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Health Services for Young Adults with Stroke: A Service Mapping Study over Two Australian States

Melita J. Giummarra ,[1] **Emma Power** ,[2,3] **Renerus Stolwyk** ,[4] **Maria Crotty** ,[5,6] **Brooke Parsons,**[7] **and Natasha A. Lannin** [1,8]

[1]*Department of Neuroscience, Central Clinical School, Monash University, Melbourne, Australia*
[2]*University of Technology Sydney, Ultimo, NSW, Australia*
[3]*Centre of Excellence for Aphasia Recovery and Rehabilitation, La Trobe University, Bundoora, Australia*
[4]*Turner Institute for Brain and Mental Health, School of Psychological Sciences, Monash University, Melbourne, VIC, Australia*
[5]*College of Medicine and Public Health, Department of Rehabilitation, Aged and Extended Care, Flinders University, Adelaide, SA, Australia*
[6]*Flinders Medical Centre, Bedford Park, SA, Australia*
[7]*The Florey, Melbourne Brain Centre, Austin Hospital, Heidelberg, Australia*
[8]*Alfred Health, Melbourne, Australia*

Correspondence should be addressed to Natasha A. Lannin; natasha.lannin@monash.edu

Despite increased incidence of stroke in young adulthood across the world, young adults report significant difficulties finding services with the expertise and experience to meet their needs. This service mapping study sought to identify and characterise the availability, accessibility, and accommodation of services to meet the needs of young adults (aged 18–44 years) with stroke in two Australian states. *Methods.* Relevant clinical, rehabilitation, and allied health services were systematically identified from previous publications; the National Health Service Directory; professional association "find a provider" listings; and Stroke Foundation service lists. Desktop audit ($n = 465$ services) and key informant interviews ($n = 321$ services) were used to collect service design and delivery characteristics; level of experience, confidence, and willingness to work with young adults with stroke; and accommodation of communication impairments. *Results.* Most services (85%) were in major cities or inner regional areas. No services worked solely with young adults with stroke; however, several reported having relevant expertise, training, experience, and programmes to provide neurological rehabilitation to meet the needs of young adults with stroke. Reported willingness (91.0%) to work with young adults with stroke was high, but only 57.0% were very confident to do so. Most services with neurorehabilitation expertise addressed psychosocial recovery needs (e.g., emotional adjustment and relationships) as well as functional recovery, but few supported return-to-driving, peer support, and sensory processing disturbances. Further gaps were the use of accessible communication materials in only 50.2% of services, and staff had completed communication training at only 60.4% of services. *Conclusion.* Findings highlight that while expert neurorehabilitation services exist, they are not sufficiently available, accessible, or accommodating of the needs of young adults with stroke. There remains a need to improve access to services where clinicians have the skills to meet the rehabilitation needs of young adults with stroke in Australia.

1. Introduction

The incidence of stroke in young adults has been steadily increasing [1, 2], with 24% of strokes occurring in people aged 54 years or younger [2]. In the context of stroke "young adults" are most often defined as those aged 18 to 65 years, particularly younger than 45 years of age. Most strokes in young adults are caused by cerebral infarction; however, a third of cases are cryptogenic [3]. Stroke tends to lead to lower levels of disability in younger adults compared to older

adults [4], particularly because timely acute stroke treatments have markedly improved survival and recovery [5–7]; however, the social, psychological, and economic impacts have been recognised as being disproportionately worse for younger adults [4, 8–13]. Therefore, young adults require access services that are suitable for their recovery goals poststroke.

Young adulthood is an important life phase focused on moving away from the parental home, establishing a family and career, and contributing to the community through civic engagement [14, 15]. Stroke during young adulthood can therefore have a devastating impact on many aspects of life. For instance, a systematic review by Daniel, et al. [16] highlighted that after stroke only an average of 44% of young adults return to work, 24–33% of people have financial problems, up to 75% have problems in their sexual relationships, and up to 54% have problems in family relationships. Moreover, young adults have reported difficulties psychologically adjusting to the impact of stroke [17]; reduced participation in leisure, social, and community activities [12, 16]; and lower quality of life than age-matched peers or older adults with stroke [4, 17–21]. Psychosocial impacts of stroke in young adulthood can also include changes in body image, identity, and social or family roles [11, 17], as well as poorer self-efficacy and self-esteem and increasedanger and fatigue, and symptoms of anxiety, depression, and stress [17]. Moreover, at least 22% of young adults with stroke experience difficulties with communication (e.g., due to aphasia or dysarthria) and 44% have cognitive impairments [22], which place greater strain on relationships, psychological wellbeing and quality of life, and increased difficulties in the workplace [20].

The importance of resuming significant life roles in young adulthood has led to widespread calls for clinical guidelines and services for stroke to specifically address the needs of young adults [12, 16, 23]. Despite this need, research continues to highlight that significant gaps in access to appropriate services remain for young adults [4, 13, 16, 24]. For instance, fe young adults receive ongoing care with a general practitioner or medical specialist poststroke [25]. However, when young adults with stroke do attend health services for stroke-related rehabilitation and therapy, they often report that the service was inappropriate for their needs or goals [16]. Instead, the services were perceived to be designed for older patients and primarily focused on restoring function while placing insufficient attention on psychological wellbeing, social issues, and return to work [11, 12]. As a result, up to 90% of young adults with stroke in Australia report unmet needs [26]. Unmet needs are particularly notable in relation to receiving support for problems with cognitive functioning, social isolation and relationships, mental health, daily activities, return to work, managing finances, and accessing peer support or information about stroke or services [11, 12, 16, 23, 27].

As young adults with stroke report difficulties finding suitable services to meet their needs, the present study was conducted to better understand the availability of rehabilitation and allied health services for young adults poststroke. The current study was undertaken as part of a five-year project to develop a new Young Stroke Service in Australia. We therefore focused on services in the two states included in that project so as to develop a map that would enable timely referrals to services in the community. The study aimed to identify and characterise the health services available for young adults poststroke, by answering the following two research questions:

(1) What rehabilitation and allied health services are available to young adults who have had a stroke?

(2) What are the characteristics of the available services, including their experience with young stroke and the accessibility of those services, particularly for people with communication support needs?

2. Methods

This study was approved by the institutional human research ethics committee, and participants gave oral or implied consent.

2.1. Study Design and Key Frameworks. A desktop audit and key informant interviews were undertaken to identify and gather information about services available for, or that work with, young adults poststroke in Victoria and South Australia, Australia. We adapted the first six steps of the mapping process defined by Price, et al. [28]: defining the relevant service types; identifying the core information to gather about service characteristics; gathering high-level information about potentially relevant services through desktop audit; identifying key informants and collecting further information about the services through surveys or telephone interviews; analysing data; and communicating findings. This approach was consistent with methods used in previous service mapping projects. For instance, previous studies identified relevant services through peak industry bodies such as the Stroke Foundation [12] or the Cancer Council in QLD [29]; searching the NHSD website and professional association websites [30]; and previous consultations, reports, and service directories [31].

The methods were informed by two key frameworks: the five As of service availability, accessibility, affordability, acceptability, and accommodation [32] and the Theoretical Framework of Acceptability [33]. First, the availability of personnel, technology, or other resources to meet the demands on the service are known to influence health service use (e.g., referral waiting lists). The affordability of the service relates to the ability of consumers to meet the costs of the service, and the funding options available to enable people to access the service. Geographic accessibility is defined by the distance between services and service users, measured by travel time [34], as well as the ability to access services through telehealth [35]. Whether services are organised or provided in ways that enable accommodation of the needs and preferences of the service user also play a key role in service use. In particular, poststroke accessibility accommodations may include adaptions for individual functional, cognitive, or communication impairments

[36, 37]. Moreover, accommodation extends to language requirements for people from culturally and linguistically diverse backgrounds. Finally, the acceptability of the service and the programmes offered impact on whether patients will attend a health service. The Theoretical Framework of Acceptability of Health Interventions [33] has defined seven main aspects of acceptability. These include the attitudes and feelings about the service; time, financial, cognitive or emotional burden; whether the service fits with the needs or goals of the patient (i.e., coherence); whether the benefits of accessing the service outweigh any costs; whether it is considered to be effective; and whether the service user is able to use the service and follow the programme or advice (i.e., self-efficacy). While not all of these can be assessed in a study that only collects characteristics of the services, and not from their patients, the assessment of the experience, willingness, confidence of staff to work with young adults with stroke, and types of needs that they can meet do nonetheless provide some indication of the overall potential acceptability of those services.

2.2. Expert Panel. An expert panel provided guidance to define the patient population, eligible services, data collection procedures and tools, and data synthesis, interpretation, and communication. The panel comprised an adult with lived experience of stroke, clinicians with expertise in stroke treatment and rehabilitation in each state, and investigators from the broader project that is designing a new Young Stroke Service. This process was critical to ensure that the findings are relevant to stakeholders seeking or providing services for young adults poststroke (i.e., consumers, carers, and clinicians) who are likely to have different information needs from a "service map" [28].

2.3. Step 1: Defining and Identifying Eligible Services and Service Providers. Rehabilitation and allied health services and sole practitioner clinicians that work with young adult patients with stroke were eligible for inclusion. For the purpose of this project, young adult was defined as 18 to 65; however, we stratified data collection into a "younger" young adult patient group (18 to 44 years) and an "older" young adult group (45 to 65 years). Service mapping focused primarily on rehabilitation services and practitioners who provide treatment or support in the community after discharge from inpatient services. Relevant service types included: outpatient stroke rehabilitation clinics, vocational rehabilitation services, psychologists (including specialists, such as neuropsychology or health psychology), community rehabilitation centres, community health centres, occupational therapists, physiotherapists, speech pathologists, and social workers.

Online and offline systematic searches were undertaken to identify eligible services and practitioners through a range of publicly available service listings, including previous publications; the National Health Service Directory (NHSD); professional association "find a provider" listings via organisations listed on the Allied Health Professions Australia website (e.g., Australian Psychological Society,

Australia Physiotherapy Association, and The Australian Rehabilitation Outcomes Collaboration); and stroke services and clinicians identified by the Stroke Line team at the Stroke Foundation, a free service that helps people who have had a stroke and their families find support and services to meet their needs.

2.4. Steps 2 to 4: Designing and Gather Information about Services. A checklist and survey were designed to collect information about services (Supplementary File 1). Information about each potentially relevant service or practitioner was collated in excel spreadsheets. The data were then imported into and managed in the REDCap Electronic Data Capture tool (REDCap; Vanderbilt University, Nashville, TN, USA), hosted, and managed by Helix (Monash University) [38, 39]. REDCap is a secure, web-based software platform designed to support data capture for research studies, providing (1) an intuitive interface for validated data capture; (2) audit trails for tracking data manipulation and export procedures; (3) automated export procedures for seamless data downloads to common statistical packages; and (4) procedures for data integration and interoperability with external sources.

2.4.1. Desktop Audit. A desktop audit was used to collect relevant information about services from publicly available sources. The information collected through destop audit primarily included the service sector (e.g., public, private, and not-for-profit), clinical specialities, any stroke-specific programmes available, referral procedures, and how patients could pay for consultations or therapy. An Internet search was also used to confirm whether the service was registered with the National Disability Insurance Scheme (NDIS), the national scheme in Australia that provides individualised support for people with significant permanent disability.

2.4.2. Key Informant Interviews. After completing desktop audits, services were contacted to identify relevant key informants who could provide further information through telephone interview or survey. Services that appeared to have an interest in stroke or neurological rehabilitation were prioritised for data collection from key informants. Key informants gave oral or implied consent by completing an interview or survey, as per the protocol approved by the ethics committee. In addition to confirming key details about their service, informants were asked to report: the approximate number of young adults with stroke accessing their service each year, types of programmes or therapies available specifically for stroke patients, stroke-related clinical needs that the service could support, and the confidence and willingness of clinicians to work with young stroke patients. Other characteristics included any limitations on when patients could attend the service poststroke, the modes of service delivery available (e.g., in clinic, telehealth, at home or in the community), and training preferences to increase knowledge and skills in working with young adults poststroke. Finally, communication

accessibility was assessed given up to a third of people poststroke have aphasia (a disorder affecting the expression and/or comprehension of language) [22, 40], and other communication impairments, such as dysarthria (i.e., difficulty producing speech due to weakness or difficulty controlling the muscles used for speech). People with communication impairment after stroke often have poorer outcomes than those without communication impairments [41, 42], and their communication impairments pose a barrier to accessing services [43]. Therefore, we identified whether written information (e.g., on websites, signs, forms, and materials provided to service users) was available in communicatively accessible formats (e.g., simplified language, pictures, key words); and whether staff had received training (e.g., from a speech pathologist) in communicating with people with moderate to severe difficulties understanding, reading, and/or expressing themselves. As challenges with communication may also occur for patients who speak other languages, we also asked whether interpreters were available for people from culturally and linguistically diverse backgrounds. These key criteria were selected as very brief indicators of communication accessibility [44].

2.5. Step 5: Data Analysis and Synthesis. The data were stored in a REDCap database and analysed in Stata (Version 15, Texas, StataCorp, 2017). Descriptive characteristics were summarised by higher level geographic (i.e., state and remoteness area) and/or service features (e.g., clinical discipline, service setting) to identify areas of excellence and gaps in service availability or accessibility. Free-text fields from key informant survey responses and interviewer notes were examined to identify additional insights into service delivery and training preferences.

Spatial maps depicting point locations of services were created in QGIS [version 3.30.1-s-Hertogenbosch] [45], using the Natural Earth vector package. Australian Bureau of Statistics shapefiles were used to define state borders, Urban Centre and Locality names for metropolitan local government areas, and Statistical Area 3 locality names for regional areas.

2.6. Step 6: Communication of Findings. The findings were shared with the services that participated, the Australian Stroke Foundation, the Young Stroke Service project investigator team, and the broader clinical and academic community (e.g., through conference presentations).

3. Results

A total of 2,134 services were identified, of which data were collected on 465 services within 244 organisations (136 organisations in Victoria, 108 organisations in South Australia) through desktop review (Figure 1). The characteristics of all included services are summarised in Table 1, and the young stroke-specific characteristics of services that participated in key informant interviews ($n = 322$ services) are summarised in Table 2.

Most services were located in major cities ($n = 279$, 60.0%) and inner regional areas ($n = 125$, 26.9%) (Figures 2 and 3). Two hundred and seventy-seven services (59.6%) were community health or multidisciplinary services, followed by physiotherapy ($n = 115$ services), psychology ($n = 45$ services), and other allied health services ($n = 28$ services). Across all services ($n = 465$), the most prevalent disciplines were physiotherapy ($n = 372$, 80.0%), psychology (including neuropsychology; $n = 224$, 48.2%), occupational therapy ($n = 231$, 49.7%), and speech pathology ($n = 203$, 43.7%). Geospatial maps are provided in Supplementary Figures 1–10. While eight community health or multidisciplinary services had no allied health clinicians embedded in the team, they indicated that they could typically organise these therapies from other services if needed. Amongst the remaining community health or multidisciplinary services, the majority had three or more disciplines ($n = 217$, 78.3%) with physiotherapy ($n = 259$, 93.5%), occupational therapy ($n = 223$, 80.5%), and speech pathology ($n = 180$, 65.0%) being the most common disciplines. Few multidisciplinary services included neuropsychology ($n = 56$, 20.2%). Overall, 248 services (53.3%) were private for-profit businesses, 167 (35.9%) were government-funded, and 50 (10.8%) were private not-for-profit services. In Victoria, 52.2% of services were government or public health services, whereas in South Australia, 71.4% of included services were in the private for-profit sector. It should be noted that this does not reflect the availability of public versus private services in each state, but the timeframe during which the research team accessed lists of Victorian private service providers, limiting the audits and interviews undertaken for Victorian relative to South Australian services.

Patients could use NDIS funding at 274 (58.9%) services; however, only 203 (74.1%) of those services were registered with the NDIS. NDIS registered services included 124 (74.3%) of the government-funded services, 117 (47.2%) of the private for-profit services, and 31 (62.0%) of the private not-for-profit services. People were expected to pay a gap in the fee at just over half of all services ($n = 266$, 57.2%; unknown for $n = 128$), unless they were paying with their NDIS funding where the full fee was usually covered. Only 326 services provided their typical waiting time to access their service. Those services reported that patients typically wait 1–4 weeks or longer to access the service ($n = 272$ services, 68.6%); however, 108 (31.4%) services reported varied waiting times (e.g., different wait times for different clinical specialities). The larger proportion of South Australian services with a shorter wait time is likely due to a higher proportion of private for-profit services included from that state.

Three hundred and ninety-eight services provided information about the location for clinical encounters. The majority of those services worked from a clinical space ($n = 355$, 89.2%). Telehealth was offered by 64.6 percent of services ($n = 257$), with the majority of those services being based in major cities ($n = 137$, 53.3%) or inner regional areas ($n = 80$, 31.1%). Just under two thirds of services ($n = 242$, 60.8%) offered home visits, and 137 services (34.4%) offered support in community settings.
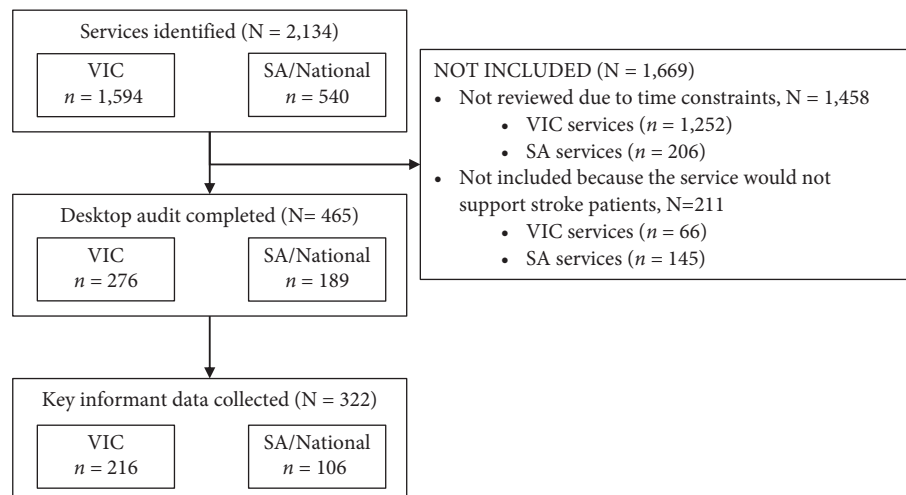
Figure 1: Service inclusion flowchart.

3.1. Stroke-Specific Service Characteristics.

Detailed information was collected for 322 services in 143 organisations (89 organisations in Victoria, 54 in South Australia) through key informants, including 169 (52.8%) services based in major cities and 105 (32.6%) in inner regional areas (Table 2). While most services reported being "very willing" to work with people with stroke aged 18–44 years ($n = 233$, 90.7%, not known for $n = 65$) or 45–64 years ($n = 233$, 91.0%), fewer reported that their clinicians were "very confident" to work with young adults with stroke aged 18–45 years ($n = 138$, 56.8%) and 45–64 years ($n = 161$, 66.5%).

3.1.1. Services with Expertise or Programmes Focused on Neurological Rehabilitation.

Only 23 services that participated via a key informant specifically worked with adults with stroke, although they did not necessarily work only with young adults. One hundred and fifty four services (47.8%, not known for $n = 107$) had neurological rehabilitation programmes or staff with training in neurological rehabilitation, most of which reported being very ($n = 95$, 61.7%) or moderately confident ($n = 48$, 31.27%) to work with young adults with stroke aged 18–44 years. A small number of services with expertise in neurological rehabilitation reported seeing no young adults (18–44 years) with stroke in a typical year ($n = 19$ services, 12.3%), and the remaining services saw one to five patients ($n = 42$, 27.3%), five to nine patients ($n = 27$, 17.5%), 10 to 19 patients ($n = 35$, 22.7%), or more than 20 patients ($n = 21$, 13.6%), not known for 10 services. Thirty-six services (23.4%) with neurological programmes or expertise reported that no staff had training in accessible communication (not known for seven services), and patients had to wait less than one week ($n = 26$, 16.9%), 1–4 weeks ($n = 55$, 35.7%), 1–2 months ($n = 15$, 9.7%), more than 3 months ($n = 13$, 8.4%), or varied waiting periods (e.g., for different disciplines; $n = 42$, 27.3%) to access a service with neurological programmes or expert clinicians.

The needs that expert services reported that they could meet are summarised in Table 3. In brief, nearly all services were recorded as being able to meet young adult rehabilitation needs related to emotions and self-concept and social functioning, and the majority would meet needs related to functional recovery, pain management, cognitive functioning, and work or study poststroke. Few of the "expert" services reported that they would meet young adult needs related to transport or driving, bladder and bowel functioning, or access to peer support.

3.1.2. Rehabilitation Needs.

The needs that services reported they could meet are summarised in Table 2. Three quarters of services reported that they could support exercise and physical activity rehabilitation needs, and the majority reported that they could meet social support, emotional and self-concept, and relationship-related needs. Several key informants indicated in free-text notes that these psychosocial needs were typically met through a social worker rather than a psychologist or counsellor. More than half of the services reported that they supported pain-related needs, daily living needs related to "looking after one's household," work or study, general health and diet, accessing entitlements, and managing finances. Half of the services stated that they could support swallowing, speech, or communication-related needs. Key informants at several services reported that in addition to the functional and daily living rehabilitation support needs listed in the survey they also provided equipment or wheelchair prescription, and supported assessment and rehabilitation of spasticity, dizziness, and balance for people who have had a stroke. Some metropolitan and regional community health services reported that they offered a healthy lifestyle programme (e.g., the Life! Program developed by Diabetes Victoria) for adults who are at risk of recurrent stroke or developing type two diabetes or cardiovascular diseases by enhancing physical activity and managing psychosocial wellbeing.

Overall, rehabilitation needs were not consistently met across services, and few services addressed impairments related to vision, hearing, and sensory hypersensitivity. Moreover, there were gaps in addressing peer support needs and community access (i.e., transport use and driving rehabilitation).

TABLE 1: Characteristics of included services that do or could work with young adults poststroke, n (%).

	Victoria $n = 276$	South Australia/national $n = 188$
Service type		
Multidisciplinary/community health	208 (75.4)	69 (36.7)
Physiotherapy service	39 (14.1)	76 (40.2)
Psychology/neuropsychology service	26 (9.4)	19 (10.1)
Other allied health service[a]	3 (1.1)	25 (13.3)
Clinical disciplines		
Physiotherapy	233 (84.4)	139 (73.5)
Occupational therapy	168 (60.9)	63 (33.3)
Psychology	134 (48.6)	52 (27.5)
Neuropsychology	65 (23.6)	23 (12.2)
Speech pathology	137 (49.6)	66 (34.9)
Social work	125 (45.3)	18 (9.5)
Geographic location of services		
Major cities	131 (47.5)	148 (78.3)
Inner regional areas	108 (39.1)	17 (9.0)
Outer regional areas	37 (13.4)	19 (10.1)
Remote/very remote areas	0 (0.0)	5 (2.7)
Sector		
Government/public health organisations	144 (52.2)	23 (12.2)
Private for-profit organisation	113 (40.9)	135 (71.4)
Private not-for-profit or charitable organisation	19 (6.9)	31 (16.4)
Years providing service to young adults poststroke		
Less than 1 year[b]	5 (1.8)	7 (3.7)
Less than 5 years	7 (2.5)	13 (6.9)
5 to 10 years	16 (5.8)	14 (7.4)
11 to 20 years	176 (63.8)	78 (41.5)
Not known	72 (26.1)	74 (39.2)
Payment options		
NDIS budgets	168 (60.9)	106 (56.1)
Government funding (state or commonwealth)	149 (54.0)	25 (13.3)
Government funding (Medicare)	118 (42.8)	99 (52.4)
Private health insurance	113 (40.9)	107 (56.6)
Personal funds	104 (37.7)	120 (63.5)
There are gap fees to be paid by the patient	176 (63.8)	89 (47.3)
Typical waiting time[c]		
<1 week	16 (7.8)	38 (31.4)
1 to 4 weeks	70 (34.1)	32 (26.4)
1 to 2 months	33 (16.1)	8 (6.6)
3 to 6 months	16 (7.8)	5 (4.1)
>6 months, or varied	70 (34.1)	38 (31.4)
Location for clinical encounters[d]		
In clinic	217 (78.6)	138 (73.0)
Via telehealth	181 (65.6)	76 (40.2)
In the patient's home	175 (63.4)	67 (35.4)
In the community	68 (24.6)	69 (36.5)

[a]"Other allied health" services were all speech pathology services, except for five OT-specific service providers in South Australia. [b]Six services had not yet worked with young adults poststroke (two in Victoria and four in SA) but indicated that they could work with that patient group. [c]Waiting time was not known or reported for 71 Victorian and 68 South Australian services, which were not included when calculating the percentage of services with different waiting times. [d]Clinical encounter location was not known for 81 (in clinic), 123 (telehealth), 117 (in the home), and 124 (in the community) services.

However, some services that were not able to provide driving assessments were still able to provide rehabilitation towards supporting a driving goal, and thus, there is potential for fragmented service for the young adults with stroke.

3.1.3. Communication Accessibility and Training. Just over one third of services ($n = 124$, 38.5%) reported that their resources were provided in communicatively accessible formats, and one third reported that they did not provide accessible documents ($n = 103$, 32.0%). The remainder ($n = 23$, 7.1%) neither agreed nor disagreed about whether they provided accessible documents or ($n = 72$, 22.4%) did not know if their information was communicatively accessible. One third of all services ($n = 107$, 33.2%) reported most or all staff had training in accessible communication, 87 said that some staff had training (27.0%), 54 (16.8%) reported that no staff had training, and 74 (23.0%) services

TABLE 2: Stroke-related characteristics of services that completed key informant interviews, n (%).

	Victoria $n = 216$	South Australia/national $n = 105$
Geographic location of services		
Major cities	89 (41.2)	80 (75.5)
Inner regional areas	92 (42.6)	13 (12.3)
Outer regional areas	35 (16.2)	12 (11.3)
Remote areas	0 (0.0)	1 (0.9)
The service works primarily with:		
Adults who have had a stroke	18 (8.3)	5 (4.7)
People with a range of conditions	187 (86.6)	98 (92.4)
Not reported	11 (5.1)	3 (2.8)
There are clinicians or programmes focused on stroke or neurological rehabilitation	81 (37.5)	73 (68.9)
Young stroke patients aged 18–44 years p/a		
None	25 (11.6)	25 (23.6)
<5	88 (40.7)	28 (26.4)
5 to 9	15 (6.9)	24 (22.6)
10 to 20	30 (13.9)	8 (7.5)
>20	14 (6.5)	14 (13.2)
Not known	44 (20.4)	7 (6.6)
Young stroke patients aged 45–64 years p/a		
None	6 (2.8)	11 (10.4)
<5	61 (28.2)	30 (28.3)
5 to 9	31 (14.4)	11 (10.4)
10 to 20	25 (11.6)	14 (13.2)
>20	44 (20.4)	32 (30.2)
Not known	49 (22.7)	8 (7.5)
Willingness to work with people poststroke aged 18–44 years		
A little willing	2 (0.9)	3 (2.8)
Moderately willing	7 (3.2)	12 (11.3)
Very willing	152 (70.4)	81 (76.4)
Not known	55 (25.5)	10 (9.4)
Willingness to work with people poststroke aged 45–64 years		
A little willing	1 (0.5)	4 (3.7)
Moderately willing	7 (3.2)	11 (10.4)
Very willing	152 (70.4)	81 (76.4)
Not known	56 (25.9)	10 (9.4)
Confidence to work with people poststroke aged 18–44 years		
A little confident or not at all confident	6 (2.8)	2 (1.9)
Moderately confident	53 (24.5)	44 (41.5)
Very confident	89 (41.2)	49 (46.2)
Not known	68 (31.5)	11 (10.4)
Confidence to work with people poststroke aged 45–64 years		
A little confident	1 (0.5)	3 (2.8)
Moderately confident	32 (14.8)	45 (42.5)
Very confident	114 (52.8)	47 (44.3)
Not known	69 (31.9)	11 (10.4)
Information is available in communicatively accessible formats		
Agree	78 (36.1)	46 (43.4)
Neither agree nor disagree	21 (9.7)	2 (1.9)
Disagree	57 (26.4)	46 (43.4)
I am not sure	60 (27.8)	12 (11.3)
Are staff trained in accessible communication		
No staff have received training	27 (12.5)	27 (25.5)
Some staff have received training	60 (27.8)	26 (24.5)
Most staff have received training	46 (21.3)	21 (19.8)
All staff have received training	19 (8.8)	21 (19.8)
Support is available to staff as needed	0 (0.0)	1 (0.9)
Not known	64 (29.6)	10 (9.4)

TABLE 2: Continued.

	Victoria $n = 216$	South Australia/national $n = 105$
Are interpreters used		
No	10 (4.6)	24 (22.6)
Yes	167 (77.3)	72 (67.9)
Not known	39 (18.1)	10 (9.4)
Do staff want training in stroke rehabilitation for young adults		
Yes	156 (56.5)	83 (43.9)
No	3 (1.1)	1 (0.5)
Not known	117 (42.4)	105 (55.6)
Training preferences[a]		
Online resources, websites, or webinars	128 (82.1)	70 (84.3)
Through a community of practice or mentorship	81 (51.9)	16 (19.3)
Group training in person	65 (41.7)	42 (50.6)
Reading a book or manual	47 (30.1)	43 (51.8)
Stroke-related needs that are met by the service		
Physical functioning	168 (77.8)	75 (70.8)
Health, wellbeing, nutrition, and diet	157 (72.7)	29 (27.4)
Social support needs	157 (72.7)	48 (96.0)
Relationship support needs	153 (70.8)	43 (89.6)
Emotions and self-concept support needs	151 (69.9)	55 (96.5)
Looking after the household or self-care	134 (62.0)	63 (59.4)
Pain or altered sensation and feeling	132 (61.1)	67 (63.2)
Accessing entitlements	124 (57.4)	45 (42.5)
Swallowing, speech, or communication	109 (50.5)	54 (50.9)
Work or study	123 (56.9)	67 (63.2)
Managing finances	121 (56.0)	46 (43.4)
Cognitive functioning, fatigue, and sleep	83 (38.4)	59 (55.7)
Bladder or bowel functioning	83 (38.4)	20 (18.9)
Transport and driving	39 (18.1)	23 (21.7)
Information about peer support	20 (9.3)	23 (21.7)
Vision, hearing, or hypersensitivity to sound/light	12 (5.6)	19 (17.9)

[a]The proportion of people with each training format preference is reported only for services where the key informant indicated that staff would want or need further training.
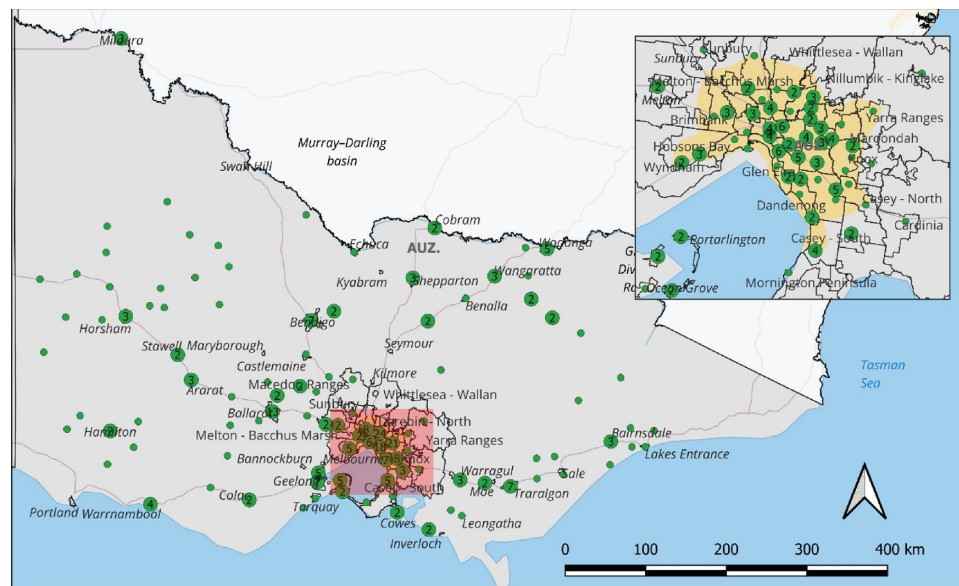

FIGURE 2: Distribution of all included health services in Victoria. The pink shaded region indicates the area depicted for the snapshot of services in the metropolitan Melbourne region. Town names are only shown for regions with ≥5000 residents.

did not know if staff had received training in accessible communication. Among services that reported that they could meet the needs of young adults between 76.9% and

93.0% of services reported that some, most, or all staff in those services had training in accessible communication (Table 4).
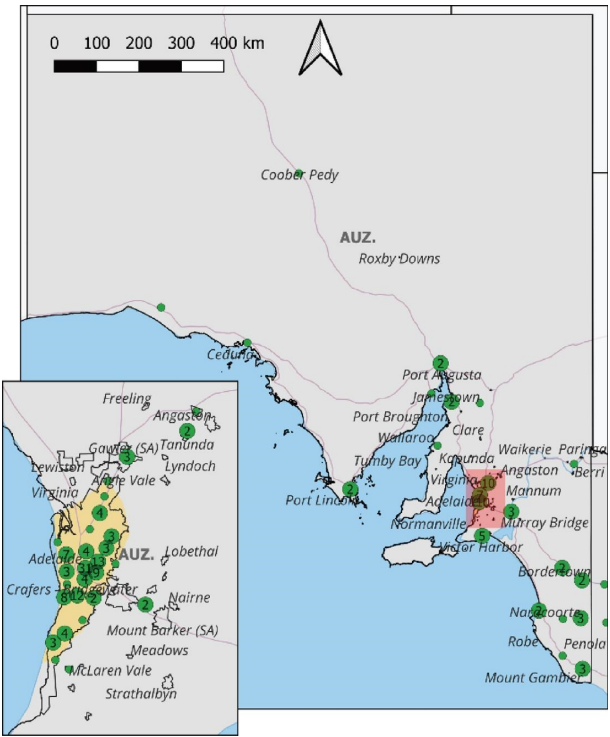
Figure 3: Distribution of all included health services in South Australia. The pink shaded region indicates the area depicted for the snapshot of services in the metropolitan Adelaide region. Town names are only shown for regions with ≥500 residents.

Table 3: Number (percent) of the services reporting they have expertise, training, or programmes in neurological rehabilitation that could meet different needs of young adults, n (%).

	Number (%) of expert services that reported that they could meet the respective needs of young adults
Physical functioning	108 (70.1)
Health, wellbeing, nutrition, and diet	76 (49.4)
Social support needs	92 (99.0)
Relationship support needs	87 (97.0)
Emotions and self-concept support needs	97 (100.0)
Looking after the household or self-care	92 (59.7)
Pain or altered sensation and feeling	103 (66.9)
Accessing entitlements	72 (46.8)
Swallowing, speech, or communication	84 (54.5)
Work or study	103 (66.9)
Managing finances	85 (55.2)
Cognitive functioning, fatigue, and sleep	103 (66.9)
Bladder or bowel functioning	47 (30.5)
Transport and driving	43 (27.9)
Information about peer support	28 (18.2)
Vision, hearing, or hypersensitivity to sound/light	21 (13.6)

Note. The percent of services that reported some, most, or all staff had training in accessible communication does not include the services for which these data were not known by the key informant.

In the open-text response fields, some services indicated that for many clinicians supported communication training was received "on the job" (not-for-profit allied health and rehabilitation service). Services with speech pathologists, neurophysiotherapists, or neuropsychologists often stated that they developed communication skills through their formal training, or in roles within neurological rehabilitation services; however, some of those specialised clinicians reported that they did not have formal communication accessibility training. For services where not all staff had received training, several key informants noted that staff would be able to access training or support through a speech pathologist in the team as needed (e.g., through case conferencing). Others stated that they would do interdisciplinary assessments if communication difficulties were noted (metropolitan stroke rehabilitation service). However, an informant at one regional community rehabilitation servicereported that speech pathologist availability outside their own clinical workload limited the support that speech pathologists could give to other clinicians. One key informant at a metropolitan community rehabilitation service reported that their service had "individual handouts that are aphasia friendly". At one service, the informant stated that they usually used the Stroke Foundation handouts, but felt that those were "pretty complicated for someone with communication difficulties," and their speech pathologists would usually need to adapt materials further and an informant at a regional community health service reported that they did not have "standard" accessible documents. Several informants at regional community rehabilitation services commented that access to communication aids was limited and another private physiotherapist in a metropolitan service reported that they would "love to have training or advice regarding making our material more accessible, for both admin staff and allied health clinicians". A clinician at a metropolitan community rehabilitation service reported that they wanted to improve their accessibility processes.

3.1.4. Service Geographic Location. More services in major cities reported having expertise in neurological rehabilitation, experience working with young adults with stroke, and being very willing or very confident to work with this group compared withservices based in rural or regional areas. That is, a larger proportion of services with expertise in neurological rehabilitation ($n = 127$, 82.5%) that saw more than five young adults aged 18 to 45 years with stroke per year ($n = 88$, 83.8%) or that were very willing ($n = 138$, 59.2%) or very confident ($n = 101$, 73.2%) to work with young adults with stroke were in major cities. Moreover, a larger proportion of services that reported higher communication accessibility accommodations were in major cities; that is, 64.5% of services that provided written materials in communicatively accessible formats and 73.8% of services where most or all staff had accessible communication training were in major cities.

3.1.5. Training. Only four service providers reported that they did not want or need further training in young stroke, all of which reported that they were already very confident to

TABLE 4: Number (percent) of services reporting they could meet young adult rehabilitation needs and whether some, most, or all staff had communication training, N (%).

	Total number of included services that could meet the respective need	Number (%) of services that could meet the respective need where some, most, or all staff had training in accessible communication	
	N	Yes* N (%)	Not known N
Physical functioning	188	156 (83.0)	55
Health, wellbeing, nutrition, and diet	141	119 (84.4)	45
Social support needs	158	135 (85.4)	47
Relationship support needs	145	119 (82.1)	51
Emotions and self-concept support needs	157	135 (86.0)	49
Looking after the household or self-care	153	136 (88.9)	44
Pain or altered sensation and feeling	169	143 (84.6)	30
Accessing entitlements	135	116 (85.9)	34
Swallowing, speech, or communication	143	133 (93.0)	20
Work or study	157	136 (86.6)	33
Managing finances	139	120 (86.3)	28
Cognitive functioning, fatigue, and sleep	139	113 (81.3)	3
Bladder or bowel functioning	88	79 (89.8)	15
Transport and driving	61	52 (85.2)	1
Information about peer support	39	30 (76.9)	4
Vision, hearing, or hypersensitivity to sound/light	28	25 (89.3)	3

*The percent of services that reported some, most, or all staff had training in accessible communication does not include the services for which the key informant did not know if staff had received training.

meet the needs of young adults with stroke. Of the 219 services that reported wanting training and that selected a training preference, 178 (81.3%) selected two or more preferred training formats. The most popular training format was through online resources, websites, or webinars ($n = 198$, 82.8%) followed by group training ($n = 107$, 44.8%), or through engaging with a community of practice or mentors ($n = 97$, 40.6%). The least popular format was passive learning through written materials ($n = 90$, 37.7%). The training preferences across remoteness areas are shown in Figure 4, which shows that while online resources and webinars are popular across all geographic areas, there is increasing preference for receiving support from a community of practice across increasing levels of remoteness.

In the open-text response fields, some key informants indicated that webinars and online training options were easier for staff to attend during the workday, especially for services in regional areas; however, the value of in-person training was recognised as giving better opportunities "to link in with other therapists who share clinical interests" and to get more "practical" experience. Moreover, it was noted that clinicians in regional areas often "like to travel to training opportunities as it's a good opportunity to network." Several key informants emphasised that their service has regular "in-service" training and that they often look for external presenters to share knowledge on specific rehabilitation topics. Some private practitioners noted that it was difficult to justify travelling for training if they would "lose a day of work." Similarly, some services that did not see a lot of young adults with stroke indicated that it is difficult to justify sending staff to training opportunities specifically for that patient cohort, and that being able to access "the

mentor and community of practice option would be most appropriate so that they can access expertise when it is needed."

4. Discussion

The present study found that while no service providers in Victoria and South Australia work exclusively with young adults with stroke, there are several services that do have relevant expertise, training, experience, and programmes to meet the needs of young adults with stroke. However, the availability, accessibility, and capacity of these services to accommodate the needs and preferences of young adults poststroke does not appear to be sufficient to ensure that all young adults are supported after a stroke. We now discuss the implications of the present findings for young adults with stroke in the current sector in relation to the five As of service use (i.e., availability, accessibility, affordability, acceptability, and accommodation) [32], as well as the implications for improving service delivery alongside the existing expert services identified.

The availability of services is considered in relation to the presence of services that have expertise, experience, confidence, and short enough waiting times for young adults with stroke. Overall, just over half of all services that participated in key informant interviews reported that their clinicians were very confident to work with young adults with stroke aged 18 to 44 years old, and 91% were very willing to work with them. Nearly half of the services had relevant neurological rehabilitation expertise, training, or programmes for people with neurological conditions. The majority of the expert services were located in major cities, were typically
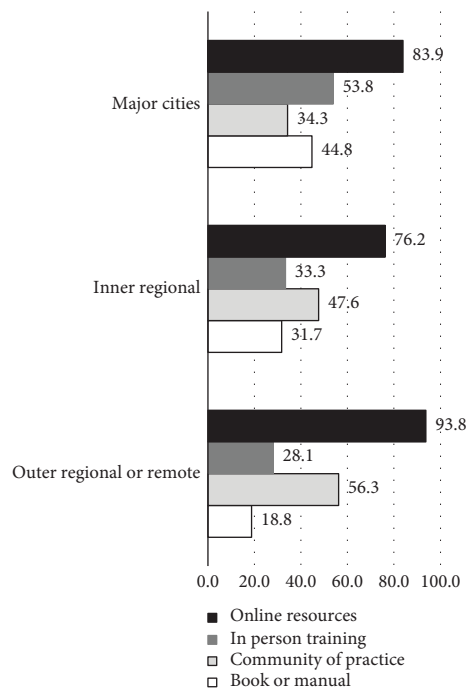
FIGURE 4: Training preferences across remoteness areas.

available within four weeks of referral, and had clinicians who were reported to be moderately or very confident to meet the needs of young adults with stroke. In particular, nearly all of the expert services reported that they could meet the psychosocial support needs of young adults (e.g., emotional functioning, social participation or belonging, and relationships), and most reported that they would meet functional recovery needs, cognitive functioning, and work-related goals of young adults with stroke. These are frequently reported as important unmet needs of young adults with stroke [12, 23, 27], particularly the need to address psychosocial functioning alongside physical functioning. However, some caution must be exercised about assuming that these services are suitable for a young adult stroke patient population given that few services reported that they would meet other important needs (including driving rehabilitation, bladder and bowel rehabilitation, and linkage with peers who have had a stroke), and staff in many services lacked training in accessible communication. Therefore, many of these services may not ultimately be ideal for the clinical population, particularly the one in five young adult patients who have a speech or language impairment poststroke [22]. Altogether, when considering most services with availability, experience, and expertise in neurological rehabilitation expertise are located in major cities, the sector remains unlikely to reliably meet the needs of young adults with stroke in the community, particularly young adults living in regional areas. Furthermore, training or mentoring to enable existing services to meet the needs of young adults with stroke is clearly warranted, even for expert services.

The affordability of services can be a vital factor in whether young adults will receive sufficient support. This is particularly important given that young adults experience

significant loss of income and financial insecurity poststroke [11, 16, 23, 46], which is known to lead to lower health service use often due to difficulty paying for treatment [46]. For services included in the present study, patients were expected to pay a fee at just over half of the included services, including gap fees for outpatient allied health or community rehabilitation services at many government rehabilitation services. While gap fees at government-funded services are typically stratified by patient income level and can be waived for people facing financial hardship, it is important that the financial barriers to accessing services are not underestimated in both the private and public sectors for this young population. In Australia, people with a significant and permanent disability can become participants of the NDIS, which provides individualised funding to support core needs (e.g., daily living, or social and community participation), capacity building (e.g., therapies to improve functioning, employment, or independent living), and capital support (e.g., to buy assistive technology) [47]. However, young adults with stroke are not always eligible for NDIS funding, despite having ongoing support needs.

The accessibility of services is typically considered in terms of their geographic location and the distance required to the service. In this study, most services were based in major cities where the majority of the population lives; however, given the increased incidence of stroke in more remote geographic areas in both Victoria and South Australia [2], it appears that many young adults with stroke will not have equitable access to services. That said, three quarters of the services that participated in key informant interviews reported that they offered services via telehealth (usually in addition to at least some assessments or therapy in the clinic), which may partially overcome the tyranny of

distance for people living in regional areas. The relatively widespread use of telehealth amongst rehabilitation and allied health services is probably partly due to the increased accessibility and availability of telehealth throughout the height of the COVID-19 pandemic in 2020–2023, particularly in Victoria which faced the most extensive lockdowns in Australia [48, 49]. Prior to the pandemic, we have previously found that there was generally low desire for both healthcare providers and patients to use telehealth for rehabilitation in regional and remote areas in Victoria [50, 51]. Anecdotally, many key informants commented that most people now prefer to come into services in person if they can; however, continued provision of telehealth does enable people to continue to access support if they live far from metropolitan areas or regional towns.

Finally, the accommodation of patient needs and preferences and the likely acceptability of services to patients are critical factors that impact on whether services are suitable for this young adult patient population. In particular, given that at least one in five young adults with stroke will have a speech and language impairment like aphasia [12], it is important that staff have the required skills or support to use supported and accessible communication strategies. Aligned with the present findings, previous research has indicated that provision of supported communication training to unfamiliar communication partners (such as staff) [52] and communicatively accessible written materials varies widely and is often absent [53]. Some barriers to using supported and accessible communication strategies include a lack of access to or interest in improving communication accessibility with some unfamiliar communication partners; however, as found in the present study, some providers do want to access training to improve their communication interactions with people with aphasia [54]. Barriers to providing communicatively accessible written materials, especially beyond speech pathology-specific resources can include the time and skill it takes to create accessible resources, awareness by staff of the need to provide resources in accessible formats, and the availability of accessible resources or organisational policies on communication accessibility [53]. These factors therefore need to be accounted for when improving service accessibility and staff competency to work with young adults with communication impairments after stroke.

Overall, the majority of services indicated that they could meet the most common unmet needs currently reported by young adults with stroke [11, 12, 16, 23, 27], including assistance to improve physical and emotional functioning, to maintain or build social support and relationships, as well as to return to work, manage pain, complete daily activities, access entitlements, and manage finances. However, there were relatively few services that reported that they would address disruptions to sensory processing or sensitivity, which is reported to be an unmet need for just over a quarter of young adults poststroke [12]. Moreover, few services could link people with other young adults who have had a stroke through peer support networks. Peer support is particularly lacking for people attending routine rehabilitation services where the majority

of patients are older. The opportunity for young adults with stroke to meet with other young adults helps people to share the "enormity and significance" of the challenges that they experience with others who understand what it is like for them (p. 210) [11]. Moreover, peer connections with other young adults with stroke have been reported to play an important role in learning how others cope with the difficulties that they face due to their stroke [55]. Finally, only a third of services could provide support to help people to return-to-driving. This is understandable given the additional training and time required for an occupational therapist to complete driving competency assessments. However, the limited number of services that support return-to-driving highlights that this remains a persistent unmet need and that young adults probably face fragmentation in access to both assessment and therapy to return to driving at existing services. This fragmentation in care poses a significant barrier to resuming significant life roles (e.g., taking children to school or returning to work) [12].

4.1. Implications.
While services with expertise in supporting young adults in the community exist, the present study shows that there is significant need to build capacity across the sector to provide more systematic and timely access to evidence-based supports that will meet the needs of young adults with stroke. This could partly be addressed through the delivery of further training and mentorship to existing services, particularly in accessible communication and provision of communicatively accessible resources so that service providers will be able to work well with all people with stroke, including people with aphasia or other speech or communication impairments. Online free or low cost communication partner training for aphasia is available (e.g., The Aphasia Institute Supported Conversation for Adults with Aphasia (SCA™)) [56] and other agencies offer resources for the development of communicatively accessible materials (e.g., SCOPE, Australia [57], or the UK Stroke Association [58]). Further training in supported communication strategies is particularly important given that people with aphasia face significantly greater challenges in maintaining relationships and returning to work [12, 13, 20]. Nearly all services reported that they would want further training in supporting young adults with stroke, including most "expert" services, with a clear preference for both online webinar-based training as well as in-person opportunities and engagement with a community of practice or mentors for services that see very few young stroke patients. Given that significant unmet needs have consistently been reported by young adults attending existing services, however, the present findings highlight the need for and centralised and coordinated services to help young adults to access suitable rehabilitation and support poststroke in a timely way.

4.2. Study Strengths and Limitations.
A key strength of the present study was the systematic approach taken to identify and characterise existing services, and to identify their

suitability for young adults with stroke. Despite the rigorous approach taken to generate this service map, it should be noted that the study had several limitations that impact the depth and generalisability of the findings. First, there are inevitable gaps in the data collected due to the short timeframe for the study, and the need to design the shortest survey possible to maximise participation and reduce the responder burden [28]. Even with this short survey, many informants were not able to answer key questions about the experience of clinicians working with young adults with stroke, particularly the number of patients seen each year and the willingness or confidence of clinicians to work with young adults with stroke. Moreover, the service map does not include sufficient information on all relevant services given that many services identified in the desktop audit did not respond to requests for key informant interviews. Furthermore, the types of services included from each state varied with a larger proportion of public services in Victoria and fewer community and outpatient rehabilitation services in South Australia. This may reflect the lower proportion of public services in South Australia, which has a much smaller population than Victoria (1.7 million vs 6.7 million). While most services reported they could meet several needs, this does not necessarily mean that they are effectively meeting those needs. Further research is required to compare the experiences of patients with those of service providers. Finally, it is widely recognised that any service map or directory is only accurate at the time when the data are collected [28, 59]. Indeed, key informant interviews highlighted that several websites provided inaccurate information about the service; therefore, while the key findings from this study have been shared with the included services and relevant stakeholders, the information contained in the service map should ideally be kept up-to-date and made accessible to both patients and providers in the community.

5. Conclusion

In conclusion, the present study found that although services with expertise, experience, willingness, and confidence to work with young adults poststroke are available, they may not be sufficiently accessible or able to accommodate the unique needs of all young adults with stroke. Nearly all services reported a very strong willingness to access further training or mentorship in providing services to this clinical group highlighting an important opportunity to build capacity in the sector. However, as the majority of young adults report one or more unmet needs from existing services [26], there is clearly a strong need to further improve access to expert services.

Data Availability

The source data are included in Supplementary File 2. Some variables that contain more sensitive information about the services (e.g., the willingness or confidence of clinicians to work with young adults with stroke at individual services) have not been included, as per the study protocol approved by the institutional human research ethics committee.

Conflicts of Interest

The authors declare that there are no conflicts of interest.

Acknowledgments

Supplementary Materials

Supplementary File 1: key informant interview/survey template. Supplementary File 2: study dataset. Supplementary Figure 1: physiotherapy services in Victoria. Supplementary Figure 2: physiotherapy services in South Australia. Supplementary Figure 3: occupational therapy services in Victoria. Supplementary Figure 4: occupational therapy services in South Australia. Supplementary Figure 5: psychology (including neuropsychology) services in Victoria. Supplementary Figure 6: psychology (including neuropsychology) services in South Australia. Supplementary Figure 7: speech pathology services in Victoria. Supplementary Figure 8: speech pathology services in South Australia. Supplementary Figure 9: social work services in Victoria. Supplementary Figure 10: social work services in South Australia. (*Supplementary Materials*)

References

[1] D. Smajlović, "Strokes in young adults: epidemiology and prevention," *Vascular Health and Risk Management*, vol. 11, pp. 157–164, 2015.

[2] Deloitte Access Economics, *No Postcode Untouched, Stroke in Australia 2020*, Deloitte Access Economics for the Stroke Foundation, Melbourne, Australia, 2020.

[3] D. Griffiths and J. Sturm, "Epidemiology and etiology of young stroke," *Stroke Research and Treatment*, vol. 2011, Article ID 209370, 9 pages, 2011.

[4] N. A. Lannin, C. S. Anderson, J. Kim et al., "Treatment and outcomes of working aged adults with stroke: results from

a national prospective registry," *Neuroepidemiology*, vol. 49, no. 3-4, pp. 113–120, 2017.

[5] E. S. Donkor, "Stroke in the 21(st) century: a snapshot of the burden, epidemiology, and quality of life," *Stroke Research and Treatment*, vol. 2018, Article ID 3238165, 10 pages, 2018.

[6] A. K. Terent, B. Asplund, K. M. Farahmand et al., "Stroke unit care revisited: who benefits the most? A cohort study of 105 043 patients in riks-stroke, the Swedish stroke register," *Journal of Neurology Neurosurgery and Psychiatry*, vol. 80, no. 8, pp. 881–887, 2009.

[7] D. A. Cadilhac, M. F. Kilkenny, C. R. Levi et al., "Risk-adjusted hospital mortality rates for stroke: evidence from the Australian stroke clinical registry (auscr)," *Medical Journal of Australia*, vol. 206, no. 8, pp. 345–350, 2017.

[8] J. Shipley, J. Luker, T. Vincent, and J. Bernhardt, "The personal and social experiences of community-dwelling younger adults after stroke in Australia: a qualitative interview study," *BMJ Open*, vol. 8, no. 12, p. e023525, 2018.

[9] L. Tancredi, F. Martinelli Boneschi, M. Braga et al., "Stroke care in young patients," *Stroke Research and Treatment*, vol. 2013, Article ID 715380, 7 pages, 2013.

[10] A. Bhat, V. Mahajan, and N. Wolfe, "Implicit bias in stroke care: a recurring old problem in the rising incidence of young stroke," *Journal of Clinical Neuroscience*, vol. 85, pp. 27–35, 2021.

[11] B. Wolfenden and M. Grace, "Identity continuity in the face of biographical disruption: it's the same me," *Brain Impairment*, vol. 13, no. 2, pp. 203–211, 2012.

[12] J. Keating, K. Borschmann, H. Johns, L. Churilov, and J. Bernhardt, "Young stroke survivors' preferred methods of meeting their unique needs: shaping better care," *Neurology*, vol. 96, no. 13, pp. e1701–e1710, 2021.

[13] N. Kodumuri, A. Edmunds, A. Seidel et al., "Development and initial validation of a patient-centered stroke outcome measure in young stroke survivors," *European Journal of Neurology*, vol. 28, no. 12, pp. 4069–4077, 2021.

[14] P. C. Scales, P. L. Benson, S. Oesterle, K. G. Hill, J. D. Hawkins, and T. J. Pashak, "The dimensions of successful young adult development: a conceptual and measurement framework," *Applied Developmental Science*, vol. 20, no. 3, pp. 150–174, 2016.

[15] L. Buchinger, D. Richter, and J. Heckhausen, "The development of life goals across the adult life span," *The Journals of Gerontology: Serie Bibliographique*, vol. 77, no. 5, pp. 905–915, 2022.

[16] K. Daniel, D. A. Charles, M. A. Busch, and C. McKevitt, "What are the social consequences of stroke for working-aged adults?" *Stroke*, vol. 40, no. 6, pp. e431–e440, 2009.

[17] R. Morris, "The psychology of stroke in young adults: the roles of service provision and return to work," *Stroke Research and Treatment*, vol. 2011, Article ID 534812, 10 pages, 2011.

[18] H. T. Phan, S. L. Gall, C. L. Blizzard et al., "Sex differences in quality of life after stroke were explained by patient factors, not clinical care: evidence from the Australian stroke clinical registry," *European Journal of Neurology*, vol. 28, no. 2, pp. 469–478, 2021.

[19] E. Gurkova, L. Sturekova, P. Mandysova, and D. Sanak, "Factors affecting the quality of life after ischemic stroke in young adults: a scoping review," *Health and Quality of Life Outcomes*, vol. 21, no. 1, p. 4, 2023.

[20] J. S. Kim, S. Choi-Kwon, S. U. Kwon, H. J. Lee, K. A. Park, and Y. S. Seo, "Factors affecting the quality of life after ischemic stroke: young versus old patients," *Journal of Clinical Neurology*, vol. 1, no. 1, pp. 59–68, 2005.

[21] S. Schneider, N. Taba, M. Saapar, R. Vibo, and J. Korv, "Determinants of long-term health-related quality of life in young ischemic stroke patients," *Journal of Stroke and Cerebrovascular Diseases*, vol. 30, no. 2, 2021.

[22] R. P. C. Weterings, R. P. C. Kessels, F. E. de Leeuw, and V. Piai, "Cognitive impairment after a stroke in young adults: a systematic review and meta-analysis," *International Journal of Stroke*, vol. 18, no. 8, pp. 888–897, 2023.

[23] S. L. Crichton, C. D. Wolfe, A. G. Rudd, and C. McKevitt, "Comparison of provision of stroke care in younger and older patients: findings from the South London stroke register," *Stroke Research and Treatment*, vol. 2012, Article ID 319581, 9 pages, 2012.

[24] M. S. Ekker, M. A. Jacob, M. M. E. van Dongen et al., "Global outcome assessment life-long after stroke in young adults initiative—the goal initiative: study protocol and rationale of a multicentre retrospective individual patient data meta-analysis," *BMJ Open*, vol. 9, no. 11, p. e031144, 2019.

[25] D. A. Levine, C. I. Kiefe, T. K. Houston, J. J. Allison, E. P. McCarthy, and J. Z. Ayanian, "Younger stroke survivors have reduced access to physician care and medications-national health interview survey from years 1998 to 2002," *Archives of Neurology*, vol. 64, no. 1, pp. 37–42, 2007.

[26] Stroke Foundation, *Australian Stroke Survivor and Carer Needs Assessment Survey: Final Report*, Stroke Foundation, Melbourne, Australia, 2013.

[27] S. Fraser, L. Pabst, and F. Smith, "Stroke in the young," *Current Opinion in Neurology*, vol. 36, no. 2, pp. 131–139, 2023.

[28] A. Price, A. Janssens, S. Dunn-Morua et al., "Seven steps to mapping health service provision: lessons learned from mapping services for adults with attention-deficit/hyperactivity disorder (adhd) in the UK," *BMC Health Services Research*, vol. 19, no. 1, p. 468, 2019.

[29] L. J. Whop, G. Garvey, K. Lokuge, K. A. Mallitt, and P. C. Valery, "Cancer support services--are they appropriate and accessible for indigenous cancer patients in queensland, Australia?" *Rural and Remote Health*, vol. 12, p. 2018, 2012.

[30] J. Chapman and V. Sharp, *Development of a New Health Service Delivery Model for Major Trauma Clients Living in Rural and Remote Victoria: Part 1 Current State Analysis*, Turner Institute for Brain and Mental Health, Monash University, Melbourne, Australia, 2020.

[31] Brisbane South Primary Health Network, *Mental Health and Alcohol and Other Drugs Service Mapping Project*, Brisbane South Primary Health Network, Australia, 2016.

[32] C. G. McLaughlin and L. Wyszewianski, "Access to care: remembering old lessons," *Health Services Research*, vol. 37, no. 6, pp. 1441–1443, 2002.

[33] M. Sekhon, M. Cartwright, and J. J. Francis, "Acceptability of healthcare interventions: an overview of reviews and development of a theoretical framework," *BMC Health Services Research*, vol. 17, no. 1, p. 88, 2017.

[34] M. F. Guagliardo, "Spatial accessibility of primary care: concepts, methods and challenges," *International Journal of Health Geographics*, vol. 3, no. 1, p. 3, 2004.

[35] C. English, M. G. Ceravolo, S. Dorsch et al., "Telehealth for rehabilitation and recovery after stroke: state of the evidence and future directions," *International Journal of Stroke*, vol. 17, no. 5, pp. 487–493, 2022.

[36] K. Hilari, S. Northcott, P. Roy et al., "Psychological distress after stroke and aphasia: the first six months," *Clinical Rehabilitation*, vol. 24, no. 2, pp. 181–190, 2010.

[37] T. A. Rose, L. E. Worrall, L. M. Hickson, and T. C. Hoffmann, "Aphasia friendly written health information: content and design characteristics," *International Journal of Speech Language Pathology*, vol. 13, no. 4, pp. 335–347, 2011.

[38] P. A. Harris, R. Taylor, R. Thielke, J. Payne, N. Gonzalez, and J. G. Conde, "Research electronic data capture (Redcap)-- a metadata-driven methodology and workflow process for providing translational research informatics support," *Journal of Biomedical Informatics*, vol. 42, no. 2, pp. 377–381, 2009.

[39] P. A. Harris, R. Taylor, B. L. Minor et al., "The redcap consortium: building an international community of software platform partners," *Journal of Biomedical Informatics*, vol. 95, 2019.

[40] S. T. Engelter, M. Gostynski, S. Papa et al., "Epidemiology of aphasia attributable to first ischemic stroke: incidence, severity, fluency, etiology, and thrombolysis," *Stroke*, vol. 37, no. 6, pp. 1379–1384, 2006.

[41] K. Hilari, "The impact of stroke: are people with aphasia different to those without?" *Disability & Rehabilitation*, vol. 33, no. 3, pp. 211–218, 2011.

[42] R. Hewetson, P. Cornwell, and D. Shum, "Cognitive-communication disorder following right hemisphere stroke: exploring rehabilitation access and outcomes," *Topics in Stroke Rehabilitation*, vol. 24, no. 5, pp. 330–336, 2017.

[43] C. Shiggins, B. Ryan, R. O'Halloran et al., "Towards the consistent inclusion of people with aphasia in stroke research irrespective of discipline," *Archives of Physical Medicine and Rehabilitation*, vol. 103, no. 11, pp. 2256–2263, 2022.

[44] The Aphasia Institute, "Communicative access measures for stroke (cams)," 2022, https://www.aphasia.ca/wp-content/uploads/2017/03/Communicative_Access_Measures_for_Stroke_CAMS_Questions_only.pdf.

[45] Qgis Geographic Information System, "Open source geospatial foundation project," https://Qgis.Org/En/Site/.

[46] B. M. Essue, M. L. Hackett, Q. Li, N. Glozier, R. Lindley, and S. Jan, "How are household economic circumstances affected after a stroke? The psychosocial outcomes in stroke (poise) study," *Stroke*, vol. 43, no. 11, pp. 3110–3113, 2012.

[47] Ndis, "Plan budget and rules," 2023, https://www.ndis.gov.au/participants/creating-your-plan/plan-budget-and-rules#core-supports-budget.

[48] S. H. Dykgraaf, J. Desborough, L. de Toca et al., "A decade's worth of work in a matter of days: the journey to telehealth for the whole population in Australia," *International Journal of Medical Informatics*, vol. 151, 2021.

[49] L. Smyth, S. Roushdy, J. Jeyasingham et al., "Clinician perspectives on rapid transition to telehealth during COVID-19 in Australia – a qualitative study," *Australian Health Review*, vol. 47, no. 1, pp. 92–99, 2022.

[50] V. L. Sharp, J. E. Chapman, B. Gardner et al., "Perspectives of major traumatic injury survivors on accessibility and quality of rehabilitation services in rural Australia," *Disability & Rehabilitation*, vol. 45, no. 8, pp. 1379–1388, 2023.

[51] V. L. Sharp, B. Gardner, J. L. Ponsford et al., "Providing rehabilitation services to major traumatic injury survivors in rural Australia: perspectives of rehabilitation practitioners and compensation claims managers," *Disability & Rehabilitation*, vol. 46, no. 2, pp. 334–343, 2024.

[52] H. F. Chang, E. Power, R. O'Halloran, and A. Foster, "Stroke communication partner training: a national survey of 122 clinicians on current practice patterns and perceived implementation barriers and facilitators," *International Journal of Language & Communication Disorders*, vol. 53, no. 6, pp. 1094–1109, 2018.

[53] C. Briffa, R. Sullivan, J. Murray, and M. van den Berg, "Providing aphasia-friendly information in the healthcare setting: applying the theoretical domains framework to identify factors that influence speech pathologists' self-reported practice," *Aphasiology*, vol. 37, no. 9, pp. 1335–1362, 2023.

[54] M. Carragher, G. Steel, R. O'Halloran et al., "Aphasia disrupts usual care: the stroke team's perceptions of delivering healthcare to patients with aphasia," *Disability & Rehabilitation*, vol. 43, no. 21, pp. 3003–3014, 2021.

[55] J. Shipley, J. Luker, T. Vincent, and J. Bernhardt, "How can stroke care Be improved for younger service users? A qualitative study on the unmet needs of younger adults in inpatient and outpatient stroke care in Australia," *Disability & Rehabilitation*, vol. 42, no. 12, pp. 1697–1704, 2020.

[56] The Aphasia Institute, "Free: introduction to Sca™ elearning module," 2023, https://www.aphasia.ca/health-care-providers/education-training/online-options/.

[57] Scope Australia, "Communication access," 2023, https://www.scopeaust.org.au/business-solutions/communication-access.

[58] Stroke Association, *Accessible Information Guidelines: Making Information Accessible for People with Aphasia*, Stroke Association, London, UK, 2012.

[59] M. Ricky, A. M. R. Jessica, D. S. Natalie et al., "Improving primary care after stroke (ipcas) trial: protocol of a randomised controlled trial to evaluate a novel model of care for stroke survivors living in the community," *BMJ Open*, vol. 9, no. 8, p. e030285, 2019.