitative Interview Studies: Guided by Information Power" (2016) 26(13) *Qualitative Health Research* 1753.

[38] Malterud et al, n 37, 1754–1756.

[39] Bradshaw et al, n 34; Sandelowski, n 34.

key areas for discussion, and the coding process mainly involved summarising the data in a way that stayed as close as possible to the participants' words and descriptions, rather than trying to code more abstract theoretical concepts. Data were then analysed thematically[40] and findings were discussed among authors. A summary of the results of the study were shared with participants, who provided positive feedback on the findings.

III. Results

A. Sample

Twenty-eight (28) key informants took part in an interview. The scope of professional experience was broad, with 11 participants working in a legal role, 17 participants working in the fields of health and aged care, and one (1) participant working in law enforcement. Eleven (11) participants had worked in their field of practice for over 30 years, while eight (8) had between 16 and 20 years of experience. Five (5) participants had been working in their field for 10 years or less time. The age of participants ranged from 35 to 77, with an average age of 56 years. Fifteen (15) of the participants identified as female, while 13 participants noted their gender identity was male.

B. Key Findings

The below table summarises key results from the study.

TABLE 1. KEY FINDINGS

Topic	Results
High quality APP	• Person understands what they are documenting • Completion of full range of planning instruments • Personalised planning
Confidence in future use of completed plans	• Confidence was mixed • Higher confidence was associated with careful preparation, education of patients/clients, and communication
Advantages of APP	• Guidance for decision-makers and clinicians • Empowering for patient/client • Wishes can be respected in future • Prevention of conflict
Disadvantages of APP	• Prepared documents may not be current • Plans may not be enacted • Lack awareness of purpose of different document types • Inappropriate person appointed as decision-maker
Concerns regarding elder abuse	• Expressed mostly among legal professionals • Concerns that planning documents could be used to facilitate abuse, especially financial exploitation
Barriers	• To engagement: lack of understanding of instruments, fear of upsetting family, legislative framework, and time constraints • To quality: currency of documents, consistency of recorded wishes, and planning that was not tailored to the individual • To future use: ambiguous documents, confusion regarding identity of decision-maker, and inaccessibility of documents
Opportunities for improvement	• Education for community and professionals • Normalising conversations around death and care • Legislative reform to provide more consistent approaches to planning • Increased professional collaboration

[40] AJ Sundler et al, "Qualitative Thematic Analysis Based on Descriptive Phenomenology" (2019) 6(3) *Nursing Open* 733.

C. General Views on APP

High Quality APP

Key informants considered the most important factors relating to high quality APP to be: patients and clients actually understanding what it is they are documenting; the completion of the full range of available instruments; planning that is personalised to the individual circumstances of the patient or client; and the appointment of a trusted decision-maker. Communication was also emphasised as a key feature of high-quality planning by several key informants. Plans that were able to be dynamic and interpretable in future were also recommended.

> "I'm confident when people are confident about the people that they appoint." (Key Informant 1, Lawyer)
>
> "… |it's| the Will that triggers everything. It's very rarely that I get direct approaches, even for Powers of Attorney or Enduring Guardianship documents. You do have the planning conversation with people because they say, it's either time to update, or it's time to do a Will. … The very best time to have the overarching discussion on all of the issues that you're talking about, is really triggered by the Will." (Key Informant 3, Lawyer)
>
> "Well, I think the first point, the first part is the patient themselves or the person themselves, that they know what it is and what the purpose of it is, and that they agree with it. And so, I think if we talk about person-centred or patient-centred healthcare, that's always a starting point, is the person themselves." (Key Informant 18, General Practitioner)

Confidence in the Future Use of Completed Instruments

Mixed confidence relating to the future use of completed instruments was reported by key informants. While it was generally agreed that the instruments had the potential to be effective, the need for careful preparation, better education for patients and clients, and increased communication were flagged as key factors that influenced confidence in future use.

> "I think that the documents are a great help, but you can never protect against human misbehaviour." (Key Informant 6, Lawyer)
>
> "So, the big problem is that a lot of people say, yes, I've got an advance care plan, and they feel reasonably confident, but it's almost like having an insurance that doesn't actually work when you claim on it. And the processes to help people to get that step right are almost absent." (Key Informant 17, Intensive Care Specialist)
>
> "I don't think a tool can ever replace good communication. … I like tools as a guide and suggestions, and, from a learning perspective, I think it's really good, but mediation, negotiation, good conversations that are balanced and inclusive and all of those things is a different skill and not something that a tool will replace." (Key Informant 20, Nursing: Aged Care)

Advantages of APP

According to key informants, the main advantages of planning ahead were: it made things easier for decision-makers; the process could be empowering for patients and clients; the person's wishes were known and could be respected; plans provide vital guidance for clinicians; and future conflict could be prevented.

> "The main narrative is not only to disabled people, but to all people, is that you get to determine at a time suiting you, what you want done when you're no longer able to indicate yourself." (Key Informant 4, Lawyer)
>
> "The main benefit is choosing who you want to manage your affairs. That's your best way of resolving any conflict, because that person can hold up that document and say, I've been given authorization to make these decisions. It's power of self-determination of older people to make their own choices." (Key Informant 7, Lawyer)
>
> "Part of the benefit of having an advance care plan documented and discussed, or directive, is that as a family member you can have a sense of … Not satisfaction. It's not the right word. But a sense of that you did the right thing by your loved one because this is what they asked you to do or what they said. That has a massive impact on people's grieving journey." (Key Informant 11, Nursing: End of Life)

> "For the person, it's having an element of control in a part of their life that there's often lack of control or there isn't any. I often say, and this is through personal experience, that once your loved one goes into aged care, the facility own them." (Key Informant 25, Nursing: Dementia, End of Life)

Disadvantages of APP

Several disadvantages were also noted by key informants, including: the risk that documents may not be current; prepared plans may not be enacted in future; patients or clients may not understand the distinction between, and need for, different documents; and an inappropriate person could be appointed as a decision-maker.

> "I think perhaps one of the risks is people not understanding the distinction [between] the advance care plan and or advance care directive. And that goes for both families, patients, and us as clinicians. You can write an advance care directive on the back of an envelope as long as it's signed and dated, and you have sound mind when you wrote it [it must be followed]." (Key Informant 11, Nursing: End of Life)

> "I just think sometimes too if the instruments have been done in a flawed sense either by the parties, or by the advocate, it's difficult to overturn or change it. Especially if the older person's frail and suffered a decline. So if they're put in place without much thought, and a lot of people don't look at what they sign, or they don't consider, and it's … Not all of us probably, but everyone does it in every contract probably. Especially if it's a complicated instrument. When they realize what the implications of the instrument are and they want to change it, it's very, very difficult." (Key Informant 13, Police)

> "that's probably the main risk. They don't update them frequently enough. Or just, you don't even have to update them, you just need to review them and if you're happy with them, that's okay. But then if you obviously highlight that there's an issue there, get the document updated." (Key Informant 23, Lawyer)

Concerns Regarding Elder Abuse

Concerns regarding the abuse or exploitation of older people were raised by 10 of the key informants with a legal or law enforcement background. While carefully prepared APP instruments could help to guard against elder abuse, there were also concerns that instruments could be used to facilitate the exploitation of older people.

> "Obviously the planning mechanism is just one component of a safe environment for an older person. But it's really clear that a big driving factor in abuse of older people is finance and money. Particular[ly] relating to relatives, and family. And it's very clear that if a good instrument or regime is in place that the risks decline dramatically for the older person." (Key Informant 13, Police)

> "On several occasions you will get a child or someone, let's just call them a proposed beneficiary, bring their elderly friend or bring their elderly mother, father in here … To do a will that would, of course, be in favour of them. That would be at a point when the elderly have no concept of what they're doing." (Key Informant 23, Lawyer)

One key informant who works in emergency medicine also shared their perspectives in this area:

> "Yes, it's not very common, and I don't think we think about it enough, that's an important part of it. And if you think about vulnerable people, sometimes the emergency department is the only place that they escape. But there's been a few cases, maybe not the instrument, but the circumstances. … So, I suppose, in hospital, the ones we see are around neglect and financial and psychological [abuse], really." (Key Informant 8: Emergency Clinician)

D. Barriers Preventing Engagement with APP

The most frequently cited barriers that were thought to prevent the engagement of older people with APP included: lack of knowledge or understanding regarding the various instruments; fear of upsetting their family by raising the subject; the cost and time associated with the process; not having a trusted person to appoint as their decision-maker; not feeling ready to engage; and cultural factors including language barriers.

> "So maybe family who disagree, or they're estranged from family, or often that social context is what makes some of this decision-making hard." (Key Informant 12, General Practitioner)

> "The first is lack of education, on behalf, not only of the people in the community. You know the man or woman on the bus. But, also on the part of professionals." (Key Informant 15, Lawyer)

> "You've got people where English isn't their first language as well, from a health professional perspective as well as the older person's perspective, and families." (Key Informant 16, Palliative Care Clinician)
>
> "I think cost is a big one. So, if people can't afford it that's definitely one. … I think they are the main things for people. Access if you don't have a lot of money, you live with public transport, you don't have a car, all of those things make access difficult." (Key Informant 24, Lawyer)

Key informants also raised professional barriers, such as: time constraints; lack of knowledge of the legal status of various instruments; discussions can be uncomfortable; and the lack of compulsory legal education for law students regarding estate law.

> "But it's having the time. Normally when they fill them out is when you're in an emergency. Instead of having those discussions prior, and in a compassionate way that's not going to misrepresent the patient's medical status at the time, where they feel that they're dying tomorrow. Or the doctor's keeping a secret from them because they want this form filled out." (Key Informant 9, Nursing: End of Life)
>
> "Succession is not part of the Priestly 11 [compulsory legal education]. And some universities don't even teach it. … So I'm taken back that it's not just the professionals, the barriers. It's the universities who taught the professionals." (Key Informant 15, Lawyer)
>
> "And of course, the time is the main variant, which is, you need a proper conversation and, ideally, you need to have this conversation several times because people change their mind as the disease progresses. But in times of crisis, you don't have that actually." (Key Informant 21, Health Services Researcher)
>
> "when I speak with GPs and non-GP specialists, and other nurses and other people, when I do talks and stuff like that, a lot of those people have a lack of certainty and they're not really confident about their knowledge of these issues. And, sometimes they give away incorrect information." (Key Informant 22, Academic & General Practitioner)

Structural barriers were also recognised, including: not knowing whose role it is to commence planning discussions; difficulties associated with the existing legislative framework; technical barriers that prevent systems from working efficiently; the lack of funding in this field; and ageist attitudes within society.

> "And the thing was, is that I find it odd … We have a uniform … Evidence Act, and yet in each state and territory, we've got different legislation when it comes to Wills, estate, probates, and you name it, and I think that's what sometimes will scare some clients away from actually making a Will, or doing directives, or estate planning." (Key Informant 5, Lawyer)
>
> "I think that is a big one, not knowing whose responsibility it is [to initiate planning discussions regarding ACP]. So, a lot of the time people think it's the general practitioner's responsibility. Other times people think it's the specialist's responsibility. I can tell you from sitting on this side, it's everyone's responsibility." (Key Informant 10, Nursing: End of Life)
>
> "Nobody cares about the elderly. This society is elder-averse." (Key Informant 21, Health Services Researcher)

E. Barriers Affecting the Quality of APP

The main reported barriers affecting the quality of instruments related to the currency and consistency of the documents. Key informants reported concerns regarding documents that had not been reviewed, or instances where instruments were not tailored to the individual patient or client's circumstances. The discomfort of professionals in engaging in meaningful planning conversations and the general lack of transparency in communicating with family were also key factors. Further, a lack of knowledge of when legal documents begin to operate was also raised.

> "What is the relevance of something that was signed only five years ago? Can we actually say that because the person said they wanted this five years ago, do they actually still want that now? It's a bit of a grey stuff area, which is why I spend more of my time talking about, find out who your person responsible is [according to a statutory hierarchy in NSW legislation that recognizes a person's decision-making authority in the absence of an enduring representative for health-related matters] and talk to them." (Key Informant 11, Nursing: End of Life)
>
> "Well, first of all, we're reminded, and the person knows when they're completing this document, or the family, that it doesn't come into effect until the person loses their ability to express their wishes and make decisions. So that needs to be clear. Because while the person is able to communicate, and make these decisions, it's invalid, it doesn't come into play. It's not acted on." (Key Informant 16, Palliative Care)

> "[I]f someone says, I don't want ventilation, but they don't really understand what ventilation means. And so they may write something that's rather more broad than they actually mean. And there is that worry that they might write, I don't want to be resuscitated, but [what they really mean is] … I don't want to be resuscitated to come out badly. … So they can be more broad. If they're not written well, they can be broader and take in stuff that people didn't actually intend." (Key Informant 17, Intensive Care Specialist)
>
> "Some professionals do not know how to introduce [ACP] and have a thorough, honest and respectful conversation with people." (Key Informant 26, Nursing: Emergency & Aged Services)

F. Barriers Around the Implementation of APP Instruments

Key informants noted several barriers that related to the future use and implementation of APP instruments. The most frequently mentioned barrier was that prepared instruments were not followed in practice, usually because the document was unclear, or wishes could be overridden by family. Similarly, there may be confusion as to who a patient's decision-maker actually is, and family conflict raises additional challenges. Finally, documents may not be accessible at the point of care, meaning they are unable to be implemented.

> "Well, in those days of de facto partners, blended marriages, married with a de facto, whatever, and kids from multiple relationships. Don't you think the hospital would love the roadmap as to who's who at the zoo, no matter whose contacts, these are the key people." (Key Informant 3, Lawyer)
>
> "Certainly, the health services will take note of it [an advance care directive]. If they find it on your record, but again, they have got their own indicator. And their interpretation of that the feedback from maybe other members of your family, who have a different view, who may be guardian or not." (Key Informant 4, Lawyer)
>
> "I think if we actually got our stuff together and actually find out who is their personal responsible. In other words, who would be their voice if they can't speak? Because quite frankly an advanced care plan has no legal status. An advanced care directive? Now, that's a different kettle of fish.[41] But for an advanced care plan, pardon me, it's meaningless. And quite frankly, when people come into an ED department in a crisis, nobody looks." (Key Informant 11, Nursing: End of Life)
>
> "If you move to hospital, then they're not available. If you move to residential care, they're mostly not going to be available. So, the reality is even though they can follow, mostly, for a variety of reasons, [they] don't." (Key Informant 27, Psychiatry)

G. Opportunities for Improvement

When asked about opportunities for improvement within existing APP systems, key informants overwhelmingly cited education for the community as the area most in need of attention.

> "Every education I give, I always have a heap of questions at the end of the seminar. People do have a thirst for knowledge about their options with these documents. The more information that gets out there, the more informed people are when they see a solicitor. And if they're more informed, they're more likely to make a document that is suitable for their needs, because they've had that opportunity to get more information and to receive educations. I think that's really important. I think people feel more comfortable seeing a solicitor and getting the documents prepared when they've had the opportunity to gather as much information about them as they can." (Key Informant 7, Lawyer)

Normalising death, education for professionals, legislative reform, integration into usual care, increased interprofessional collaboration, updates to current computer-based systems, and better access to low-cost services were also recognised as other areas for improvement.

> "We see ageing and death as defeat, when in fact it is just part of the cycle of life. It's a normal part of the cycle of life. And so, preparing for death is in fact normal. Or it should be. And I don't know what it

[41] For clarity, an Advance Care Plan can include information about a person's wishes, preferences and values for future health care. They can be used to guide care decisions made by enduring representatives or health care providers but are not legally binding. In contrast, an Advance Care Directive (also known as a living will) is a legally binding document that sets out values, goals, and preferred outcomes regarding future treatment. See Advance Care Planning Australia, *Advance Care Planning Explained* <https://www.advancecareplanning.org.au/understand-advance-care-planning/advance-care-planning-explained>.

> is about our society that there's denial, and we see death as failure, when in fact it's not." (Key Informant 18, General Practitioner)
>
> "you've got to start with who the person is. … First of all, medicine and law needs to get together with society and try and establish a way of defining who the person is, what are their core attitudes and beliefs? Because out of that will come what their wishes are in regard to … not just health, but also law and living circumstances and quality of life … And those professionals, including legal ones, might want to drill down a bit and say, this is a high priority in your life. What if so and so and so? Yes, but the person is dictating the terms of the interrelationship between the health and legal professional." (Key Informant 14, Intensive Care Specialist)
>
> "So, what we need, in my view, is a complete revamp of jurisdictions and the authority. I can put it in one sentence. All the law in all the ordinary courts." (Key Informant 28, Lawyer)

IV. Discussion

A. Quality & Confidence

Factors mentioned by key informants relating to high quality APP largely echo the discussion in the available literature. That is, patients and clients should have an understanding of the planning instruments and processes[42] and appoint trusted people to support their decision-making in future.[43] Further, planning should be done early,[44] adopt a collaborative approach,[45] and emphasise communication between the relevant parties.[46]

Following questions of quality, key informants reported mixed levels of confidence regarding the future use of prepared instruments. Generally, lower levels of confidence were reported by key informants working within health-related areas of practice. This stands to reason, as it is clinicians who are involved in interpreting and implementing APP instruments at the point of care and are experiencing the challenges firsthand. Enhancing the factors influencing quality, such as knowledge and communication, may in turn improve levels of confidence.

B. Barriers to Engagement

When asked to consider barriers that prevent the effective engagement of older people with APP, key informant perspectives reinforced factors that have been frequently cited in the literature. The lack of knowledge or understanding of instruments was reported as the most prevalent barrier[47] while the fear of upsetting family was also frequently cited by professionals.[48] Concerns regarding the cost and time needed to plan ahead,[49] as well as not having a trusted person to appoint[50] were also reported by key informants. Finally, cultural factors, including language difficulties, may also prevent older people from feeling able to engage with APP.[51]

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[42] Sellars et al, n 22; LI van Dyck et al, "Understanding the Role of Knowledge in Advance Care Planning Engagement" (2021) *Journal of Pain and Symptom Management* https://doi.org/10.1016/j.jpainsymman.2021.02.011.

[43] L Qu et al, *National Elder Abuse Prevalence Study: Final Report* (Australian Institute of Family Studies, 2021); NM Ries, "Enduring Powers of Attorney and Financial Exploitation of Older People: A Conceptual Analysis and Strategies for Prevention" (2022) 34(3) *Journal of Aging & Social Policy* 357.

[44] Rodi et al, n 8.

[45] Baron, n 20; Moore et al, n 4.

[46] Carney et al, n 2; Detering et al, n 8.

[47] Baron, n 20; Batchelor et al, n 2.

[48] Orsatti, n 32; Tran et al, n 25.

[49] Close et al, n 21; G Yapp et al, "Planning for the Rest-of-Life, Not End-of-Life: Reframing Advance Care Planning for People with Dementia" in G Macdonald and J Mears (eds), *Dementia as Social Experience: Valuing Life and Care* (Routledge, 2018).

[50] Morrison, n 26; HD Lum et al, "Advance Care Planning in the Elderly" (2015) 99(2) *Medical Clinics of North America* 391.

[51] Sinclair et al, n 20; L Vearrier, "Failure of the Current Advance Care Planning Paradigm: Advocating for a Communications-Based Approach" (2016) 28(4) HEC Forum 339.

C. Barriers Affecting Quality

Key informants also provided insights regarding factors that influence the quality of completed APP instruments. While barriers mostly related to the instruments themselves, including their currency and consistency, communication was another key theme. Instances where APP documents were not tailored to the particular person,[52] contained inconsistent instructions,[53] or had not been reviewed[54] were particularly troublesome. Further, communicative factors affecting quality included a lack of discussion with people around the older person,[55] and the discomfort of professionals to initiate planning conversations.[56] A barrier that requires further attention is the fact that health professionals reported not knowing when legal documents begin to operate,[57] which highlights the need for further education and collaboration between the legal and medical fields.

D. Barriers to Implementation

The barriers to implementation were mainly reported by key informants who worked in a health-related area of practice, given that they are the professional group who are most likely to experience the challenges of interpreting completed APP instruments. Professionals shared that it was often impossible to follow prepared instruments due to instructions not being clear,[58] the adoption of a "tick-box" approach to document completion,[59] or instruments not being available at the point of care.[60] Interpersonal factors also presented challenges for implementation, including confusion over who the authorised decision-maker is[61] and family conflict[62] that sometimes overrides the person's completed instruments.

E. Opportunities for Improvement

Discussions with key informants highlighted several opportunities for improvement within existing systems. The key themes were education, shifting attitudes, interprofessional collaboration, technological improvements, and legislative reform. Education for individuals within the community may enhance the quality of planning instruments,[63] lead to increased communication of decisions,[64] and facilitate a more person-centred approach to APP.[65] Similarly, education for professionals would provide greater understanding of available planning instruments,[66] leading to easier integration within usual care[67] and

[52] Moore et al, n 4; CA Robinson, "Advance Care Planning: Re-Visioning Our Ethical Approach" (2011) 43(2) *Canadian Journal of Nursing Research Archive* 18.

[53] Vearrier, n 51; Nauck et al, n 26.

[54] Buck et al, n 6; Baron, n 20.

[55] H Malcomson and S Bisbee, "Perspectives of Healthy Elders on Advance Care Planning" (2009) 21(1) *Journal of the American Academy of Nurse Practitioners* 18.

[56] Orsatti, n 32.

[57] J Chesterman and L Bedson, *Decision Time: Activating the Rights of Adults with Cognitive Disability* (Victorian Office of the Public Advocate, 2021); K Knight, "50 Years of Advance Care Planning: What Do We Call Success?" (2021) 39(1) *Monash Bioethics Review* 28; van Dyck et al, n 42.

[58] L Panozzo et al, "Communication of Advance Care Planning Decisions: A Retrospective Cohort Study of Documents in General Practice" (2020) 19(1) *BMC Palliative Care* 1; IC Otte et al, "The Utility of Standardized Advance Directives: The General Practitioners' Perspective" (2016) 19(2) *Medicine, Health Care and Philosophy* 199.

[59] Moore et al, n 4; Robinson et al, n 5.

[60] K Buck et al, *Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services* (Advance Care Planning Australia, Austin Health, 2019); Purser and Rosenfeld, n 29.

[61] Sellars et al, n 22; Sinclair et al, n 5.

[62] Detering et al, n 25; Tran et al, n 25.

[63] Rodi et al, n 8; Baron, n 20.

[64] Moore et al, n 4.

[65] Batchelor et al, n 2.

[66] Cartwright et al, n 29.

[67] Vearrier, n 51; Robinson et al, n 5.

providing a shift in professional views regarding whose job it is to initiate planning conversations.[68] These changes in attitudes could also be enacted more broadly within the community with respect to normalising conversations regarding the future,[69] and encouraging a change in perspective that planning ahead is focused on the rest-of-life, not the end-of-life.[70]

Other suggested improvements related to the computer-based systems used by NSW Health and the urgent need for updates to ensure information is readily accessible and available when needed. Further interprofessional collaboration would also produce clear benefits,[71] including providing a more holistic approach to APP. Finally, system-level improvements were also highlighted, including legislative reform to provide more consistent and uniform approaches to planning,[72] and the introduction of a register to keep track of enduring appointments and revocations.[73]

V. Recommendations

Based on the results of this key informant study, and connections with the existing literature, the following recommendations are made to improve APP engagement, quality, and implementation at two distinct levels: individual professionals and professional groups as a whole; and from a structural perspective.

A. Recommendations for Individuals and Professions

Education for Community

Educating the community regarding the components of APP, the purpose of each instrument and the circumstance in which they operate, may improve the prevalence and quality of APP.[74] Higher quality APP can assist professionals who are responsible for preparing instruments, as people will be more likely to engage in the process from an informed place, as well as those clinicians required to interpret completed documents.[75]

Organisations such as Advance Care Planning Australia,[76] NSW Trustee & Guardian,[77] and Seniors Rights Service[78] have existing initiatives providing both resources and educational seminars to older people in the community. However, these strategies require the community to be proactive in engaging with APP. This can be problematic when APP is perceived as irrelevant or too confronting to think about.[79] Studies demonstrate that provision of online information and resources on planning ahead,[80] as

[68] J Dixon and M Knapp, "Whose Job? The Staffing of Advance Care Planning Support in Twelve International Healthcare Organizations: A Qualitative Interview Study" (2018) 17(1) *BMC Palliative Care* 1.

[69] Masters et al, n 23.

[70] Yapp et al, n 49; S Timmermann, "Planning for the Rest of Your Life: A New Perspective" (2001) 55(2) *Journal of Financial Service Professionals* 28.

[71] Orsatti, n 32; NM Ries et al, "Doctors, Lawyers and Advance Care Planning: Time for Innovation to Work Together to Meet Client Needs" (2016) 12(2) *Healthcare Policy* 12.

[72] New South Wales Law Reform Commission, *Review of the Guardianship Act 1987* (2018).

[73] Law Council of Australia, *National Register of Enduring Powers of Attorney* (2021); J Chesterman and L Bedson, *Submission to the Australian Law Reform Commission in Response to the Elder Abuse Discussion Paper 8* (Office of the Public Advocate, Melbourne, 2017); Australian Health Ministers' Advisory Council, *A National Framework for Advance Care Directives* (2011).

[74] Batchelor et al, n 2.

[75] Ng and Wong, n 30.

[76] Advance Care Planning Australia and Austin Health, *Advance Care Planning: Getting Started Guide* (2020); Advance Care Planning Australia, *Factsheet for Individuals: What Is Advance Care Planning?* (Austin Health, 2018).

[77] NSW Trustee & Guardian, *Have You Planned Ahead?* (NSW Department of Ageing, Disability & Home Care, Sydney, 2018); NSW Trustee & Guardian, *Enduring Guardianship: Planning for Your Future Health and Lifestyle Decisions* (NSW Department of Ageing, Disability & Home Care, Sydney, 2019).

[78] Seniors Rights Service, *Information Sessions* <https://seniorsrightsservice.org.au/information/information-sessions/>.

[79] Masters et al, n 23; McIlfatrick et al, n 23; Batchelor et al, n 2; Moore et al, n 4; Scott et al, n 23.

[80] NM Ries et al, "Legal Education and the Ageing Population: Building Student Knowledge and Skills through Experiential Learning in Collaboration with Community Organisations" (2016) 37(2) *Adelaide Law Review* 495.

well as other legal[81] or health topics,[82] can improve confidence and preparedness to engage in relevant processes. Delivering accessible information to the community via online learning sources represents one strategy to overcome some of the barriers preventing older adults from engaging with available APP information and education.

Education for Professionals

Professional perspectives of APP can be enhanced through education. Resources developed to educate health professionals on legal requirements regarding forms of APP[83] and other professional development initiatives have proven effective in improving confidence, understanding, and awareness of health professionals regarding dementia,[84] the needs of older LGBT+ patients,[85] and the experiences of rural health workers.[86] Further APP education initiatives could include guidance for clinicians on recognising an authorised decision-maker, the circumstances in which legal documents operate, and the purpose of distinct planning instruments.

Legal professionals would benefit from increased education regarding the use of health-related APP instruments in practice, key features impacting implementation, and the need to advise clients to discuss health-related wishes and preferences with their care provider, particularly in cases where a person is living with a specific condition or chronic illness that requires ongoing medical management.[87] Approaching professional education from an interprofessional perspective can overcome the siloed nature of health and legal professional education and practice in this field.[88] A more holistic perspective of APP, accounting for all legal, health, and personal aspects of planning, may improve both the quality of documents and the likelihood instruments are implemented effectively.

Integration into Usual Care as Part of Everyone's Role

Integrating APP into usual care of health and legal professionals can increase the likelihood these conversations become commonplace.[89] Both professions require greater familiarity and understanding of the available APP instruments to feel more confident in initiating planning with their patients and clients. For example, improved understanding of available legal protections, such as an EPA, might lead to a treating doctor asking more pertinent questions of their patients if they were to mention financial exploitation. Similarly, educating lawyers on the features of a quality ACD might increase their confidence in assisting clients to prepare this instrument and encourage their clients to speak with medical providers. This inter-professional approach can also provide patients and clients with

[81] H McDonald et al, "Uptake of Legal Self-Help Resources: What Works, for Whom and for What?" (2019) 30 *Justice Issues* 1.

[82] M Prins et al, "Use and Impact of the Alzheimer Experience: A Free Online Media Production to Raise Public Awareness and Enhance Knowledge and Understanding of Dementia" (2020) 24(6) *Aging & Mental Health* 985; B Klimova et al, "E-Learning as Valuable Caregivers' Support for People with Dementia – A Systematic Review" (2019) 19(1) *BMC Health Services Research* 1.

[83] See, eg, Australian Centre for Health Law Research, *How to Do Advance Care Planning: A Quick Guide for Health Professionals* (Queensland University of Technology, Brisbane, 2021); Australian Centre for Health Law Research, *Our Publications* <https://research.qut.edu.au/achlr/our-research/our-publications/>.

[84] A Casey et al, "GP Awareness, Practice, Knowledge and Confidence: Evaluation of the First Nation-Wide Dementia-Focused Continuing Medical Education Program in Australia" (2020) 21(1) BMC Family Practice 1; MW Bentley et al, "Behavioural Change in Primary Care Professionals Undertaking Online Education in Dementia Care in General Practice" (2019) 25(3) *Australian Journal of Primary Health* 244.

[85] A Jurček et al, "Educating Health and Social Care Practitioners on the Experiences and Needs of Older LGBT+ Adults: Findings from a Systematic Review" (2021) 29(1) *Journal of Nursing Management* 43.

[86] R Ramsden et al, "The Role of Digital Technology in Providing Education, Training, Continuing Professional Development and Support to the Rural Health Workforce" (2021) 122(2) *Health Education* 126.

[87] Orsatti, n 32.

[88] D Bozin et al, "No Passport Required: Crossing Interdisciplinary Borders in an Australian Legal Clinic" (2020) 9(17) *Laws* 1; E Tobin-Tyler and J Teitelbaum, "Training the 21st-Century Health Care Team: Maximizing Interprofessional Education through Medical–Legal Partnership" (2016) 91(6) *Academic Medicine* 761.

[89] Orsatti, n 32.

frequent and ongoing opportunities to consider, discuss, and record their intentions regarding health, legal, financial, and personal matters.[90] Making APP a part of everyone's role eliminates the uncertainty surrounding who should instigate and/or revisit planning conversations.[91]

Further Interprofessional Collaboration

Doctors and health professionals can often be excluded from a patient's health-based planning instruments.[92] Interprofessional collaboration is therefore vital to ensure best practice is followed. Facilitating increased collaboration between medical and legal professions can reduce the uncertainty regarding validity of documents and decision-maker authority.[93] By improving the quality of APP instruments, implementation and future use in practice may also be enhanced.

Cultural Shifts Around Death, Dying, Care, and Normalising Discussions

Levels of death literacy are generally low in the community.[94] Legal and health professions can play a key role in encouraging a cultural shift to normalise processes of receiving end-of-life care and dying well.[95] While confronting, normalising these discussions – in a considerate and appropriate manner – can facilitate changes in perspectives and practice.[96]

B. Recommendations for Structural Improvements

Law Reform – Unified Appointments, Register of Appointments, Legislation, Court Structure

Several reforms in the legal field would lead to structural improvements, including: actioning suggested reforms to develop a unified instrument for appointing all forms of decision-makers;[97] creating a national register of enduring appointments to provide certainty regarding the authority, and any revocations, of decision-making power;[98] legislative reform to create a more uniform approach to the various APP instruments to promote increased consistency;[99] and considering changes to the jurisdiction of tribunals and courts to provide increased access to efficient and affordable means of achieving justice when things go wrong.[100]

Better Education for Health and Legal Professionals in Training

Further attention should also be directed to education of professionals in training.[101] Detailed education which includes compulsory modules on APP processes, barriers, and facilitators in legal and medical training may enhance medical and legal trainee understanding and confidence in APP. Graduate doctors may be more alert to legal issues and link patients with existing resources. Similarly, new lawyers may be more prepared to discuss available health planning instruments with clients and encourage communication with health care providers to ensure instruments are relevant to individual circumstances.

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[90] Vearrier, n 51; Robinson, n 52.

[91] Dixon and Knapp, n 68.

[92] Vearrier, n 51, 348; Nauck et al, n 26, 52.

[93] Orsatti, n 32.

[94] McIlfatrick et al, n 23.

[95] Masters et al, n 23.

[96] Department of Health, *National Framework for Advance Care Planning Documents* (Australian Government, Canberra, 2021) 6.

[97] New South Wales Law Reform Commission, n 72, 96.

[98] Council of Attorneys-General, *National Plan to Respond to the Abuse of Older Australians (Elder Abuse) 2019-2023* (Attorney-General's Department, Canberra, 2019).

[99] Law Council of Australia, n 73, 19.

[100] Australian Guardianship and Administration Council, *Maximising the Participation of the Person in Guardianship Proceedings: Guidelines for Australian Tribunals* (2019).

[101] Ries et al, n 80; Tobin-Tyler and Teitelbaum, n 88.

VI. Strengths & Limitations

This study is the first of its kind to provide key informant perspectives from both legal and health fields in the broader context of APP. Insights from several professional areas are combined, rather than examining the experiences and perspectives of lawyers[102] and clinicians[103] separately. It also provides insights from professionals at three phases of the process: lawyers who assist clients to engage with and prepare APP documents; health professionals who interpret and implement completed instruments relating to treatment and end-of-life care; and police who investigate the aftermath of poor-quality APP resulting in elder abuse or other issues stemming from misuse. The qualitative study design[104] allowed for deeper exploration of professional experiences, perspectives, and suggestions. The detailed and nuanced data obtained from expert opinions enhances our understanding of the evolution of current processes and their operation in practice. These insights also highlight several opportunities for improvement which could be adopted by expert key informants.

Key informants were mostly located in New South Wales, meaning that results may not be generalisable to other jurisdictions. Due to the nature of the key informant approach, participants were considered experts in their field of practice. However, this could be a limitation of the study as it does not account for the perspectives and experiences of younger professionals, or those recently entering the professions. While some interviews highlighted the needs and experiences of diverse populations, including people living with a disability and people belonging to First Nations or culturally and linguistically diverse communities, further research must be conducted to ensure the advantages of APP are being realised for these groups in a meaningful and culturally appropriate manner.

VII. Conclusion

These findings contribute new data on the characteristics of high-quality APP processes and the barriers to engagement, quality, and future use of APP instruments from the perspective of health and legal professionals. Identified barriers included: limited community and professional understanding of the purpose and circumstances in which APP instruments operate; ambiguity, inaccessibility, and limited currency of prepared instruments; and uncertainty regarding the role of professionals in APP conversations and varied legislative frameworks. Opportunities for improvement include: educating community members, professionals and trainees in relation to APP processes and practice; normalising conversations about death and dying; and providing opportunities for inter-professional collaboration between medical and legal professionals.

[102] Ries et al, n 31; Helmes et al, n 31.

[103] Moore et al, n 4; Dixon and Knapp, n 68; JJ Rhee et al, "Why Are Advance Care Planning Decisions Not Implemented? Insights from Interviews with Australian General Practitioners" (2013) 16(10) *Journal of Palliative Medicine* 1197.

[104] K Ariyo et al, "Experiences of Assessing Mental Capacity in England and Wales: A Large-Scale Survey of Professionals" (2021) 6 *Wellcome Open Research* https://doi.org/10.12688/wellcomeopenres.16823.1; Rodi et al, n 8; Sellars et al, n 2.

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