Dying In The Margins: Understanding the needs and capacities of a lower socioeconomic population for end of life care

Joanne Lewis

Thesis submitted in fulfilment of the degree of

Doctor of Philosophy

University of Technology Sydney
Certificate of Original Authorship

I certify that the work in this thesis has not previously been submitted for a degree nor has it been submitted as part of requirements for a degree except as fully acknowledged in the text.

I also certify that the thesis has been written by me. Any help I have received in my research work and the preparation of the thesis itself has been acknowledged. In addition I certify that all information sources and literature used are indicated in the thesis.

Signature of student
Acknowledgments

It is with immense gratitude that I acknowledge the help and support of many. I will attempt to name many of them, but in no particular order.

Thank you to my participants, most particularly my patient and carer participants who gave their very precious time to share their stories. Giving voice to their experience kept me going in the difficult moments. For many of my patients and carers life was hard, but they remained soft and I respect them immensely.

To my principal supervisor Professor Patricia Davidson, her vision and enthusiasm pulled me to places only she knew were possible and necessary. Her research skills and her capacity to mentor and create leaders are so far reaching that I can go few places where she is not well known or highly regarded. I cannot thank her enough for including me in her fold.

A most special thanks also, to my co-supervisor Dr Michelle DiGiacomo. Michelle possesses skills and characteristics, which I both needed and regarded. Her attention to detail and strive for excellence meant that the PhD process was made easier for me. Our mutual love of Angela Lansbury and the needs of vulnerable people (likely in no way connected) meant that I never had to explain my concerns for inequity or hide my quirky nature.

To the other brilliant research minds who helped me along the way; Professor David Currow, Professor Jane Philips, Dr Philip Newton, and Dr Tim Luckett, I am also so grateful.

I would like to acknowledge my work colleagues Wendy, Pam, Siobhan and Mel for their encouragement and ongoing interest in my project. I would particularly like to thank my work colleague and great friend Kristin for her brilliant mind and wise and loving counsel which kept me motivated and focused. Thank you to librarians Marie and Sylvia for their generous support for literature searches and document retrieval. Thank you also to Anne for her skills in transcription and Sajad Shehab for skills and work in formatting.

To my friends Diane, Michael, Lisa, Mark, Debbie, Geoff, Sam and Naira thank you for your prayers and encouragement, company, fun, good food and wine, and for reminding me that there was life outside of my PhD world.

Deepest gratitude goes to my family. My husband Andrew who although is thousands of miles away as I write this, has always been my greatest fan and given me a safe place to stretch my wings and to be myself. To my daughters, Cait and Gaby who are my greatest achievement and remarkable young women, thank you for your hugs, prayers and patience, and thank you also
for the coffee and baked goods. To my parents-in-law, Lesley and Geoffrey thank you for remaining the same, caring and encouraging and also for nourishing us with Monday meal night. Thank you also to my siblings and their partners Vicki, AJ, Lyn, Anthony, Jason and Melinda for making the process more bearable by knowing your support and encouragement was ever present.

Finally I am thankful for Jesus’ example to care for the last and the least.

This study was supported by an Australian Post Graduate Award.
Anthology of Publications Associated with Thesis


Abstract

Increased disease burden and unmet health care needs are defining features of lower socioeconomic groups, both in Australia and internationally. In Australia, there is limited understanding of the needs of lower socioeconomic groups for end of life care. At the end-of-life, health disparities are often more pronounced for both patients and their caregivers. Globally, there has been scant attention on the needs of individuals from socially and economically disadvantaged groups at the end-of-life. As gaps between the rich and poor widen and the emphasis on community-based care increases, this research area is of growing significance.

The research objectives of this study were to (i) provide a snapshot of the impact of socioeconomic status on place of death and after-hours crisis service utilisation by comparing outcomes of areas of high and low disadvantage; (ii) explore and describe the socioeconomic demographics, needs, capacities and experiences of patients and/or carers from a disadvantaged area focusing on (ii a) the social, economic and care outcomes and capacities at individual, community and government levels, (ii b) the nature and impact of social capital outcomes, (ii c) the experience of access for a specialist palliative care service; and (iii) describe the appropriateness, acceptability, and feasibility of self-report tools for capturing wellbeing, consumption, health literacy, social capital and palliative care needs and capacities in this population.

This study used a concurrent embedded mixed method design with a qualitative emphasis and explicit use of social determinants of health framework and social capital concepts. The conceptual framework determined selection of self-report tools which additionally structured interviews. Integration of the quantitative and qualitative data was achieved through the study design, data collection and discussion. Four years of administrative data from a single palliative care service, located in a socioeconomically disadvantaged area was collected and analysed. Place of death and after-hours crisis service data were compared for a most and a least disadvantaged area compared over a twelve month period. Semi-structured interviews were conducted with 14 patients and/or carers from a lower socioeconomic area and five key informants who provided formal care for this group. Demographic data and outcomes of self-report tools were collected from patient and carer participants during interviews. Semi-structured interview responses to self-report tools were evaluated for appropriateness, acceptability and feasibility of these measures.
The findings demonstrate that a lower socioeconomic group experienced end of life care within margins of social and economic resources and care networks. *Social margins* were shaped by limited community trust, engagement and deficiencies in social policy (public housing). *Economic margins* reflected income loss, healthcare spending on co-payments and economic disparity in aged care facility access. *Care network margins* were defined by limited informal and formal care support. Patients from the disadvantaged area had fewer home deaths and greater home care needs warranting facility admission. Capacities within the end of life care experience were demonstrated by trust and engagement with government organisations, potential for community club, neighbourhood and friendship support, access to financial support programs and benefits, and examples of supported home care networks. Recommendations for research, clinical practice and policy to address these issues are discussed.

This thesis has provided a unique and novel contribution to the literature. Specifically, it has demonstrated the needs and capacities for a lower socioeconomic group not previously described in the Australian literature, and in particular, it has advanced conceptual and theoretical issues in investigating social and economic issues in end-of-life care.
Table of Contents

1 Certificate of Original Authorship ......................................................................................... ii
2 Acknowledgments ............................................................................................................. iii
3 Anthology of Publications Associated with Thesis ............................................................... v
4 Abstract .............................................................................................................................. vi
5 Table of Contents .............................................................................................................. viii
6 List of Tables ..................................................................................................................... xvi
7 List of Figures ................................................................................................................... xviii
8 List of Appendices ............................................................................................................. xix
9 List of Abbreviations ......................................................................................................... xx
10 Glossary of Terms ............................................................................................................ xxi
11 Chapter 1 ....................................................................................................................... 1
   11.1 Introduction ............................................................................................................... 1
   11.2 Background and context ........................................................................................... 1
      11.2.1 Dimensions of socioeconomic disadvantage .................................................. 1
      11.2.2 Outcomes for socioeconomic disadvantage in Australia ............................... 5
      11.2.3 Socioeconomic status and health inequalities .................................................. 5
      11.2.4 Socioeconomic disadvantage and health inequalities in Australia ............... 7
      11.2.5 Palliative care in Australia ............................................................................... 9
      11.2.6 Significance of the research ............................................................................ 14
      11.2.7 Chapter summary .............................................................................................. 15
      11.2.8 Research objectives ....................................................................................... 15
      11.2.9 Structure of this thesis .................................................................................... 15
      11.2.10 References .................................................................................................... 17
12 Chapter 2 ....................................................................................................................... 21
14.12 Pilot testing for self-report tools................................................................. 87
14.13 Implementation of the study............................................................................. 87
  14.13.1 Interview process........................................................................................ 87
  14.13.2 Additional data.......................................................................................... 88
14.14 Ethical considerations .................................................................................... 88
  14.14.1 Vulnerable populations............................................................................. 89
  14.14.2 Confidentiality and informed consent ..................................................... 90
  14.14.3 Data management, storage and retention .............................................. 90
  14.14.4 Positioning of the researcher................................................................. 91
14.15 Research analysis ........................................................................................... 92
  14.15.1 Qualitative analysis ............................................................................... 92
  14.15.2 Reporting of Qualitative data ............................................................... 95
  14.15.3 Evaluation of self-report tools ............................................................... 95
  14.15.4 Quantitative analysis ............................................................................. 95
14.16 Integrating qualitative and quantitative data.................................................. 96
14.17 Conclusion ...................................................................................................... 96
14.18 References .................................................................................................... 98

15CHAPTER 5 .............................................................................................................. 101
  15.1 Introduction ................................................................................................... 101
  15.2 Method ......................................................................................................... 102
  15.3 Setting ......................................................................................................... 103
  15.4 Results ......................................................................................................... 103
    15.4.1 Place of death data .............................................................................. 103
  15.5 After-hours crisis service utilisation outcomes.............................................. 106
    15.5.1 After-hours crisis service utilisation outcomes: relationship of caller to service 106
    15.5.2 After-hours service utilisation outcomes: reason for service call............. 107
15.5.3 After-hours service utilisation outcomes: service provision and admission outcomes

15.6 Strengths and limitations

15.7 Conclusion

15.8 Chapter Summary

15.9 References

16 Chapter 6

16.1 Results

16.2 Participant characteristics

16.2.1 Socioeconomic characteristics: patients and carers

16.2.2 Key informant characteristics

16.2.3 Self-report tool sample

16.3 Quantitative outcomes for self-report tools

16.3.1 Personal Wellbeing Index (PWI)

16.3.2 Needs Assessment Tool: Progressive Disease-Cancer (NAT:PD-C)

16.3.3 Rapid Assessment Adult Literacy Medicine-Revised (REALM-R)

16.3.4 Consumption Survey

16.3.5 Social capital questionnaire (SCQ)

16.4 Qualitative outcomes: Patients and carers

16.4.1 Introduction: themes and concepts

16.4.2 Conditions of economic challenge

16.4.3 Catalysts of social states

16.4.4 Bonded care conditions

16.4.5 Breaches and capacities of bridged care networks

16.4.6 Realised specialist care

16.4.7 Conclusion

16.5 Qualitative findings: Key informants
<table>
<thead>
<tr>
<th>Section</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>16.5.1</td>
<td>Introduction to themes and concepts</td>
<td>157</td>
</tr>
<tr>
<td>16.5.2</td>
<td>Enabled care contexts</td>
<td>158</td>
</tr>
<tr>
<td>16.5.3</td>
<td>Situations of vulnerability</td>
<td>163</td>
</tr>
<tr>
<td>16.5.4</td>
<td>Negotiating the system</td>
<td>171</td>
</tr>
<tr>
<td>16.6</td>
<td>Conclusion</td>
<td>176</td>
</tr>
<tr>
<td>16.7</td>
<td>Chapter summary</td>
<td>176</td>
</tr>
<tr>
<td>17</td>
<td>Chapter 7</td>
<td>178</td>
</tr>
<tr>
<td>17.1</td>
<td>Introduction</td>
<td>178</td>
</tr>
<tr>
<td>17.2</td>
<td>Personal Wellbeing Index (PWI)</td>
<td>179</td>
</tr>
<tr>
<td>17.2.1</td>
<td>Personal Wellbeing Index: appropriateness outcomes</td>
<td>179</td>
</tr>
<tr>
<td>17.2.2</td>
<td>Personal Wellbeing Index: Acceptability and feasibility</td>
<td>180</td>
</tr>
<tr>
<td>17.2.3</td>
<td>Implications for research and clinical practice</td>
<td>180</td>
</tr>
<tr>
<td>17.3</td>
<td>Needs Assessment Tool: Progressive Disease- Cancer (NAT:PD-C)</td>
<td>181</td>
</tr>
<tr>
<td>17.3.1</td>
<td>Needs Assessment Tool: Progressive Disease- Cancer (NAT:PD-C): Appropriateness</td>
<td>181</td>
</tr>
<tr>
<td>17.3.2</td>
<td>Needs Assessment Tool: Progressive Disease- Cancer (NAT:PD-C): Acceptability and feasibility</td>
<td>182</td>
</tr>
<tr>
<td>17.3.3</td>
<td>Needs Assessment Tool: Progressive Disease- Cancer (NAT:PD-C): Implications for research and clinical practice</td>
<td>182</td>
</tr>
<tr>
<td>17.4</td>
<td>Rapid Estimate Adult Literacy Medicine- Revised (REALM-R)</td>
<td>183</td>
</tr>
<tr>
<td>17.4.1</td>
<td>Rapid Estimate Adult Literacy Medicine- Revised (REALM-R): Appropriateness</td>
<td>183</td>
</tr>
<tr>
<td>17.4.2</td>
<td>Rapid Estimate Adult Literacy Medicine-Revised (REALM-R): Acceptability and feasibility</td>
<td>183</td>
</tr>
<tr>
<td>17.4.3</td>
<td>Rapid Estimate Adult Literacy Medicine-Revised (REALM-R): Implications for research and clinical practice</td>
<td>184</td>
</tr>
<tr>
<td>17.5</td>
<td>Consumption survey</td>
<td>184</td>
</tr>
<tr>
<td>17.5.1</td>
<td>Consumption Survey: Appropriateness</td>
<td>184</td>
</tr>
<tr>
<td>Section</td>
<td>Page</td>
<td></td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>------</td>
<td></td>
</tr>
<tr>
<td>17.5.2 Consumption Survey: Acceptability and feasibility</td>
<td>184</td>
<td></td>
</tr>
<tr>
<td>17.5.3 Consumption Survey: Implications for research and clinical practice</td>
<td>185</td>
<td></td>
</tr>
<tr>
<td>17.6 Social Capital Questionnaire (SCQ)</td>
<td>185</td>
<td></td>
</tr>
<tr>
<td>17.6.1 Social Capital Questionnaire (SCQ): Appropriateness</td>
<td>185</td>
<td></td>
</tr>
<tr>
<td>17.6.2 Social Capital Questionnaire (SCQ): Acceptability and feasibility</td>
<td>187</td>
<td></td>
</tr>
<tr>
<td>17.6.3 Social Capital Questionnaire (SCQ): Implications for research and clinical practice</td>
<td>188</td>
<td></td>
</tr>
<tr>
<td>17.7 Chapter summary</td>
<td>189</td>
<td></td>
</tr>
<tr>
<td>17.8 References</td>
<td>190</td>
<td></td>
</tr>
<tr>
<td>18 Chapter 8</td>
<td>191</td>
<td></td>
</tr>
<tr>
<td>18.1 Social and community margins</td>
<td>191</td>
<td></td>
</tr>
<tr>
<td>18.1.1 Structural conditions of public housing policy</td>
<td>192</td>
<td></td>
</tr>
<tr>
<td>18.1.2 Positive political engagement</td>
<td>193</td>
<td></td>
</tr>
<tr>
<td>18.1.3 Daily living conditions of social isolation and community disengagement</td>
<td>194</td>
<td></td>
</tr>
<tr>
<td>18.1.4 Daily living conditions of community engagement</td>
<td>198</td>
<td></td>
</tr>
<tr>
<td>18.1.5 Conclusion</td>
<td>200</td>
<td></td>
</tr>
<tr>
<td>18.2 Economic margins</td>
<td>201</td>
<td></td>
</tr>
<tr>
<td>18.2.1 Structural conditions of gaps too large</td>
<td>202</td>
<td></td>
</tr>
<tr>
<td>18.2.2 Structural conditions of closed gaps</td>
<td>205</td>
<td></td>
</tr>
<tr>
<td>18.2.3 Conditions of daily living for low income, low wealth and low consumption</td>
<td>206</td>
<td></td>
</tr>
<tr>
<td>18.2.4 Conclusion</td>
<td>208</td>
<td></td>
</tr>
<tr>
<td>18.3 Margins of care networks</td>
<td>209</td>
<td></td>
</tr>
<tr>
<td>18.3.1 Structural conditions of formal networks of inequity</td>
<td>209</td>
<td></td>
</tr>
<tr>
<td>18.3.2 Structural conditions of organisational support</td>
<td>214</td>
<td></td>
</tr>
<tr>
<td>18.3.3 Conditions of daily living for informal care giving margins</td>
<td>214</td>
<td></td>
</tr>
<tr>
<td>18.3.4 Daily living conditions of capacities in informal and formal care networks</td>
<td>219</td>
<td></td>
</tr>
<tr>
<td>18.4 Study Conclusion</td>
<td>222</td>
<td></td>
</tr>
</tbody>
</table>
List of Tables

Table 1.1  Palliative care service provision by subgroup populations .................................................. 11
Table 1.2  Socioeconomic status by palliative care separations ............................................................ 12
Table 2.1  Literature review outcomes .................................................................................................. 23
Table 2.2  Summary of included publications ...................................................................................... 25
Table 3.1  Social capital framework: components, analysis domains and differentials ...................... 60
Table 4.1  ABS data for Hills and Mt Druitt areas ................................................................................ 75
Table 4.2  Social capital survey items .................................................................................................. 83
Table 5.1  Place of death rates for Hills and Mt Druitt area service registrations ............................... 104
Table 5.2  Place of death rates for Hills and Mt Druitt area service registrations for sex .............. 105
Table 5.3  Place of death for patients with non-malignant illness: Hills and Mt Druitt area registrations ............................................................................................................................................ 106
Table 5.4  After-hours service utilisation relationship of caller to the service .................................... 107
Table 5.5  After-hours service utilisation reason for service call: Hills and Mt Druitt areas ....... 107
Table 5.6  After hours service provision and admission outcome from call; Hills and Mt Druitt area ............................................................................................................................................. 108
Table 5.7  Place of death for patients with non-malignant illness: Hills and Mt Druitt area registrations ............................................................................................................................................ 106
Table 5.8  Place of death for patients with non-malignant illness: Hills and Mt Druitt area registrations ............................................................................................................................................ 106
Table 6.1  Patient and carer socioeconomic and demographic characteristics .................................... 113
Table 6.2  Key informant role and experience descriptions .................................................................. 114
Table 6.3  Number of participants who completed self-report tools .................................................... 114
Table 6.4  Personal Wellbeing Index ..................................................................................................... 115
Table 6.5  NAT:PD-C Patient wellbeing ................................................................................................ 116
Table 6.6  NAT:PD-C Ability of carer or family to care ........................................................................ 117
Table 6.7  NAT:PD-C Caregiver wellbeing ............................................................................................ 117
Table 6.8  Weekly and monthly expenditure ......................................................................................... 118
Table 6.9  Question 1 Close relationships and networks; “In the last 12 months have you received help from any of the following?” ......................................................................................................................... 121
Table 6.10 Question 1 Community and government organisations and networks; “In the last 12 months have you received help from any of the following? .................................................... 122

Table 6.11 Question 2 Quality of relationships with close relations and networks ................. 123

Table 6.12 Question 2 Quality of relationships with community and government networks and relations .................................................................................................................................... 123

Table 6.13 Question 3 responses for activity in membership of formal groups ...................... 124

Table 6.14 Question 4 ‘What are some of the reasons for not being an active member of a formal group’ .............................................................................................................................................. 125

Table 6.15 Responses questions 6-15 ............................................................................. 127

Table 6.16 Themes and concepts of analysis of patient and carer interviews ..................... 128

Table 6.17 Themes and concepts from analysis of key informant interviews ..................... 157
List of Figures

Figure 1.1 Selected long term medical conditions across quintiles of disadvantage ................... 8
Figure 3.1 Commission Social Determinants of Health Framework (final form) ......................... 56
Figure 3.2 Conceptual model for this study .................................................................................. 64
Figure 4.1 Aspects of mixed methods research design (Adapted from Creswell, 2009) ............ 72
Figure 4.2 Concurrent embedded design (Adapted from Creswell, 2009) ................................. 73
Figure 4.3 Parallel Mixed Methods Sample .................................................................................. 78
Figure 4.4 Example of coding matrix from Smith and Firth (2011) ............................................. 93
Figure 4.5 Example of coding index for Smith and Firth (2011) .................................................. 94
Figure 6.1 Reasons for being part of a formal social group ......................................................... 125
List of Appendices

Appendix 1: Publications associated with this thesis ............................................................... 238
Appendix 2: Recruitment flyer for patients and carers ............................................................ 271
Appendix 3: Interview guide patients and carers ..................................................................... 273
Appendix 4: Socio-demographic data collection sheet ............................................................ 274
Appendix 5: Needs assessment tool: Progressive disease-cancer (NAT:PD-C) ....................... 275
Appendix 6: Consumption Survey ............................................................................................ 276
Appendix 7: Personal Wellbeing Index (PWI) ........................................................................... 277
Appendix 8: Rapid Estimate Adult Literacy Medicine-Revised (REALM-R) ......................... 278
Appendix 9: Social Capital Questionnaire (SCQ) .................................................................... 279
Appendix 10: Sydney West Area Health Service Human Research Ethics Approval ............... 283
Appendix 11: Amended Sydney West Area Health Service, Human Research Ethics Committee approval ........................................................................................................... 285
Appendix 12: University of Technology Sydney, Human Research Ethics approval .............. 287
Appendix 13: Participant Information Sheet and Consent Form (PCIF): Patients and/or carers .................................................................................................................................................. 289
Appendix 14: Copy of the Participant Information Sheet and Consent Form (PCIF): Formal carers .......................................................................................................................................... 296
Appendix 15: Initial concepts and themes: Framework analysis (Patient and /or carers) ...... 302
Appendix 16: Initial concepts and themes: Framework analysis (key informants).................... 303
# List of Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABS</td>
<td>Australian Bureau of Statistics</td>
</tr>
<tr>
<td>ASCAT</td>
<td>Adapted Social Capital Assessment tool</td>
</tr>
<tr>
<td>CNC</td>
<td>Clinical Nurse Consultant</td>
</tr>
<tr>
<td>CNS</td>
<td>Clinical Nurse Specialist</td>
</tr>
<tr>
<td>COAG</td>
<td>Coalition of Australian Governments</td>
</tr>
<tr>
<td>CSDH</td>
<td>Commission for Social Determinants of Health</td>
</tr>
<tr>
<td>HILDA</td>
<td>Household Income and Labour Dynamics in Australia</td>
</tr>
<tr>
<td>IRSD</td>
<td>Index of Socioeconomic Disadvantage</td>
</tr>
<tr>
<td>NHMRC</td>
<td>National Health and Medical Research Council</td>
</tr>
<tr>
<td>OECD</td>
<td>Organisation of Economic Co-operations and Development</td>
</tr>
<tr>
<td>OOP</td>
<td>Out of Pocket</td>
</tr>
<tr>
<td>PCA</td>
<td>Palliative Care Australia</td>
</tr>
<tr>
<td>PCOC</td>
<td>Palliative Care Outcomes Collaborative</td>
</tr>
<tr>
<td>SDH</td>
<td>Social Determinants of Health</td>
</tr>
<tr>
<td>SEIFA</td>
<td>Socioeconomic Indexes for Areas</td>
</tr>
<tr>
<td>SOCAT</td>
<td>Social Capital Assessment Tool</td>
</tr>
</tbody>
</table>
Glossary of Terms

**Advanced care directive**: Documents containing instructions that consent or decline specific medical treatments and/or specify care and lifestyle preferences in anticipating future situations or circumstances. These directives are activated in situations where the person is no longer able to make decisions. As legal documents, advanced care directives are distinct for legislative requirements in each State and Territory in Australia.

**Bulk Billing**: The process by which a practitioner sends the bill for services directly to Medicare, so that the patient receiving the service pays nothing.

**Consumption survey**: A self-completion 21-item survey which identifies approximate weekly, monthly, and yearly household expenditure and additional items for costs of medications and medical consumables and equipment hire/purchase costs.

**End of life care**: Combines the broad set of health and community services that care for the population at the end of their life. Inclusive of networks between specialist palliative care providers, primary generalist providers, primary specialists and support care providers and the community.

**Home care services**: The Home and Community Care (HACC) Program is a joint Australian Government, State and Territory initiative to provide community care services to frail aged people, younger people with a disability and their carers.

**Index of relative Socioeconomic Disadvantage (IRSD)**: The Index of Relative Disadvantage uses indicators of low socio-economic wellbeing as a general measure of disadvantage. Its use is appropriate for users interested in the relative disadvantage of people in an area (lower deciles), and the relative lack of disadvantage of people in an area generally (upper deciles).

**Medicare**: Australia’s government-funded health care system that subsidises the costs of personal medical services for all Australian Medicare card holders and aims to support affordability of medical care.

**Needs assessment tool**: *Progressive disease Cancer(NAT:PD-C)*: A sixteen-item, multiple section assessment tool administered by health professionals to assess levels of need in patients and carers in specialist and generalist health care settings and match these needs to specialist palliative care services as necessary.
**Personal Wellbeing Index (PWI):** An 8 item, 11 point self-report end-defined response scale, which assesses a person’s subjective quality of life across eight domains (‘standard of living’, ‘health’, ‘achieving in life’, ‘personal relationships’, ‘safety’, ‘feeling part of the community’, ‘future security’ and ‘spirituality or religion’).

**Pharmaceutical Benefit Scheme (PBS):** A publicly funded insurance scheme in Australia aimed at providing universal affordable access to prescription medicines.

**Primary care providers:** In the context of end of life care, a primary care provider is the first contact medical, nursing or allied health professional who undertakes an ongoing role in the care of a patient and their family or carer.

**Rapid Estimate of Adult Literacy Medicine-Revised (REALM-R):** An eight item instrument designed to rapidly screen adult primary care patients for low health literacy.

**Social Capital Questionnaire (SCQ):** The questionnaire is a researcher-designed tool to measure the quality and quantity of individual, community and societal relations and networks for the patient or their carer. The questionnaire has 16 questions with multiple item responses to 5 questions.

**Socioeconomic Index for Areas (SEIFA):** A measure of socioeconomic status in Australia used to define levels of disadvantage within and across areas. SEIFA scores are indicators of socioeconomic status and are the most widely used measure of socioeconomic status (SES) in Australia. They are based on international research and information collected in the census reflected in the Australian Bureau of Statistics (ABS) data.

**Specialist palliative care services:** Specialist palliative care services are provided by an interdisciplinary team of specialist palliative care professionals whose substantive work is with patients who have an eventually fatal condition. Specialist palliative care services are provided in care settings including community, home, hospitals, aged care, homes and hospices and palliative care units.