



Title: State of Stroke Rehabilitation in Australia: A WHO STARS Assessment to Identify Strengths and Gaps Across Policy, Practice and Funding

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Abstract

Purpose of Review Rehabilitation following stroke is a complex series of assistive and catalytic interventions enabling a survivor to recover and adapt to their stroke. To achieve adaptation, rehabilitation should supplement healthcare across the continuum, however comprehensive evidence on the provision of stroke rehabilitation in Australia is lacking. The aim of this paper was to describe stroke rehabilitation provision, collecting data using the World Health Organisation (WHO) template for rehabilitation information collection (TRIC). Data were analysed descriptively to complete the Systematic Assessment of Rehabilitation Situation (STARS) assessment.

Recent Findings Challenges include inadequacies in reporting and poor data integration between state- and nationally-funded rehabilitation programs and a lack of evidence illustrating continuity of care across rehabilitation settings. Particular gaps in data on stroke rehabilitation in Indigenous populations and a lack of research to date on cultural acceptability of effective interventions were noted.

Summary The economic benefit of improved access to stroke rehabilitation nationally is clear, however achieving this needs collaborative and integrated efforts from multiple stakeholders. Findings will inform the establishment of national priorities to strengthen stroke rehabilitation in Australia.

Keywords Stroke rehabilitation · Rehabilitation · Data · Allied health

Introduction

Stroke is a leading cause of disability in Australia [1, 2], costing the Australian disability sector an estimated \$9 billion a year [3]. In 2023, 45,785 Australians experienced a stroke, there were 440,481 survivors of stroke living in the community [3] and > \$1.08 billion of paid supports were provided by the National Disability Insurance Scheme [4]. Acute treatment of stroke has undergone enormous improvements and more people survive stroke, [2] leaving an increasing number of Australians with varying degrees of disability [5, 6]. Rehabilitation (the process) has been shown to effectively reduce disability [7] and to be of benefit to people with stroke – with benefits covering a breadth of outcomes (including quality of life) and time-periods post stroke [8, 9]. Commonly confused to be limited to a specific

time-period after stroke, the process of rehabilitation is in fact a complex series of interventions [10, 11] which enable a survivor to recover and adapt [12] to their stroke by addressing the loss of function at the levels of impairment and activity limitations [13]. Rehabilitation has, therefore, a pivotal role in reducing disability, promoting functional recovery and increasing adaptation alongside healthcare and with management of environmental factors [14]. To achieve this, rehabilitation should supplement healthcare across the continuum.

Failing to provide rehabilitation has known negative consequences for Australia at the level of stroke survivors, their family, the government and society at large. The ability to drive recovery and improve quality of life after stroke with specialist rehabilitation is an urgent, unmet need in Australia [5]. Despite the burden on survivors of stroke and the Australian health and disability sectors, the implementation of evidence-based rehabilitation interventions [15] is variable [16]. Survivors of stroke report challenges in accessing

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rehabilitation across their lifespan and people living with the ongoing burden of stroke lack opportunity to achieve their life goals [5].

Consistent with the challenges faced in Australia, the World Health Organisation (WHO) Rehabilitation 2030 initiative highlights the global, unmet need for rehabilitation services, WHO has developed the Systematic Assessment of Rehabilitation Situation (STARS) tool to assess local rehabilitation capacity through the Template for Rehabilitation Information Collection (TRIC), which gathers standardised data across key health system pillars (governance, finance, workforce, information, assistive technology, and services).

Australian Context

In 2023, Australia's population grew to 26.6 million, with 73% of people concentrated in major cities [18]. Over the last 30 years, the median population age increased to 38.3 years and the proportion of the population aged 65 years and older increased to 17% [18]. An estimated 1 in 6 people in Australia had a disability in 2018 [19]. Given the increase in the ageing population, the likelihood of experiencing a disability increases [20].

The infrastructure and resources available for stroke rehabilitation vary: rehabilitation interventions are provided clinically within acute care, inpatient rehabilitation settings, community rehabilitation programs, and private providers in both the community and residential care settings. While acute and inpatient rehabilitation services are generally funded by the Department of Health and Aged Care through the National Health Reform Agreement, the services themselves are operated by state and territory governments with state-level governance. Community rehabilitation services are less consistently funded, and the age of the survivor will dictate service eligibility criteria [5, 21]. As noted by Scrivener et al. [5] survivors of stroke “are caught between the health, disability and ageing sectors” and there is no specific organisational unit that oversees rehabilitation.

In Australia, the health professionals involved in stroke rehabilitation include rehabilitation physicians, nurses, dietitians, occupational therapists, orthotists/prosthetists, physiotherapists, psychologists/neuropsychologists, social workers, speech-language therapists, and allied health assistants, supported by families, carers, and communities [22]. There are broader professionals (such as exercise physiologists, podiatrists, health psychologists, and general practitioners) more commonly accessed in the community. Rehabilitation training at an entry (undergraduate) level for these core rehabilitation professions is well-established, but remains profession-specific within Australian universities and with little to no stroke rehabilitation specialisation.

Australia's healthcare system is underpinned by the Right to Health, an obligation under the International Covenant on Economic Social and Cultural Rights, and a number of Commonwealth laws (e.g. National Health Act 1953, Aged Care Act 1997, Disability Services Act 1986 and the Australian Institute of Health and Welfare Act 1987). There is a focus on promoting and protecting the health of priority populations within these Acts, such as Aboriginal and/or Torres Strait Islander people, who experience disadvantage and health inequity [23]. There is, however, a distinct lack of focus on stroke or rehabilitation within these Acts. In the past, there was a National Rehabilitation Strategy auspiced by the National Rehabilitation Professional Organisations through a coalition of professional bodies led by the Australasian Faculty of Rehabilitation Medicine [24]. This strategy called for national workforce planning, national service planning, comprehensive ambulatory and community rehabilitation programs and the establishment of culturally appropriate rehabilitation services at a national level. Now out of date, these recommendations remain unfulfilled. In 2022 the Stroke Foundation released their National Rehabilitation Stroke Services Framework [22], capturing similar recommendations along with the call for rehabilitation be provided throughout the care continuum, with specialised rehabilitation services of aphasia rehabilitation, work rehabilitation and driving rehabilitation receiving particular advocacy.

With constrained health resourcing and competing health priorities, there has been limited investment in Australia in building rehabilitation services or capacity. However, the cost of this lack of rehabilitation has now been recognised as long-term disability costs, costs which can be significantly reduced with access to rehabilitation [25]. To identify priority actions to strengthen stroke rehabilitation advocacy, capacity and resourcing in Australia, we applied the Systematic Assessment of Rehabilitation Situation (STARS) tool to conduct a situation assessment of current stroke rehabilitation nationally [26].

Method

Data Collection

A mixed method design was used and guided by the template for rehabilitation information collection (TRIC). By collecting and synthesising data from the template, the research team were able to complete the STARS assessment [26, 27]. Data collection was approached in two phases. First, the research team purposively identified informants in stroke rehabilitation who held key data on rehabilitation systems, service delivery, capacity, barriers and workforce issues. These informants included Stroke Foundation of Australia,

the Australasian Rehabilitation Outcomes Centre (AROC), the Australian Stroke Clinical Registry (AuSCR), Darak (Australian Stroke Alliance program), and Registry of Senior Australians (ROSA) Research Centre, Australian Institute for Health and Welfare, the Organisation for Economic Co-operation and Development (OECD) policy forum, and the Faculty of Rehabilitation Medicine. Second, a literature review provided the opportunity to identify additional sources of Australian data from online sources, research evidence and guidelines. A participants/concepts/context (PCC) approach was applied to identify data relating to individuals with stroke (P), TRIC items (C) in the current Australia rehabilitation context (C). Reports commissioned by the Stroke Foundation were reviewed [2, 3, 15, 22, 28, 29] as were stroke specific reports from AROC [30] and reports from The Australian Institute of Health and Welfare (AIHW), the statutory national agency for information and statistics on Australia's health and welfare [1, 18, 19]. Co-authors were included who represent the national stroke audit and registry programs (KH, DAC).

Data Extraction

Two authors (LJC and NAL) contacted stakeholders, and three authors (LJC, MS, NAL) searched the literature and mapped data to components of the Template For Rehabilitation Information Collection (TRIC) [27]. Where discrepancies in data existed between different data sources, data available from the Stroke Foundation were used as the primary data source. The Stroke Foundation data set was selected for this purpose due to variations in health service participation in data collection initiatives between states. In circumstances where we were unable to identify the required information for a particular component of the TRIC, the authors then further liaised with the data custodians of the key data sources and if the information were unable to be

identified, then the field was recorded as 'information not available'.

Data Analysis

Data were compiled in Microsoft Excel and then mapped against WHO STARS domains; for quantitative items, numbers or percentages were included and descriptive statistics were derived whenever possible. Where possible quantitative data were standardised relative to the denominator (i.e. population size or total number of survivors of stroke).

Results

Results are structured against the WHO STARS, with insufficient data available for the TRIC domains of 'assistive technology', 'rehabilitation infrastructure' and 'emergency preparedness'. Therefore, we focused on the other seven items to categorise the data (Fig. 1).

Stroke Rehabilitation Needs

Sociodemographic Profile of Survivors of Stroke

In Australia, stroke is more common in older age groups, with over two thirds (72%) of stroke survivors aged 65 years and over [31]. However, recent stroke incidence data indicate an increasingly significant impact on younger people, with between 20 to 30% of stroke survivors being of working age [31]. Leading risk factors for stroke include modifiable vascular risk factors (e.g. high blood pressure, atrial fibrillation) [1]. In Australia, men (62%) are more likely than women (50%) to have three or more risk factors for cardiovascular diseases [1] and this likely contributes to the noted higher prevalence of stroke in males (1.6%) than females (1.1%) [1]. People with lower socioeconomic

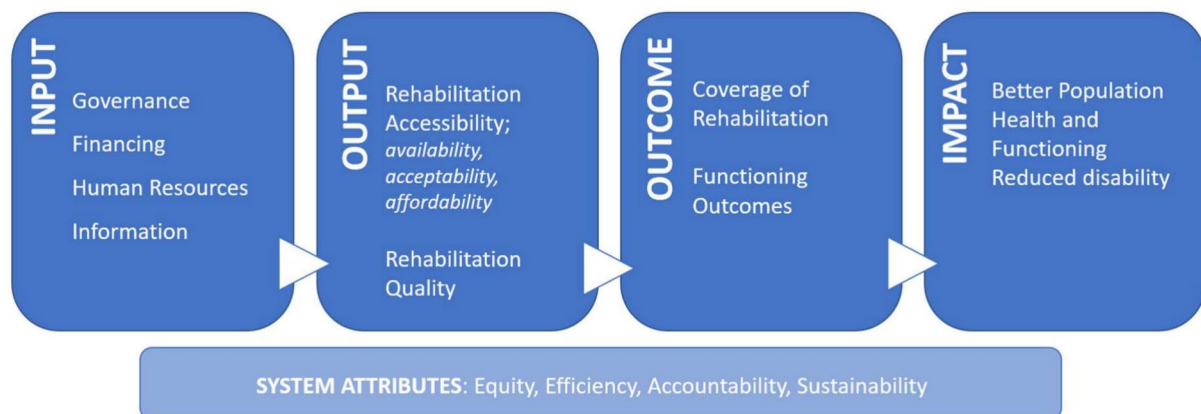


Fig. 1 Logic model for the systematic assessment of rehabilitation situation in Australia

status in Australia also experience greater disease burden after stroke [32]. Concerningly Indigenous Australians have a stroke incidence rate that is about twice that of non-Indigenous Australians [1, 33], experience stroke at a younger age [33, 34], are more likely to have concomitant health conditions (such as diabetes) [34] and yet are less likely to have access to rehabilitation services [35, 36]. Remote areas of Australia have the largest proportion of Indigenous Australians [37], and these remote areas are characterised as having low levels of healthcare provision (often reliant on visiting primary healthcare services, and requiring travel to access rehabilitation) [36]. People from culturally and linguistically diverse backgrounds have also been reported to have a larger stroke risk and be more likely to experience poorer outcomes post stroke with an increased need for rehabilitation [38, 39]. National rehabilitation data are, however, limited with respect to survivors of stroke from Indigenous or culturally and/or linguistically diverse backgrounds within comprehensive data collection systems, and there are little to no data available on the sociodemographic profile of survivors of stroke accessing community rehabilitation.

Rehabilitation Profile of Survivors of Stroke

Rehabilitation needs after stroke are significant and persistent [5, 16]. Of those assessed in the national acute stroke audit, 66% of stroke survivors were found to have ongoing rehabilitation needs when in acute care [6]. Half of stroke survivors (50%) report ongoing problems with mobility after returning to the community [31]. Approximately half of stroke survivors in acute care experience upper limb impairments (57%) and/or lower limb impairments (48%) and over a third will have swallowing problems at admission (35%) [6]. Communication and speech impairments are also common, with over half of people admitted with acute stroke experiencing speech and/or communication problems [6]; as are cognitive and perceptual disabilities (59% and 36% of stroke survivors who receive inpatient rehabilitation, respectively) [16]. At the completion of inpatient rehabilitation, ongoing activity performance difficulties across self-care (grooming, bathing, dressing, toileting, management of continence), mobility (transfer ability, walking, climbing stairs), speech comprehension and expression, social interaction and cognition (problem solving memory) prevail [40] and there is no data available for those Australians who do not receive inpatient rehabilitation, highlighting the gap in current provision (see service delivery domain) and the ongoing rehabilitation needs of survivors of stroke that are only incompletely met by current service provision.

Leadership and Governance in Stroke Rehabilitation

As outlined internationally, rehabilitation services are ideally delivered by a multidisciplinary team of healthcare professionals under the leadership of physicians trained in rehabilitation [41]. Australian state and territory governments are largely responsible for the governance of public hospitals who provide inpatient and limited community rehabilitation services, while the Australian Government (federal) is responsible for national health policy and administers the public health sector through Medicare (primary health care) [42]. Alongside this system is the private sector supported by private health funds. While inpatient rehabilitation is led by specialist rehabilitation physicians, the nature and organisation of stroke rehabilitation services beyond hospital care is varied and there is no overarching governing body. The previous National Rehabilitation Professional Organisations coalition [24] sought to show leadership in rehabilitation reform, however there is no longer national leadership consistent with this now defunded coalition.

Instead, governance for rehabilitation largely falls to individual services where decisions about a survivor of stroke's rehabilitation needs, access to rehabilitation and provision of rehabilitation interventions are made by clinicians locally (clinician discretion), often with limited input from the survivor or their family [43]. There is a lack of detailed information on what factors influence clinical decision making, and therefore, access to rehabilitation beyond service availability, local health service processes and team dynamics [43].

Financing Rehabilitation

In 2020–21, an estimated 6.9% of total allocated expenditure in the Australian health system (\$983.8 million) was spent on stroke [1] however, the specific attribution to rehabilitation care remains unknown and understanding more broadly, the number of rehabilitation beds in Australia (irrespective of diagnosis) is currently not possible. Consistent with healthcare funding arrangements in Australia, stroke rehabilitation is largely funded as a hospital-based system primarily by the Department of Health and Aged Care (Commonwealth government) through the National Health Reform Agreement.

There is also no clear pathway for survivors of stroke to fund ongoing specialist stroke rehabilitation, even if the means were available. Post-hospital discharge, stroke survivors may access limited financial support from the Department of Health and Aged Care through a Chronic Disease Management Plan, funded through Medicare. A Chronic Disease Management Plan is capped at five individualised allied health sessions per year, regardless of discipline or need [44], which is known to be inadequate to meet stroke

rehabilitation needs. In the disability sector, stroke survivors who had their stroke prior to 65 years of age, may access funding for care supports from the National Disability Insurance Scheme (NDIS) provided that they have evidence of permanent and significant disability [45]. Eligibility to the scheme is determined on an individual basis for survivors of stroke [46], often with significant waiting times to determine eligibility and to access supports [47]. Further, while NDIS will fund disability support needs, it does not provide funding support for rehabilitation interventions. This is despite the evidence that rehabilitation interventions reduce disability, which highlights the potential cost savings that would come from the provision of community rehabilitation services (an estimated \$118million) [34].

Acknowledging the government view that the health system has responsibility for providing survivors of stroke with clinical and medical treatment, yet does not provide funding support for those treatments beyond initial phases of recovery, there is an undeniable gap post-hospital in financing rehabilitation. Further complicating the matter is that the costs to the public health budget are borne in Australia by state health systems (under the National Health Reform Agreement) while the economic and social benefits of rehabilitation would be experienced longer-term (and financially not by the state governments) [48]. Together, these findings highlight the need to establish a national funding model that acknowledges the life-long requirements of survivors of stroke so as to finance the necessary support for evidence-based rehabilitation in the community.

Rehabilitation Workforce

Stroke rehabilitation requires specialised, multidisciplinary teams to deliver person-centred assessment, treatment and community integration. There is a lack of data on human resourcing for rehabilitation outside of hospital-based (inpatient) rehabilitation programs and no data available to estimate rehabilitation personnel density (i.e. number of stroke-trained rehabilitation personnel per capita). Not all health professions are registered in Australia, and there is no requirement to have specialisation in stroke rehabilitation when working with survivors of stroke. Together these represent an undeniable gap in the assessment of the state of rehabilitation. What we do know is that the majority of survivors of stroke who receive inpatient rehabilitation services in Australia will have access to dietitians, occupational therapists, physiotherapists, social workers, and speech therapists, supported by allied health assistants [16]. Access to rehabilitation nurses, clinical psychologists and neuropsychologists is lower in Australia [16]. What remains unknown is the stroke-readiness of these health professionals and their accessibility outside of inpatient rehabilitation contexts. There are also no Australian minimum standards for human

resourcing for inpatient rehabilitation, beyond medical care from a rehabilitation physician. The Royal Australasian College of Physicians has, however, published recommendations for rehabilitation services in which they do call for “*an adequate number of professional and support staff to allow the service to provide contemporary, evidence-based rehabilitation management in a safe, effective and efficient manner*” [49]. These recommendations lack specificity with respect to staffing levels, experience and support that is required to deliver guideline-recommended stroke rehabilitation. This gap is due to a lack of research— we do not know the staffing levels needed to provide best practice stroke rehabilitation and acknowledge this will vary by setting.

Staffing numbers are not the only important human resourcing factor. The knowledge of stroke and skills of staff will influence outcomes. Professional education in stroke rehabilitation is an essential strategy for developing stroke specialisation in rehabilitation, but 30% of Australian inpatient rehabilitation services do not provide such education [16]. In the context of outpatient or community based rehabilitation, in both the public and private sectors, the level of access to continuing education and training is unknown. Not only is understanding stroke rehabilitation knowledge and skill gaps in Australian healthcare professionals important, so too is determining who should be responsible for monitoring these levels and providing essential education (i.e. governance).

Stroke Rehabilitation Service Delivery

There are no published data on Australian stroke rehabilitation beds (inpatient) or places (community), and as such current beds per capita has been estimated to be 2.95 stroke rehabilitation beds per 100,000 population (drawn from Stroke Foundation audit data; on the day of completion of the Organisational Survey, 785 patients with stroke were admitted to an inpatient rehabilitation service) [16]. Access to high intensity, longer stay rehabilitation required for people with complex needs and more significant deficits after stroke is limited within Australia. Access to rehabilitation services in Australia is known to be highest during hospitalisation (within acute care, followed by inpatient rehabilitation) with reduced access within the community [21]. For this reason, data were collated by setting wherever able.

Service Delivery in the Context of Assessment for Stroke Rehabilitation

Stroke clinical guidelines recommend that every stroke survivor should have their rehabilitation needs assessed within 24–48 h of an acute hospital admission [50], to enable an early rehabilitation plan to be developed. In recent years, there has been an increased use of standardised processes to

assess stroke survivor suitability for inpatient rehabilitation [16]. In the most recent Stroke Foundation audit of acute stroke care services, 83% of stroke survivors were assessed for rehabilitation, an increase from 67% in 2021 [6]. Most inpatient rehabilitation services (91%) also reported using a standardised process for assessing suitability for rehabilitation admission [16]. There do, however, remain gaps: only half (50%) of the services provided standardised early rehabilitation assessment within 3–4 days of admission [16]. Similarly, survivors of stroke admitted to hospitals in major cities (86%) were more likely to be assessed for rehabilitation than those in inner (80%) or outer regional areas (75%) [6]. A large Australian clinical trial ($n=668$) identified that nearly a quarter of survivors of stroke in their study did not receive any rehabilitation services in the first 3 months post-stroke [51]. On this background, the assessment for rehabilitation should be viewed as a gateway to accessibility.

Service Delivery in the Context of Accessibility to Stroke Rehabilitation

Australia does not yet have a comprehensive model of stroke care to support the > 45,000 Australians who experience a stroke each year [3], nor one that provides ongoing service delivery to the growing number of > 440,481 survivors of stroke living in the community [3].

While the annual numbers of Australians receiving rehabilitation remains unknown, the audit data from the Stroke Foundation provides an indication that approximately 20% of Australians who experience a stroke each year will access inpatient rehabilitation, and for those who do access rehabilitation, they will stay for a median of 24 days [16]. Sixty percent of inpatient services are located in major cities, the other 40% in regional areas with only one service located remotely [16]. A recent map of stroke rehabilitation services across two states in Australia (Victoria and South Australia) highlights that community rehabilitation providers are even more centralised in metropolitan areas of Australia [52]. Disadvantaged areas of Australia need to receive the services survivors of stroke need, and rehabilitation service models and places should be developed to meet the demands of future population growth.

Inequities are present in stroke rehabilitation services availability beyond issues of regional and rural access. An indicator of highly effective stroke care in the clinical guidelines is the presence of co-located rehabilitation beds [50], which enables staffing models that support expertise and team collaboration. However, only 13% of Australian inpatient rehabilitation services report co-locating stroke beds (only 169 dedicated stroke rehabilitation unit beds for all of Australia) [16].

There was a significant increase in stroke-specific Early Supported Discharge (ESD) services from 17% in 2016 to

29% in 2024 [16] – Australia lacks data on the comparative effectiveness of an ESD model of care as it is currently delivered. Studies demonstrating the effectiveness of ESD services were conducted decades earlier when length of acute stay was longer, and only with a population of survivors with moderate-slight disability on the Barthel Index (e.g. [53]). It is unknown whether these same eligibility criteria are applied to determine the most effective setting for rehabilitation today. Efficient rehabilitation is not only driven by length of stay, but importantly also delivery of guideline recommended care, and there are evidence-based rehabilitation interventions that would not be possible to deliver within the home setting (such as treadmill training, robotics). Comprehensive data collection on the quality of rehabilitation delivered within inpatient bed substitution models of rehabilitation are largely untested in Australia.

The accessibility of stroke rehabilitation in the community setting is largely unknown. Centre-based rehabilitation services, including the traditional outpatient services as well as the less-common day hospital models, are known to be the most common services referred to following stroke [16] however the rehabilitation interventions provided, availability in the sub-acute (> 3mo) period, and intensity remains unknown. There is evidence that home-based community rehabilitation as opposed to hospital-based day rehabilitation programs may be less burdensome on caregivers (although survivors received less rehabilitation sessions) [54], but how much this is used is not known. Overall, in Australia we have no national information on the accessibility of community rehabilitation services with respect to amount, quality, setting, or culture, delivery models or waitlists.

Service Delivery in the Context of Quality of Stroke Rehabilitation

The National Rehabilitation Services Framework provides 10 national recommendations that rehabilitation services should meet [55] and these are monitored in Australia by the Stroke Foundation through a biennial audit program. A median of 6 of the 10 framework elements were met in the last audit of 103 stroke rehabilitation services [16]. Only 3% of services met all 10 framework elements. Rehabilitation services with co-located stroke rehabilitation beds and those with a larger volume of stroke admissions were more likely to adhere to more guideline recommendations [16], suggesting that specialisation and models of care that support specialisation are part of the solution to increasing quality of stroke rehabilitation. It is recommended that rehabilitation services provide person-centred and tailored care [50]; while in metropolitan areas hospitals report having formal processes for developing and documenting rehabilitation goals with stroke survivors [16], this was less consistent in rural areas of Australia. Understanding the reasons for

geographical inequity is of importance across a number of these factors relating to service delivery (beyond access). One area where the majority of services were aligned to guideline recommendations (irrespective of location) was in survivors and their families being involved in their own rehabilitation management (93%). This is encouraging, as active engagement of stroke survivors and their carers in the rehabilitation process is indicative of high quality stroke rehabilitation [16].

Aligning clinical practice with recommended guidelines is fundamental to successful outcomes [56, 57]. A summary of evidence-based recommendations to guide stroke rehabilitation from the Stroke Foundation Living Clinical Guidelines for Stroke Management are summarised in Supplementary Table 1. Audit data demonstrates these are not routinely provided within Australian inpatient rehabilitation services [16]; the use of guidelines in community services is unknown as these services are not audited or tracked. Key guideline recommendations in stroke rehabilitation relate to dose – there is strong research evidence that survivors of stroke should receive scheduled therapy as much as possible. Less than a quarter (23%) of Australian inpatient rehabilitation services provided three or more hours and only 10% of services ($n=8$) provided therapy 7 days a week [16]. The quality of therapy provided post-hospitalisation and community service adherence to guidelines remains unknown in Australia; given it is under-dosed and under-delivered in the inpatient setting, it is anticipated that these services also do not meet clinical practice guideline standards.

In an environment of healthcare cost containment, and given the complexity of rehabilitation, the argument is not being made these inpatient models of care are the only models capable of delivering quality stroke rehabilitation. What needs to be better understood, however, is the profile of interventions, their effectiveness and the patient cohorts that benefit from each stroke rehabilitation model – along with clear data of its effectiveness. These data are currently missing from Australia. Outcome measures allow health professionals to evaluate the effectiveness and efficacy of rehabilitation interventions and therapies and within Australian stroke rehabilitation outcomes collected include discharge destination, length of rehabilitation stay and level of dependence on discharge [16, 40]. Inpatient rehabilitation reduces a survivor of stroke's risk of death and disability after stroke [10, 40, 57, 58] but there are acknowledged complications arising each year from Australian rehabilitation programs; these include falls (16%), shoulder pain (12%) and urinary tract infection (12%). There are also known areas where quality of stroke rehabilitation is less likely to be given, and three areas are consistently raised across Stroke Foundation audits: incontinence management and rehabilitation, communication rehabilitation, and mood assessment and treatment [16]. Disappointingly, the accessibility to these

specialised stroke rehabilitation interventions is lower in the community (where we do not yet know quality of provision).

Service Delivery in the Context of the Community Setting Almost half of stroke survivors are left with lifelong disabilities, financial challenges and psychosocial impacts that may impact their quality-of-life well beyond hospitalisation [59]. The total cost of productivity loss and informal care for stroke has been estimated to be \$10.1 billion with a cost of reduced employment of almost \$3 billion [3]. Clinical guidelines recommend that stroke survivors and their families/carers are given access to resources and support upon discharge to the community [50] – with the intent of ongoing access to rehabilitation services. Disappointingly there are no available data sources for community-delivered rehabilitation in Australia. At the time of discharge from inpatient services, however, three quarters (but not all) Australians are provided with a rehabilitation plan [16], and most are given information about driving and around two-thirds education with respect to return to work. However, receipt of specific information about more complex rehabilitation issues including self-management programs, peer support and sexuality are less common. Currently there is insufficient data to report on access to long term rehabilitation in the community, particularly outside of public health services, however anecdotal reports suggest the issues are enormous.

These service delivery issues encompass the need for survivors of stroke to know the availability of rehabilitation services even many years after stroke, as suggested by this qualitative quote:

“Well, I think I should be made more aware of what is available to me” (Participant 6, female, age 81) [60].

For survivors to receive stroke-specialist rehabilitation sufficient to meet their ongoing goals, as suggested by this qualitative quote:

“Through the Commonwealth Home Support Programme, I could get a physio to come to my place once a week for half an hour but the limit was 15... sessions.” (stroke survivor, male [61]).

But most of all, service delivery models in Australia need to adapt to the reality that stroke is a long-term, chronic condition, and that survivors of stroke can and will continue to make gains well beyond the period in which inpatient rehabilitation services are funded.

“[Recovery] does plateau a bit... I will say that most of my recovery happened in the first couple of years, but I'm 15 or 16 years post-stroke now and I still notice changes this year compared with last year” (stroke survivor [62]).

Rehabilitation Information

There is a disconnection in data and reporting across stroke rehabilitation – access to person-level data across systems is not currently possible in Australia. The National Stroke Audit is an initiative of the Stroke Foundation and provides snapshot data every second year on inpatient rehabilitation services at participating hospitals. This audit collates both process and outcome data from hospitals providing stroke care, using Australasian Rehabilitation Outcomes Centre (AROC) linked data, an organisation survey and a clinical audit of medical records ($n=40$); reports are published, shared with participating hospitals and are free to access. However, participation in the National Stroke Audit is voluntary and there is an underrepresentation of rural services. The Australasian Rehabilitation Outcomes Centre (AROC) is a clinical quality registry of all rehabilitation services, and annually a stroke-only report is produced [30]. There is greater participation of services in AROC however process of care data are not collected, and neither Stroke Foundation nor the AROC registry collect data on rehabilitation intervention provision. Therefore, a more comprehensive evaluation of acute and rehabilitative stroke care in Australia is necessary to gain a more inclusive evaluation. Unmet needs surveys of community-living stroke survivors suggest ongoing long-term needs that are not fully met within rehabilitation services in Australia [63].

Technology

Technology for rehabilitation is expensive for devices in Australia, with higher import costs acknowledged by the sector. There is no current database of technology at a service, or a survivor (individual Australian) level. While telerehabilitation for stroke is considered mainstream, and hospitals are equipped for telerehabilitation in Australia, there is a currently lack of consistent information about the availability, use, training and/or equipment needs within stroke rehabilitation.

Discussion

The main finding of this STARS review is that stroke rehabilitation services are not universally accessible to all Australians, and that data for rehabilitation beyond inpatient rehabilitation in public hospitals is lacking. There are definite groups of Australians for whom access to rehabilitation is most lacking—with both geographical as well as cultural gaps noted in data, along with a clear lack of stroke rehabilitation available within the community. Given the potential for rehabilitation services to reduce long-term disability, the lack of investment in

stroke rehabilitation in Australia is troubling. Unfortunately, there are no population level data in Australia to guide clear understanding of the scope or prevalence of this underinvestment.

While rates of assessment for rehabilitation have improved according to the Stroke Foundation, these data are drawn from only a portion of acute services and not all hospitals, and do not cover those Australians who experience a stroke but are not admitted to hospital. Our review suggests that less than a quarter of Australians who experience stroke receive rehabilitation from specialists in the hospital setting, and that certain groups are more likely than others to miss out (those from indigenous backgrounds and those living in rural areas). Notably our data also suggest that many of those who are at a socioeconomic disadvantage for stroke risk reside in rural and regional areas. Thus, there is a need to appropriately resource hospitals and streamline rehabilitation access across all of Australia, ensuring not only geographically accessible services but also those which are culturally safe for all Australians.

At a service delivery level, our assessment also suggests there are workforce inconsistencies across Australia. In the inpatient rehabilitation setting, access to rehabilitation physicians, occupational therapists, physiotherapists and speech pathologists was common, but social workers, psychologists, neuropsychologists and rehabilitation nurses were less represented; there is no available data on staffing levels or access to professions outside of inpatient rehabilitation. Access to guideline recommended rehabilitation remains the ongoing priority and a sufficiently trained workforce is key to achieve this priority. For example, it is recommended that changes in mood are addressed during inpatient rehabilitation [50] but a quarter of Australian hospitals do not employ psychology services [16] which in turn contributes to ongoing challenges with mood reported by survivors of stroke experienced after discharge from inpatient rehabilitation [31].

Finally, we report a lack of evidence testing the efficiency of models of stroke rehabilitation in Australia. There is a lack of research testing models within the Australian context, with guideline recommendations reliant on international trials, or trials conducted outside of the realities of contemporary stroke care. The lack of national data has limited our understanding of the rehabilitation pathways people are on after stroke, but significantly, it prevents governments from understanding the health services needs of stroke. There are two national clinical quality registries of relevance to stroke rehabilitation care in Australia: the Australian Stroke Clinical Registry (AuSCR) and the AROC. While both incompletely present data of interest, neither integrates health outcomes data completely with national, state and territory government data outside of inpatient data, and neither is able to provide the data that is critically required to continuously improve rehabilitation for Australians with stroke.

Conclusion

There is sufficient awareness of the need for rehabilitation information at a national level as outlined in this report; healthcare policy and data collection are government driven, and steps must therefore be initiated to close this knowledge gap. Stroke rehabilitation in Australia can be considered primarily an inpatient (hospital) delivered service provided in the early subacute phase of recovery (that is, up to 3 months). However, it is now recognised that rather than being a single event, stroke is in fact a life-long disability [5] and while the majority of endogenous plasticity occurs up to the 3 months timepoint, the possibility for behavioural changes even years after stroke is well-recognised [64]. Models of rehabilitation fit for the Australian context, focused on delivering rehabilitation care that harnesses the critical timepoints for biological recovery and that address gaps in access and acceptability are urgently needed. Such models of care would need to address the current barriers of the culture of rehabilitation in Australia (short-term, time-limited, delivered early after stroke onset) and the economic realities of a government funding system where the costs are borne by one government but benefits realised by another.

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Declarations

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