

Stroke interventions provided by community rehabilitation teams in Auckland

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Abstract

Community stroke rehabilitation (CSR) provides rehabilitation in the home after a person has had a stroke. It has the important function of returning the person to their abilities as much as possible and the usual activities they participated in before the stroke. Despite the value of this work, there are no mechanisms in place to investigate the type, frequency, and reasons why particular interventions are provided. Without this knowledge, it is difficult to determine whether the services are meeting patient needs, complying with stroke guidelines, and providing equitable interventions to people of all ethnicities. To investigate the provision of interventions and reasons why particular interventions are provided, this research had the following aims: (1) to identify the patterns of community stroke rehabilitation interventions in Auckland; (2) to determine whether CSR interventions were addressing the full scope of patient problems identified by the Extended International Classification of Functioning, Disability and Health Core Set for Stroke (EICSS); (3) to determine whether there were differences in the provision of interventions between Māori and non-Māori; and (4) to explore how the CSR staff explain the identified intervention patterns.

This study used a mixed methods sequential explanatory design. Study 1 was a retrospective observational study that extracted interventions from 113 randomly selected digital files of patients who had received CSR between March 2016 and March 2017 in Auckland and had coded interventions to the EICSS. Using 10 files from Study 1 and a contracted researcher, an inter-rater reliability study was used to evaluate and improve the coding methods. In Study 2, 15 CSR staff members were interviewed about their explanations for the frequency of interventions in Study 1. The qualitative data were analysed using thematic analysis and integrated with quantitative data from Study 1.

By combining the results from the two studies, it was found that intervention provision was facilitated by the patients' common experience of physical impairment and patient goal planning and fatigue management education to support patients' engagement in rehabilitation. Intervention provision was limited by organisational factors such as the duration of service provision, how the CSR resources were used, lack of staff time, low hours of psychological and social worker support, and the outsourcing of interventions to other services. Participants identified that interventions were limited by their lack of training to address somatosensory, vision, and sexuality issues. The observed differences between Māori and non-Māori interventions were thought to be due to barriers to engagement by Māori in the rehabilitation process brought about by the extra pressures of complex medical conditions, low income, and housing insecurity.

Uncovering information on exactly what is provided, what is missing, and what is driving intervention choice and frequency has the potential to inform targeted improvements in the quality of service delivery

as it enables health funders and policymakers, CSR managers, staff, and health educators to make changes that will improve stroke outcomes for patients receiving CSR.

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List of Abbreviations

ACC	Accident Compensation Corporation
ADHB	Auckland District Health Board
ADL	Activities of daily living
AHANZ	Allied Health Aotearoa New Zealand
ANZLCGSM	Australian and New Zealand Living Clinical Guidelines for Stroke Management
CMDHB	Counties Manukau District Health Board
COPM	Canadian Occupational Performance Measure
CSR	Community stroke rehabilitation
DHB	District health boards
DNA	Did not attend
EICSS	Extended ICF Core Set for Stroke
ESD	Early supported discharge
FAI	Frenchay Activity Index
FIM	Functional Independence Measure
FSS	Fatigue Severity Scale
ICF	International Classification of Functioning, Disability and Health
ICHI	International Classification of Health Interventions
MSD	Ministry of Social Development
NGO	Non-governmental organisations
NIHSS	National Institutes of Health Stroke Scale
NZ	New Zealand
NZCGSM	New Zealand Clinical Guidelines for Stroke Management 2010
NZTA	New Zealand Transport Authority
OT	Occupational therapist
PHO	Primary Healthcare Organisation
PRE	Progressive resistance exercise
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RCT	Randomised control trial
RP	Repetitive practice
SEIQoL	Schedule of the Evaluation of Individual Quality of Life
WDC	Workforce development councils
WDHB	Waitematā District Health Board
WINZ	Work and Income New Zealand

Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor used artificial intelligence tools or generative artificial intelligence tools (unless it is clearly stated, and referenced, along with the purpose of use), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Melissa Evans

Co-Authored Works

This thesis contains one jointly authored article published in a peer-reviewed journal, presented in Chapter 5.

Evans, M., Sykes, C., Hocking, C., Siegert, R., & Garratt, N. (2022). Inter-rater agreement when linking stroke interventions to the extended international classification of functioning, disability and health core set for stroke. *Disability and Rehabilitation*, 44(25), 8022–8028.

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Candidate’s contributions to co-authored works (signatures have been removed for publication of thesis):

Name	Contribution	% of contribution	Signature
Melissa Evans	Analysed the percentage agreement of the two sets of data from 10 patient notes. Wrote the first draft and responded to supervisors’ and reviewers’ feedback.	80	_____
Catherine Sykes	Selected interventions targets and coded them to the EICSS. Contributed to a consensus meeting for the non-agree interventions and codes found in the inter-rater agreement study. Provided feedback on the article.	10	_____
Clare Hocking	Contributed to the design of the study and provided feedback on the article.	4	_____
Richard Siegert	Contributed to the design of the study and provided feedback on the article.	3	_____
Nick Garret	Contributed to the design of the study, analysis of the data, and provided feedback on the article.	3	_____

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The Health and Disability Ethics Committees gave ethical approval for Study 1 on December 11, 2017, ethics reference 17/CEN/244, and for an amendment on February 18, 2019, ethics reference 17/CEN/244/AM02.

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Chapter 1: The background to the study

In Aotearoa New Zealand (NZ), little information about therapy services provided to people discharged into the community after a stroke is available. It has been found that community stroke rehabilitation (CSR) has the potential to significantly reduce anxiety and depression and improve functional independence, allowing for reintegration into normal living for both patients and caregivers (Allen et al., 2014). In order to understand whether this potential is being reached, this research intends to investigate what interventions are provided to patients receiving CSR and why interventions are provided. It is hoped that this research will identify areas for improvement of service delivery and staff training needs and that this information will be used to improve the outcomes of people receiving CSR.

The research used a mixed methods sequential explanatory design in two studies. The first was a retrospective observational study identifying the type and frequency of interventions provided to patients who received CSR. The second qualitative study asked CSR professionals their views on the reasons for the frequency of interventions identified in Study 1. For Study 1, the data comprised interventions extracted from a random sample of 113 digital patient records from three Auckland district health boards (DHBs). The therapy target of each extracted intervention was linked to a code in the *Extended International Classification of Functioning, Disability and Health Core Set for Stroke* (EICSS). This *International Classification of Functioning, Disability and Health* (ICF) core set was chosen as it provides a comprehensive and internationally agreed description of the important functional problems people experience post-stroke (Starrost et al., 2008). Furthermore, the EICSS has been validated by patients and rehabilitation professionals as representing the key problems people face after a stroke (Glässer et al., 2012; Glässer et al., 2010). Study 2 gathered in-depth interview data from 15 CSR health professionals employed by the three DHBs.

For this research, CSR was defined as rehabilitation provided in people's homes and communities. As mentioned, the data for this research came from three CSR services: an early stroke discharge service that provided intense 6-week rehabilitation to people with mild to moderate stroke-related impairment and two 12-week CSR services that provided a less intensive service. An intervention was defined as what was done with a patient during a treatment session, allowing multiple interventions to be delivered within a single visit and the administrative work necessary for patients to receive adaptive equipment. Interventions do not include assessments, phone calls, referrals, and team meetings.

The research questions for Study 1 were:

1. What are the patterns of community stroke rehabilitation interventions in Auckland?
2. Do CSR interventions address the scope of patient problems identified by the EICSS?

3. Are there differences in the type and frequency of interventions provided to Māori and non-Māori?

Study 2 addressed the following research question:

1. What are the CSR therapists' explanations for the patterns of interventions found in Study 1?

Why did I start this research?

My interest in stroke interventions was generated from many years of working as an occupational therapist in inpatient rehabilitation wards, community rehabilitation services, and a private rehabilitation clinic. From this experience, I became aware that many patients are discharged from CSR services who want continued rehabilitation services as they have not returned to their pre-stroke abilities. My interest in stroke rehabilitation has also been encouraged by having the opportunity to teach stroke rehabilitation interventions to occupational therapy students. Teaching in that context also deepened my understanding of the ICF (2001) and the shift it signalled from remediating impairments to people's body structures and functions to working towards participation in real-life situations. This background influenced my decision to complete a small preliminary study investigating the type and frequency of community stroke interventions provided by a single service and categorising the interventions to the EICSS (Evans et al., 2017). As CSR is set in the home, I expected the results to show that therapists provided more functional than impairment-type interventions. Consequently, it was surprising that the study results showed therapists provided more body function interventions than activity and participation interventions (40.1% vs 36.7%). In addition, there were indications that Māori patients were receiving a different intervention pattern than non-Māori. As this study could not be generalised to other community stroke services, I decided to investigate this topic in greater depth for my doctoral research. It is hoped that the findings contribute to improvements in CSR services in Auckland, wider NZ, and other services with a similar health system. The next section introduces the bodies of knowledge that informed the study design.

Introduction to the conceptual background of the study

As the 166 categories of the EICSS describe the most important and common functional problems post-stroke, the EICSS was used to categorise the rehabilitation interventions provided to people discharged home after stroke by three publicly funded community stroke services in the Auckland region. From this, it was anticipated that the extent to which a stroke service meets all the patient needs identified by the EICSS could be measured. The literature review chapter discusses its validity and reviews studies that have used the EICSS and other core sets to measure service quality to substantiate the use of the EICSS.

To give context to the process of categorising community stroke interventions against the areas of function identified in the EICSS, the literature review will discuss the findings of NZ and international

studies focused on the outcomes of multidisciplinary interventions commonly employed in community-based stroke rehabilitation services.

As this study collected data on interventions from March 2016 to March 2017, the literature review considers the recommendations for interventions provided by *The New Zealand Clinical Guidelines for Stroke Management 2010* (NZCGSM 2010) (Stroke Foundation of New Zealand and New Zealand Guidelines Group, 2010) which pre-date the study, and the *Living Clinical Guidelines for Stroke Management 2022* (Stroke Foundation, 2022) which represents new evidence from which practice can be evaluated.

The context

This next section provides a brief background to the context of the study so the reader can understand the bicultural nature of NZ health services, the NZ health system, and the inequitable impact of stroke in the NZ population. This is followed by an overview of how community stroke services are governed, the service types, and the makeup of multidisciplinary teams. The last section describes the characteristics of the population served by the three DHBs that contributed data to this study.

New Zealand history

New Zealand is a small island nation with a surface area slightly smaller than Colorado in the United States and slightly larger than the United Kingdom (Blyth et al., 2023). New Zealand society has been shaped by its history of colonisation. To protect the interests of Māori, the indigenous people of NZ, and to establish a peaceful colony, the British Crown and Māori signed the Treaty of Waitangi/Te Tiriti o Waitangi in 1840. After the Treaty was signed, there were disagreements over its meaning and interpretation. This was due to the creation of two versions of the Treaty, one in English and one in Māori, each with a different meaning. In the English version of the Treaty, Māori ceded sovereignty to the Crown while keeping their land, while the Māori version allowed governance over the land, but Māori kept control over their land, villages, and treasures. Both versions stated that only the Crown could buy Māori land, the British would protect Māori interests, and Māori had the same rights as British subjects. The English meaning of the Treaty prevailed, but successive NZ governments ignored many obligations of the Treaty. This led to the underrepresentation of Māori in government, wars between the Crown and Māori, and the confiscation of Māori land (Blyth et al., 2023). These actions and the process of colonisation resulted in “misappropriation of power and resources, and the destruction of the social structures of indigenous peoples” (Health Quality & Safety Commission New Zealand, 2021, p. 43). These changes had long-lasting effects over successive generations of Māori and resulted in unequal distribution of resources and benefits for Māori. This is evident in that 40% of Māori live in areas of high socioeconomic deprivation in parts of Northland, Tairāwhiti, and parts of South and West Auckland (Ministry of Health, 2020). As economic status is one of the main determinants of health, socioeconomic

deprivation has contributed to the disparities in health outcomes for Māori (Ministry of Health, 1998, 2020). To redress these breaches, the Treaty of Waitangi/Te Tiriti o Waitangi Act 1975 established the Waitangi Tribunal to make recommendations on claims where the Crown may have breached the promises of the Treaty of Waitangi/Te Tiriti o Waitangi (Ministry of Justice, 2016).

The New Zealand health system

When this study commenced, most of NZ's health services were publicly funded by the NZ Government under the *New Zealand Public Health and Disability Act 2000*. The objectives of the Act were to: a) improve, protect, and promote health for all New Zealanders; b) promote the inclusion, independence, and participation of people with disabilities; and c) improve the health outcomes for Māori and other population groups. The government, via the Ministry of Health, provides direction for health services through annual health targets and by providing strategy documents.

As a result, 20 regional District Health Boards (DHBs) were responsible for purchasing and providing health services for their resident populations in their geographical region. The government funded each DHB based on the population needs of each region, and they were expected to provide services as outlined by the government's annual service schedule (Goodyear-Smith & Ashton, 2019). Each DHB was responsible for funding the region's hospital care, primary care, mental health, public health (preventative care), maternity care, assessment, treatment and rehabilitation, durable medical equipment, inpatient and outpatient medicines, dental care for children, long-term care, home help, hospice care, and disability support services (Gauld, 2020). If a DHB did not have specialist services such as maternity and surgical services, it could purchase these services from private hospitals and clinics (Goodyear-Smith & Ashton, 2019).

Each DHB partially funded doctor visits (primary care) via a regional primary healthcare organisation (PHO). A PHO is a regional collection of doctors' practices that aims to improve access to health care and provide public health care. The DHB funded each PHO depending on the number of patients enrolled, and additional funding was provided to doctors' practices for low-income patients, health promotion, primary mental health, and chronic care management (Gauld, 2020; Goodyear-Smith & Ashton, 2019).

DHBs were also required to fund non-profit healthcare organisations or non-governmental organisations (NGOs) to provide healthcare services. These services ranged from local to large national organisations, and generally, their role was to provide support for individuals and families and consequently relieve the pressure on the healthcare system (Goodyear-Smith & Ashton, 2019).

To improve health outcomes for Māori, in 2002, the New Zealand Government published *He Korowai Oranga*, which provided strategies to improve the health and well-being of Māori families. The strategy was informed by the Crown's interpretation of the Treaty of Waitangi/Te Tiriti o Waitangi and was based

on principles of partnership, participation, and protection (Ministry of Health, 2002). Improved Māori health would be achieved by Māori working in partnership with the Crown so that they were involved in strategy development, decision-making, design, and the delivery of health services. The Crown would ensure that Māori had the same level of healthcare as non-Māori and would protect Māori cultural views and practices. To produce these outcomes, the government annually monitored how DHBs implemented the strategies in *He Korowai Oranga* (Ministry of Health, 2002). Building on this work, there have been the following government Māori health strategies: *The Guide to He Korowai Oranga – Māori Health Strategy 2014* and *He Korowai Oranga 2019*. The government outlined specific actions to address the Māori health strategy in *Whakamaua: Māori Health Action Plan 2020–2025* (Health Navigator New Zealand, 2022).

New influences on the health service since starting this research

This next section briefly outlines the recent health reforms outlined in the Pae Ora (Healthy Futures) Act 2022 (New Zealand Government, 2022) and the recent changes in health policy since the election of the National Party to Government in 2023. This section provides the political context against which the findings of the study will be considered. This is because the recommendations from this study may contribute to changes in the provision of community stroke services in NZ. The intention of the Pae Ora Act (2022) was to improve the health of all New Zealanders by improving the access, consistency, and equity of health services across the country. It will do this by reducing the duplication of services, embedding the principles of Te Tiriti o Waitangi in the running of health services, providing a comprehensive range of health services in each region, and providing health programmes that meet the needs of local communities. The new Act resulted in the development of three new entities: Te Whatu Ora/Health New Zealand, Māori Health Authority, and the Public Health Agency. This meant that the functions of the previous 20 DHBs and the Ministry of Health's role of commissioning and managing health services are now carried out by one national organisation called Te Whatu Ora. Under this system, the Ministry of Health's role is to monitor the performance of Te Whatu Ora and develop national strategies and policy. Te Whatu Ora will manage primary and community-based services by four regional services and 30 PHOs. By combining all the DHB services under one organisation and with the formation of regional health localities, Te Whatu Ora will have a national perspective on health and will also be able to respond to local health needs. The new Māori Health Authority's role was to develop policies and services to achieve the long-term aim of healthcare equity for Māori. It was to achieve this aim by representing Māori interests in the design, delivery, and funding of health services at all levels of Te Whatu Ora and with the new national Public Health Agency (Little, 2021; The Health and Disability Review Transition Unit, 2021).

However, since the National Party entered government in 2023, legislation was introduced in March 2024 to disestablish the Māori Health Authority. The government's rationale was that this organisation

introduced unnecessary bureaucracy and the centralisation of services. Instead, the government intends to address inequities in Māori health by developing services that are more responsive to local needs, and by introducing more accountability into health service design. The previous functions of the Māori Health Authority for developing Māori health policy and monitoring how health services are meeting the needs of Māori will be performed by the Ministry of Health, and the planning and commissioning of local Māori health services will now be taken over by Te Whatu Ora/Health New Zealand. Some aspects of the Māori Health authority have been retained, most of the staff are now employed by the Ministry of Health, the Hauora Māori Advisory Committee continues with its role monitoring the performance of health services, and iwi-Māori partnership boards continue to provide a voice on priority health needs of Māori communities (Ministry of Health, 2024).

Stroke in New Zealand

In NZ, stroke interventions are guided by the NZCGSM 2010 (National Stroke Foundation, 2010; Stroke Foundation of New Zealand and New Zealand Guidelines Group, 2010). These guidelines emerged from a collaboration between the New Zealand and Australian Stroke Foundation and the Australian and NZ Governments. The guidelines are intended to provide health professionals, consumers, managers, and policymakers with the best evidence available to support decisions in the care and rehabilitation of people after stroke. The recommendations were developed following the processes provided by Australia's National Health and Medical Research Council and the New Zealand Guidelines Group. These processes involved selecting, evaluating, and synthesising the evidence for specific clinical questions. Following this, health professional groups and consumers provided feedback that was incorporated into the guidelines. To ensure that the recommendations were relevant to the NZ population, the New Zealand Reference Group evaluated and adapted the Australian version to represent the NZ context. As a result, Māori and Pacific questions and recommendations were included. The development and dissemination of the guidelines were financially supported by The Stroke Foundation and NZ's Ministry of Health. As a result, the NZCGSM 2010 were used to audit the practice of stroke services in delivering stroke care. Following the 2010 edition, the guidelines were reviewed in 2017 and, in 2022, evolved into a digital living guideline called the *Australian and New Zealand Living Clinical Guidelines for Stroke Management* (ANZLCGSM) (Stroke Foundation, 2022). Although the EICSS was not referenced in the NZCGSM 2010, most of the recommendations were represented in the EICSS chapters.

In March 2016, just before the quantitative data for Study 1 were collected between 2016 and 2017, it was estimated that there were 4,695,000 people in NZ (Stats NZ, 2016). In the 2015/16 New Zealand Health Survey update, 57,000 adults had reported living with a stroke (1.5% of the population) (Ministry of Health, 2016). Of this group, 64% had a stroke under 75 years of age. Men were 1.4 times more likely to have a stroke than women (Ministry of Health, 2016). Based on the 2015 National Minimum Dataset, 8,275 people (185/100,00) were discharged from hospital after a stroke (Ranta, 2018). Looking to the

future and accounting for the increase in the ageing population, the incidence of stroke admissions is projected to rise to 11,828 in 2028, 14,282 in 2038, and 15,532 in 2048. Numbers of strokes in Māori and Pacific peoples are also expected to rise. In 2015, 836 Māori experienced a stroke, with a projected rise to 976 in 2028 and to 1,195 in 2038. In 2015, the number of strokes for Pacific people was 470 and is expected to increase to 589 in 2028 and 725 in 2038 (Ranta, 2018). Between 2010 and 2012, stroke was the second-leading cause of death in non-Māori females, the third-leading cause of death in non-Māori males, and the fifth-leading cause of death in Māori females (Ministry of Health, 2018). Living with a stroke decreases the person's life expectancy. Using data from NZ and Australia, the probability of survival rate at 3 months was 79.4%, at 1 year 73.0%, at 5 years 52.8%, and 36.4% at 10 years. In comparison to the general population, on average, 5.5 years of life are lost due to stroke (Peng et al., 2022).

Although there has been a decline in stroke mortality and stroke incidence, there has been less of a decline for Māori compared to NZ Europeans. The outcomes of four Auckland Regional Community Stroke studies from 1981–2012 found that stroke mortality decreased over this time from 98/100,000 people to 40/100,000 people in all ethnic groups. This was more apparent in NZ Europeans, with a decrease of 2.0% per year compared to a 1.4% decrease for Māori (Feigin et al., 2015). Over this time, stroke incidence in the general population decreased by 2.95%, but there were non-significant increases in stroke incidence for Māori, Pacific, and Asian populations. It was found that for people under 75 years of age, the incidence of stroke in Māori and Pacific was twice that of NZ Europeans (Feigin et al., 2015). Māori and Pacific had a stroke on average 15 years earlier than NZ Europeans, which has been confirmed in a more recent NZ study (Feigin et al., 2015; Thompson et al., 2022). Measuring the outcomes of stroke rehabilitation using the Modified Rankin Scale (mRS), compared to European patients, Māori were found to have significantly reduced odds of a favourable outcome at 3 months (aOR = 0.66, 0.43–0.99) and at 12 months (aOR = 0.59, 0.36–0.96) (Thompson et al., 2022).

CSR services in New Zealand

Community stroke rehabilitation consists of individualised rehabilitation for stroke patients provided in the home by a multidisciplinary team of health professionals (Allan et al., 2013). In NZ, community rehabilitation is provided free by NZ's publicly funded health and disability system. There are four types of government-funded rehabilitation services offered after discharge from the hospital: 1) home-based services, such as CSR; 2) early-supported discharge (ESD); 3) clinic-based services, such as attending therapy as an outpatient; and 4) attending for 1 or 2 days per week at a day hospital. A CSR service is a team of health professionals providing specialised stroke rehabilitation in the home for 45 minutes or more, 2–5 days per week. An ESD service enables early discharge home for people with mild to moderate stroke who can transfer from bed to chair independently or with assistance. This service provides

multidisciplinary care 5 days per week at the same intensity of rehabilitation found in a rehabilitation unit (Dworzynski et al., 2015).

To ensure that essential health services are consistent across the country, the Ministry of Health provides specifications for services that DHBs are required to follow. The service requirements for community rehabilitation are described in the *Community Health, Transitional and Support Services (DHB funded) Tier One Service Specification* (Ministry of Health, 2016) and in the *Community Health, Transitional and Support Services – Allied Health Services (Non-inpatient) Tier Two Service Specification* (Ministry of Health, 2015). The Tier One document outlines the range of community health services that CSR services can refer patients to if needed. The most commonly linked services are continence education and consumables, podiatry, home and community support (personal care, housework, and meal preparation) services, and meals on wheels. The Tier Two specifications cover allied health services to support patients in remaining in their own homes. Under the Tier Two specifications, allied health services are for people of all ages who have long-term or chronic health conditions, disability, or those who require specialist palliative care services in the community. Patients eligible for the service can benefit from allied health care to improve or prevent deterioration of health or disability. Consequently, patients accessing CSR may have mild, moderate or severe stroke impairment. However, only stroke patients with mild to moderate stroke severity can access an Early Stroke Discharge service. Entry and exit to the service are based on the clinical assessment of health risk and level of physical and disability needs. To manage waiting lists, CSR services have guidelines on what is considered a high-, medium-, and low-priority patient. A person is considered high priority and is seen within 2 days of referral if the provision of community rehabilitation would allow the patient to be discharged from the hospital. A medium-priority patient is seen within 15 days of referral. People are considered medium priority if they are considered unsafe doing activities, if a delay in service would result in a deterioration of functional status, or if care at home would place significant pressure on family members. A low-priority patient is seen within 3 months of referral if their health is stable and the person has the potential to improve their independence to prior levels. The criterion for exiting the service is when the patient no longer has a high-, medium-, or low-priority status.

A CSR service may include the following health professions and their assistants:

- Dietitian
- Health social worker
- Occupational therapist
- Physiotherapist

- Psychologist – excludes services provided for mental health
- Podiatrist
- Speech language therapist

The Tier One specifications state there must be documentation showing an initial assessment, a treatment plan on how interventions will be delivered and by whom, the support needed to carry out the intervention, an evaluation of the client’s progress towards achieving the desired outcomes, and a discharge plan (Ministry of Health, 2016).

The Tier Two specifications broadly outline the components of the service provided to CSR recipients. This includes the requirement to conduct a comprehensive assessment that identifies patient goals, the provision of loan equipment to assist independence, an intervention which is based on best practice, the provision of education and advice, self-management education, a lifelong service provision when the person is at risk of functional decline, and an individual discharge plan. Neither specification includes clear specifications on the intensity, duration, and type of interventions that should be provided (Ministry of Health, 2015).

The next section presents background knowledge of the population within the three DHBs from which intervention data were gathered. It is anticipated that this will help readers determine the context of the health service and the possible barriers impacting health in each DHB. This information is from 2016–2017, as the patient records used in Study 1 were written at this time.

Counties Manukau District Health Board

Counties Manukau is in the southern region of Auckland and had approximately 528,340 people living in the districts of Mangere/Otara, Eastern (a large region from Pakuranga to rural Clevedon), Manukau, and Franklin. Of this, 16% were Māori, 39% were New Zealand European, 24% were Asian and 21% were Pacific. Compared to other DHBs in NZ, Counties Manukau had the highest number of Pacific people. In 2015/16, 59,140 people were 65 years and over, which is expected to increase by 80,000 in 2025/26. The 2013 census found this DHB had high numbers of people facing economic hardship, with 36% of people being classified as the most socioeconomically deprived or considered to be living in decile 9 or 10 areas (Counties Manukau Health, 2016). Depending on patient needs, this DHB offers high- and low-intensity CSR services to all regions of the DHB except for people living in the Franklin district. The high-intensity service offers up to 5 visits per week and the low-intensity service provides 1–3 visits per week. Both services have a service duration of 8 weeks (Counties Manukau Health, n.d.). These service parameters remain unchanged.

Auckland District Health Board

Auckland DHB comprised of the following district wards: Waitemata, Albert-Eden, Orakei, Puketapapa, Maungakiekie-Tamaki, Whau, Otahuhu, Waiheke Island and Great Barrier Island. It was home to more than 515,000 people and was expected to rise to 645,000 by 2025. The population comprised 8.0% Māori, 49% European/Other, 32% Asian, and 10% Pacific peoples. In 2015, 56,700 people (11% of the population) were 65 years and older. Of the people living in the Auckland DHB region, one in five lived in the areas with the lowest deciles. Rehabilitation services were spread over several sites. Inpatient rehabilitation services were at Auckland Hospital, and outpatient rehabilitation and community services were based at Greenlane Clinical Centre and the Buchanan Rehabilitation Centre (Auckland District Health Board, 2016/2017). Community stroke rehabilitation was provided by the Community Rehabilitation Team (CoRe), which provided rehabilitation to people with various health conditions. Since starting this research, ADHB has also established an ESD that provides intensive stroke rehabilitation at home (Health Point, 2022).

Waitemata District Health Board

Waitemata DHB covered the areas of North Shore, Waitakere, and Rodney, served 598,000 people and was expected to have an extra 90,000 by 2025. The population comprised 10% Māori, 62% European or other, 21% Asian, and 7% Pacific peoples. Out of all the three DHBs, Waitemata had the highest percentage of people over 65 years at 14%. One in 12 people lived in areas of high deprivation, mostly situated in Waitakere and Henderson (Waitemata District Health Board, 2015/2016). Waitemata DHB had an Early Discharge and Rehabilitation Service (EDARS) for people with mild to moderate stroke and other health conditions who would benefit from intensive rehabilitation. Patients with more severe stroke were admitted to the hospital inpatient rehabilitation wards situated at Northshore Hospital and Waitakere Hospital and on discharge received less intensive community rehabilitation from the community rehabilitation team separate from the EDARS service (Te Whatu Ora Waitemata, 2022).

Why is this study important?

This study used the ICF linking rules that were updated by Cieza and colleagues in 2005. In this update, Cieza et al. (2005) advise that when linking interventions, the aim or target of the intervention should be identified and then linked to a matching concept in the ICF. I identified the target of interventions recorded in patients' clinical records using this method and linked the target to a concept in the EICSS. Using the results of this study, I asked CSR staff who provided these interventions for their reasons why interventions were missing or had high or low frequency patterns. This study is important as it provides a reflective mirror or feedback loop on what is currently provided by CSR teams. The information generated from this research will provide service managers with a benchmark from which service improvements can be measured and monitored. This research will also enable a comparison of service provision across

different DHBs, between Māori and non-Māori, and between health disciplines. This comparison will highlight inequities and inconsistencies in practice and inform change to address these issues. Without this information, health services cannot advocate for funding or plan future services.

The EICSS represents the typical problems people face post-stroke; consequently, classifying interventions provided according to the EICSS can identify areas of unmet need. Health professionals and researchers must address the issue of unmet needs, as patients are unlikely to be aware of current best practices in stroke rehabilitation and may find it difficult to advocate for change. By including a large number of patient files, unmet needs and disparities in service provision across the DHBs can be quantified. Quantifying unmet needs in this way means it is tangible and concrete instead of solely subjective impressions that something is not right and needs to change. Information on the intervention types being provided also allows service managers and health professionals to evaluate if therapists are using evidence to inform their practice decisions, thus informing decisions about training, resourcing, and staff mix in CSR teams.

There is evidence that unmet needs exist, as Thompson et al. (2020) found gaps in the provision of stroke care by surveying 28 NZ hospitals that admitted people with acute stroke. The survey found 21 CSR and 3 stroke early discharge services (Thompson et al., 2020). Twelve of the CSR services imposed a maximum duration for service (44.4%). Of these, 7 provided a service time of 6 weeks, 3 for 12 weeks, 1 for 6 months, and 1 for 1 year. The remaining 13 CSR services were provided until all goals were met (42.9%). On average, there were low numbers of treatment sessions per week as non-urban centres provided just 1.5 contacts and urban centres provided 2.5 contacts per week (Thompson et al., 2020). This is concerning, as the Stroke Foundation of New Zealand and New Zealand Guidelines Group (2010) recommended that patients undergoing active rehabilitation should receive a minimum of 1 hour of physical therapy (occupational therapy and physiotherapy) per day, 5 days per week, and patients with communication difficulties should receive as much therapy as tolerated. Of the 28 hospitals, 12 services provided psychology staff, 15 used a standardised rehabilitation assessment process, and 14 provided a guideline on culturally appropriate care. These variations indicate inequity of services across the country and that people are not being provided with interventions recommended by the NZCGSM 2010.

Only one study has researched the longer-term outcomes of CSR in NZ (Hodge, 2018). Seventy-six participants who had received CSR in Auckland from 2011–2012 were interviewed 4 years post-CSR using a variety of outcome measures. Hodge found that 89.5% presented with a cognitive disability on the Montreal Cognitive Assessment, and the EuroQol Quality of Life Scale found that 42.1% had moderate to severe problems with mobility, 22.4% had moderate to severe problems with self-care, 43.3% had moderate to severe problems with usual activities, 36.8% had moderate to severe problems with pain and discomfort, and 26.3% had moderate to severe problems with anxiety and depression. Although

these results reflect services provided in 2011–2012, they indicate that many patients either continued or developed disability after receiving stroke rehabilitation in the community. These results also indicate that patients may have benefitted from increased cognitive, mobility, self-care, daily activities, and emotional interventions.

As mentioned, I have previously conducted a small study of community stroke interventions that linked interventions to the EICSS in NZ (Evans et al., 2017). The study was a retrospective observational study that extracted and linked interventions to the EICSS from 18 patients (9 Māori and 9 non-Māori) from one service. This was the first study that found missing and low numbers for interventions that are considered common problems after stroke. Specifically, it found no interventions for *b152 emotional functions*, *d710 basic interpersonal functions*, *d760 family relationships* and very few interventions for *d240 handling stress* (0.1%) and *d920 recreation and leisure* (0.3%). In addition, it found inequities in the interventions provided to Māori and non-Māori. Non-Māori received more total interventions than Māori (53.0% vs 47.0%) and more activities and participation interventions than Māori (22.3% vs 14.3%). The study raised the following questions that it is hoped will be answered in this research: are important interventions not being provided to people receiving CSR, and what are the reasons this is occurring?

How this study was conducted

This research used a mixed methods design called *sequential quantitative to qualitative explanatory design*. The first study was a retrospective observational study that extracted community stroke interventions from patient records written between 2016 and 2017. The patient files were randomly chosen from the three Auckland DHBs and represented the number of stroke patients admitted into the hospital in each region. This resulted in 113 patient files, and of this group, 34 were Māori and 79 were non-Māori. The target of the intervention was then linked to the EICSS. The frequency of interventions was summed, and a comparison of the interventions was made to determine the pattern of interventions provided to all the patients, interventions per DHB, to Māori and non-Māori, and by health professional. To determine the reliability of my linking interventions to the EICSS, I asked an independent researcher to link the interventions of 10 patient records. Following this, the selected interventions and linked codes from the independent researcher and me were compared. This comparison found less than expected inter-rater agreement. The method used to compare the linking from each person, and the reasons for the differences was published, and is included in the thesis in Chapter 5.

The second study was a qualitative exploration of the underlying reasons for the intervention patterns found in Study 1. The data came from 15 individual interviews with staff members employed in a CSR service. Participants were shown the pattern of interventions for their DHB from Study 1 and were asked to comment on the reasons why interventions were missing and to explain why some interventions were provided at a higher or lower frequency than others. Ten therapy staff were asked to comment on the

patterns of interventions for their DHB and five staff members from the DHB with the Māori data were asked to comment on the observed differences in interventions provided to Māori and non-Māori. The organisation of the group interview data was aided by the use of NVivo and themes were developed from the data using the thematic analysis method described by Braun and Clarke (2019). The final findings merged the convergent data in Study 1 and Study 2. The results were then presented to the CSR services for feedback to validate the findings.

Thesis outline

Chapter 1 introduced the research questions and explained why they were chosen and why they are important. A brief introduction was given to the EICSS and the NZCGSM 2010, as these two documents guided the methods and data analysis for Study 1 and Study 2. This was followed by a brief history of the NZ health system, its current role, and recent changes to the management of the health service and the type of CSR services. An overview of how CSR are organised was presented to understand how the CSR services studied in this research may differ from other CRS services found internationally. I then presented the socioeconomic characteristics of the geographic regions served by the three CSR services as these factors may give context to the interpretation of the findings of this research.

In Chapter 2, evidence and recommendations from the NZCGSM 2010 will be presented for the two types of services discussed in this research: ESD and CSR services. Following this, evidence will be presented on the post-stroke problems considered to be the most important after discharge from hospital. These are unmet needs of stroke patients in the community, the impact of stroke on carers, activities of daily living (ADL) limitations, fatigue, cognition, and depression. This body of knowledge will be used to analyse the results from Study 2. The main findings of this body of literature will be presented to understand what is already known about the service gaps and the provision of CSR.

Chapter 3 presents some of the main philosophical ideas from John Dewey that guided the choice of the research questions and the use of the mixed methods approach. One of Dewey's concepts that will be explored is "experience", or how humans interact with the environment. It is a unifying concept that rejects the idea that we should investigate either what humans think or how the natural world behaves. In Dewey's view, both aspects cannot be separated. Other concepts explored are Dewey's view of knowledge creation and what is considered "a truth". All these ideas support the use of mixed methods, whereby a research project combines quantitative and qualitative methods to answer a research question. Following this, I will discuss why the sequential quantitative to qualitative explanatory design was chosen for the study.

Chapter 4 describes the methods used in Study 1, which include the rationale for using a retrospective observational design, the sampling criteria, the method to extract and link intervention targets from

patient notes to the EICSS, methods used to improve reliability, the data cleaning process, ethical approval, and how the data were analysed.

Chapter 5 presents the method used in an inter-rater reliability study to assess the reliability of data extraction and the linking processes employed in Study 1. This study was undertaken as it was not possible to use the recommended method of having two linkers and periodic reliability checks. The coding of the whole data set was reviewed using the inter-rater agreement findings and analysis of variations between the raters. This chapter presents a final pre-publication copy published in 2022 (Evans et al., 2022).

Chapter 6 describes the methods for Study 2 designed to address research question 3: “What are the CSR staff explanations for the patterns of interventions presented in Study 1?”. This chapter presents the data collection tool and procedures, ethical approval, how reflexive thematic analysis was used to analyse the data, and the steps taken to improve rigour.

Chapter 7 presents the results of Study 1. The first section will present the demographics of the patients who contributed data. This will be followed by the results for research questions 1, 2, and 3. For research question 1, “What are the patterns of community stroke rehabilitation interventions in Auckland?” this will be answered using graphs and tables showing the type and frequency of interventions linked to EICSS categories for body function, activities, and participation and environmental factors. In addition, graphs and tables compare the frequency of interventions across the three CSR services and the provision of interventions by the allied health staff in each of these services. For research question 2, “Do CSR services address the scope of patient problems identified by the EICSS?”, missing categories will be identified, and the relevance of the missing categories will be established by comparing the missing categories with the recommendations in the NZCGSM 2010. For research question 3, “Are there differences in the type and frequency of interventions provided to Māori and non-Māori”, graphs and tables that compare the type and frequency of interventions linked to the EICSS categories for Māori and non-Māori will be presented.

Chapter 8 addresses research question 4, “What are the staff viewpoints on patterns of service provision for community stroke interventions in Auckland?”. This question is based on integrating the observational data from Study 1 and themes generated from Study 2. Based on these data, seven themes and sub-themes answer the research question, explaining what facilitates and limits interventions. The facilitation of interventions is due to the common experience of physical disability, the use of patient goals, and the need to provide interventions that enable the patient to engage in rehabilitation. Interventions are limited by problems that present infrequently in this patient group, the health service organisation, therapist factors, and inequities experienced by Māori for health, income, and housing.

Chapter 9 presents the discussion, in which I explain how the results from Studies 1 and 2 relate to the research literature on these topics. A summary of the results is provided for research questions 1 and 3. For questions 2 and 4, I explore the explanations for the results by reviewing the literature and the recommendations from the NZCGSM 2010. By situating the results against what is already known about these topics, I evaluate the validity of the findings and provide a summary of the main points.

Chapter 10 presents the conclusion and provides a rationale for Study 1, Study 2, and the inter-rater reliability study, an overview of the methods used, the findings, and the significance and implications of these findings. Following this, recommendations are made on how CSR can be improved with specific recommendations for health funders, CSR managers, and educators of future health professionals based on the research outcomes. Finally, the limitations of the research are outlined, and suggestions are made for further research that would advance this area of knowledge.

Chapter 2: Literature Review

This chapter has three sections. The first section reviews the evidence that supports the provision of CSR. The second section presents the prevalence and associated factors for common problems experienced by patients 1 year post-stroke and aims to understand the range of issues that CSR services can address. This section then serves as a background for the third section, which discusses the service gaps for interventions in CSR in NZ and internationally. This overview of available evidence clarifies why it is important to know about the type and frequency of stroke interventions provided to recipients of community stroke services and the importance of explicating the reasons why stroke interventions are provided.

Evidence supporting the provision of CSR services

There are various ways community rehabilitation is provided. This next section presents evidence supporting the delivery of two forms of CSR in NZ: ESD and community rehabilitation services, also called home-based services.

Early-supported discharge

Early-supported discharge services for stroke are specifically for patients with mild to moderate stroke. There is quantitative and qualitative evidence supporting this mode of delivery. For example, a Cochrane review (Langhorne et al., 2017) of 13 studies of ESD services delivered by a dedicated multidisciplinary team in the community, found that the median duration of service was 6 months. The review found there were significant improvements compared to conventional hospital or community services regarding the outcomes of death (OR 0.78, 95% CI 0.54–1.00, $p = .17$), death or institutional care (OR 0.65, 95% CI 0.49–0.87, $p = .003$), death or dependency (OR 0.73, 95% CI 0.60–0.89, $p = .002$), and a median reduction of length of stay by 6 days (95% CI 3–9, $p < .001$). There were no clear differences between ESD and conventional stroke rehabilitation services for ADL, subjective health status, and mood of the carer or stroke patient. The strength of this research was the ability to assess the outcomes of studies with similar service delivery models.

Regarding carer and patient outcomes, a qualitative synthesis of 14 studies of patient and carer experience of ESD services found both benefits and limitations (Connor et al., 2023). The benefits were that the home environment enhanced the rehabilitation process, with patients reporting better sleep, return to pre-stroke routines and activities, and more personalised and meaningful therapy. Patients felt that goal setting was a collaborative process, and they identified goals that were meaningful for them. Patients with impaired cognition had greater awareness of their difficulties and were more able to problem-solve solutions. There were some limitations after being discharged from the ESD service. Patients and caregivers had difficulty transitioning to new therapy services or found therapy services in

the community were lacking. In addition, carers felt a sudden shock at their new responsibilities of looking after their family member at home, and some reported that safety concerns restricted them from going out. Despite many improvements resulting from the service, patients and caregivers said they lacked information on the causes and prevention of stroke, medications, and access to social support and had unmet needs for emotional support, cognition, and return to social, work, and vocational activities. While the review methods were sound, variability in the duration of service provision (4–29 weeks) and therapy intensity (1–5 therapy visits per week) may have impacted the overall experiences of the patients and carers. The impact of these factors was not analysed separately.

Community rehabilitation services

Two comprehensive systematic reviews have evaluated community rehabilitation for stroke. Hillier and Inglis-Jassiem (2010) compared the functional outcomes of patients receiving community rehabilitation services (home based) versus outpatient services from inception to 2008, including 11 randomised control studies. Using the Barthel index, it was found that community rehabilitation had a significant impact on functional independence at 6 weeks ($p = .03$) and 3–6 months ($p = .01$) and no studies reported a benefit for outpatient treatment. In addition, 4/11 studies found community rehabilitation reduced carer strain. There were several limitations to this systematic review. Two trials included participants who had not received inpatient stroke hospital care and 6/11 studies provided a single discipline intervention rather than interventions provided by an interprofessional CSR team. Although the quality of studies was relatively high (ranging from 7–9/11 on the PEDro scale), there was significant heterogeneity in the characteristics of the participants and the interventions they received. Lastly, the Barthel index has a limited focus, primarily on continence and mobility, and could not evaluate the impact of community rehabilitation on cooking, shopping, mental status, and social well-being.

A more recent systematic review of community rehabilitation using the Barthel index, modified Barthel index, and functional independence outcomes found that community rehabilitation significantly improved physical function (effect size $K = 43$; Hedges $g = 0.58$, 95% CI 0.45–0.70, $p < .001$) (Chi et al., 2020). This review provided much stronger evidence, as it removed any outliers and analysed 43/49 studies with similar qualities. As a result, all the studies used CRS where rehabilitation was provided in the home, with the main interventions being ADL training or exercise, and 29 of the studies provided interventions using a multidisciplinary team. All the studies were randomised control studies and compared community rehabilitation to active treatment (outpatients or day hospital) and inactive treatment such as health education, usual care, or no treatment. This review found that patients who had the most improvement in physical function were those who had a first-ever stroke, were younger, male, patients whose caregivers had received training in stroke management, and those who received rehabilitation in the first 6 months after the stroke. One weakness of this review was that only 50% of studies reported whether patients had a first or recurrent stroke and the time between stroke diagnosis

and the patient starting community rehabilitation. Consequently, it is still not clear whether CSR is more effective for people with first or recurrent stroke and whether early or later community rehabilitation is more effective. Nonetheless, there is clear evidence supporting the community-based delivery of stroke rehabilitation services.

In addition to improving function after stroke, CSR teams can increase social participation. Two studies demonstrate how CSR can achieve this outcome (Daviet et al., 2023; Reunanen et al., 2016). Reunanen et al. explored patients' understanding of CSR at a follow-up appointment 6 months after patients had experienced their first stroke. In this service, patients received 3 months of rehabilitation with an average of two sessions per week. Treatment was directed by patient goals and included social participation interventions such as using cashpoint machines, walking in different community settings, shopping, and attending leisure activities such as swimming and gymnastics. From this experience, patients reported they received: a) strategies for solving ADL problems in the home and the community, b) exercise coaching, c) exploration of community services and facilities, d) dialogue with health professionals, and e) engagement in activities aimed at returning to work.

In France, community stroke teams specifically focus on improving social participation (Daviet et al., 2023). Patients receive, on average, 46 days of inpatient rehabilitation. On discharge home, a CSR service provides rehabilitation to these patients and to patients with persistent disability who wish to receive ongoing rehabilitation. This service has some unique features; the team consists of a part-time rehabilitation medical doctor, a neuropsychologist, an occupational therapist, a physical education teacher, and a full-time nurse coordinator. After acceptance into the service, goals are established with the patient, and regular team meetings are held to discuss the patient's progress. The CSR role is to visit weekly, provide interventions, and coordinate and engage with other health professionals who can assist the patient (physiotherapy, occupational therapy, and speech therapy). In addition, patients and carers are offered care education workshops to assist them in managing common problems after stroke. To explore the impact of this service, Daviet et al. followed the progress of 206 patients' pre and post-treatment between 2018 and 2020. The means of the outcome assessments were compared pre and post-intervention. This comparison showed the Frenchay activity index (FAI) improved from 12.9–17.85 ($p < .00001$), carer burden decreased from 2.49–2.06 ($p < .001$), quality of life increased from 57.51–66.36 and functional independence improved from 66.42–84.81. This programme may have had these outcomes as the median duration of the programme was 145 days, and 70% of the patients and their relatives received a stroke care education programme. In addition, the interventions were focused on improving achieving home tasks and involvement in the community. This was evident as this study classified interventions to the ICF domains and chapters. The highest frequency of interventions was for Chapter 4 Mobility (88%); Chapter 2 General tasks and demands (74%); Chapter 9 Community, social, and

civic life (55%); Chapter 7 Interpersonal interactions and relationships (30%); and in environmental factors, Chapter 3 Support and relationships (63%).

Stroke guideline recommendations for community rehabilitation service provision in New Zealand

At the start of this project, recommendations on CSR service provision were guided by the Stroke Foundation of New Zealand and New Zealand Guidelines Group (2010). Consequently, the services that participated in Study 1 were expected to provide interventions that conformed to these guidelines. In this document, A-grade evidence on the outcomes of ESD supported the provision of ESD services wherever possible to people with mild to moderate stroke. Concerning community rehabilitation, A-grade evidence supported the provision of this service, which included an organised inpatient stroke unit or specialised stroke service. Regardless of whether a specialised inpatient stroke service was present or not, B-grade evidence supported the recommendation that all stroke patients discharged home should be offered community rehabilitation.

In 2017, one year before this project commenced, those guidelines were replaced by the *Living Clinical Guidelines for Stroke Management* (Stroke Foundation, 2022). These guidelines specifically cover NZ and Australia and are updated as new evidence emerges. In these guidelines, there is a strong recommendation for ESD services to be offered to people with mild to moderate disability. The service should have staffing levels similar to those of a stroke unit and should be provided for 4–5 weeks. Community rehabilitation is given a weak recommendation, which means that the benefits outweigh the harms, but this service may not suit everyone. The guidelines explain further that a weak recommendation does not always mean there is not sufficient evidence to support the recommendation. In this case a weak recommendation was given as some of the studies used to evaluate this topic were considered to have a risk of bias and were of low research quality. Compared to the previous 2010 guidelines, community rehabilitation is considered the preferred rehabilitation model over outpatient treatment.

The NZCGSM 2010 recommended that CSR services should be provided in all DHBs with a population of over 200,000 people; however, there were no recommendations for providing ESD services based on the DHB population size. The National Stroke Network, a group representing clinicians who work with stroke patients, has recently provided stronger recommendations for CSR services in NZ (National Stroke Network, 2020). They recommend that all DHBs provide ESD and CSR services for stroke patients. For patients in remote locations, it is recommended that the DHB develop telehealth and other systems to provide CSR. Of particular interest to this research study is the recommendation that all CSRs should collect and report outcome data to improve service development. One outcome tool that was promoted

was the ambulatory outcome measure used by the Australasian Rehabilitation Outcomes Centre (Simmonds & Stevermuer, 2007).

What is known about the post-stroke problems of patients who are discharged home?

Unmet needs

An unmet need is defined “as a need for something or help from someone that would help overcome the effects of the stroke” (Lin et al., 2021, p. 2). One recent systematic review discusses the unmet needs of stroke patients from discharge home to 6 months post-discharge. This literature is included as it indicates the general needs of people that CSR could address. The reviewers selected 23 quantitative studies to review unmet needs after stroke published up to 2020 (Lin et al., 2021). This study found that the median prevalence of unmet needs was 67.20% (15.08%–97.59%). Based on 20 articles, unmet needs were more prevalent within the first 6 months (63.14%) and 2–3 years post-stroke (81.37%). This result indicates that stroke survivors have ongoing needs over time, and as these needs go beyond the usual CSR contract, these needs are most likely not being addressed. Across the studies the highest prevalence of unmet needs reported as a median percentage related to the provision of information (57.00%) and rehabilitation (50.33%), ongoing problems with physical impairment (49.80%), self-care (49.45%), fatigue (47.00%), memory and concentration (44.00%), cognition (43.40%), mood and emotions (41.00%), secondary prevention 40.30% and social life or participation (37.57%).

Impact on carers

To further understand the need for stroke interventions provided by CSR, the next section will review the evidence on the impact of stroke on carers.

A study of 159 unpaid family carers of stroke survivors living in Auckland, NZ, found that after 6 months of being in this role, 59% reported that life had changed for the worse (Parag et al., 2008). Over 50% of carers reported reduced time for family members and social activities and reduced levels of energy and emotional well-being. A more recent study of 19 unpaid caregivers of stroke survivors living in NZ explored the impacts of being a caregiver in more depth (Qureshi et al., 2022). It was found that carers experienced long-term grief for the loss of the person they had known before the stroke. This was due to permanent changes to the stroke survivor’s personality and the loss of their shared plans and dreams for the future. Negative feelings and stress were caused by the carer having to adapt to a new reality. This involved adapting to a permanent change in the relationship between the carer and the stroke survivor. Diminished social contacts were attributed to the demands of caring, guilt, or fear that the stroke survivor may display inappropriate behaviour. All carers felt a financial strain. For some, this was caused by having to give up employment to look after the stroke survivor or having to pay costs linked to looking after the person. Carers felt that the hospital had not adequately prepared them for caring. They were not given information on health and social systems or provided training on how to look after the person’s

ADL. As a result, carers felt anxious about looking after the person and experienced high levels of exhaustion. The participants said their emotional, social and financial ability to manage the long-term care of their partners was not assessed, nor were they provided any support to manage these needs (Qureshi et al., 2022). This study indicates that on discharge from hospital, carers have psychological, financial, information, and training needs that are not currently addressed well when the family and stroke survivors receive hospital and CSR services.

A large Australian survey of 369 pairs of stroke survivors and carers supports the findings of Parag et al. (2008) and Qureshi et al. (2022) and adds to the evidence that higher stroke severity increases the negative impact on carers (Andrew et al., 2015). Andrew et al. (2015) collected data on the unmet needs of stroke survivors 12 months or more post-stroke and the impacts on caregivers in the domains of vocational work, leisure and family, and spousal and friendship relationships. It found that since taking on the caregiving role, 21% of carers were not receiving enough social support, 28% had a loss of income, 50% reported an increase in financial costs due to the caregiving expenses, 40% had a moderate to extreme reduction in the ability to do vocational work, and 47% had a reduction in leisure activities. Across all domains except work, there was a significant positive relationship between the number of unmet needs of the stroke survivor and the impact on the carer. Greater impacts on the caregiver were particularly associated with stroke survivors needing help with ADL or if the person had cognitive or emotional problems (Andrew et al., 2015). These findings suggest that meeting the long-term needs of survivors may reduce caregiver burden. The studies on the impacts on carers in Australia and NZ from 2008–2022 show that these issues have not improved or resolved for caregivers over this period. CSR services directly contribute to this area of need as they improve stroke patients' functional abilities, teach carers the skills to look after the stroke survivor, and link carers to health and social supports. As these outcomes are not improving, this suggests that this area is still not sufficiently addressed by CSR services.

Activities of daily living limitations after stroke

This section discusses the literature on the proportion of people with ADL limitations up to 1 year after a stroke. Two large studies have investigated the changes in ADL post-stroke from hospital discharge over 12 and 24 months after stroke, one of which researched improvements in basic ADL (Lee et al., 2022; Ullberg et al., 2015). Lee et al. included only participants with an ischaemic stroke who had been through a rehabilitation ward in South Korea ($n = 798$). Following participant selection, the National Institutes of Health Stroke Scale (NIHSS) was used to classify participants as having moderate ($n = 673$) or severe impairment ($n = 125$), and both groups were evaluated over 12 months using the NIHSS and the Functional Independence Measure (FIM). Ullberg et al. included all patients on the Swedish stroke register who were dependent on ADL due to the stroke when admitted to hospital ($n = 35,064$ at 3 and

12-month follow-up) and asked participants to complete a short questionnaire on whether they were dependent or not for dressing, toileting, and mobility.

Tracking stroke severity over 24 months, Lee et al. (2022) found that patients classified with moderate severity significantly improved in stroke severity at 3 months and 6 months after discharge, whereas the patients with severe stroke only made significant improvements at 3 months post-discharge. However, functional improvement was found to continue for both groups over the 24-month period using the FIM. The moderate group significantly improved over the following time periods: discharge to 3 months, 3–6 months and 6–12 months, and the severe group made significant improvements from discharge to 3 months, 3–6 months, and 12–18 months. The finding that ADL independence continues to improve for up to 18 months and that the rates of change vary depending on stroke severity is very relevant for the provision of CSR services. Currently, in NZ, the maximum rehabilitation period is usually 3 months after discharge from hospital. Lee et al.'s (2022) results mean that the current service provision does not correspond to the natural recovery periods for people with moderate or severe stroke.

In contrast, Ullberg et al. (2015) found that at 3 months, 16.2% of participants said they were dependent in ADL, which increased to 28.3% at 12 months. Factors that were predictive of ADL deterioration from 3–12 months were being female, having a current smoking habit, having diabetes mellitus, having decreased consciousness level at admission, having a previous stroke, and haemorrhagic stroke. This study shows that ADL recovery is not stable after 3 months and that further CSR from 3–12 months would be of benefit to address ADL deterioration.

These studies had several strengths and limitations. Lee et al. (2022) only included participants with ischaemic stroke, so the sample was not representative of all the patients seen in CSR. However, the results of this study have strong validity as patients were interviewed in person using a standardised ADL scale. A strength of Ullberg et al.'s (2015) study was the large sample size. Further analysis of the people lost to follow-up at 3 and 12 months showed a higher proportion of people who had experienced a previous stroke, lived alone, or had decreased consciousness on admission. If these people had been included in the study, the results would likely have shown greater ADL dependency. Both studies indicate that ADL status can improve or deteriorate in the 12–24 months following stroke, and Lee et al.'s study highlights that moderate and severe stroke have different time windows for ADL recovery. Both studies support the continuation of CSR beyond the current 3-month period to maximise and maintain ADL ability.

Both studies present different findings, and this is most likely because of the different measurement scales. Lee et al. (2022) were able to report on small changes in a larger number of ADL areas, whereas Ullberg et al. (2015) reported on dependence or independence in three ADL areas of dressing, toileting, and indoor mobility.

Fatigue

There have been two recent large systematic reviews investigating the prevalence of fatigue post-stroke, one using 66 studies ($n = 11,697$) from 1999–2022 (Zhan et al., 2022), while the other used 35 studies ($n = 9,004$) from inception to 2020 (Alghamdi et al., 2021). Across all the studies, Zhan et al. (2022) found that the prevalence of fatigue was 46.79% (95% CI 43.41%–50.18%). Subgroup analysis found that time since stroke did not influence the result, which suggests that fatigue is prevalent at all stages after stroke. Closely aligned with that, by pooling 44 studies that used the Fatigue Severity Scale (FSS), Zhan et al. found a fatigue prevalence of 47.44% (91% CI, 43.20%–51.67%). This result is similar to the findings of Alghamdi et al., who found that fatigue prevalence was 48% (95% CI 42%–53%) in 31 studies that used the FSS. Both reviews found a higher prevalence of fatigue in people with haemorrhagic stroke (57.54% and 66.0%; Zhan et al. and Alghamdi et al., respectively) compared to ischaemic stroke (46.04% and 36.0%; Zhan et al. and Alghamdi et al., respectively) and that fatigue was not significantly associated with depression. High levels of study heterogeneity were found in both reviews. Further analysis revealed that heterogeneity was due to the different factors in the study design, such as the country where the study was conducted, time since stroke, different fatigue scales (Alghamdi et al., 2021; Zhan et al., 2022), sex of participants, married status, and higher education (Zhan et al., 2022).

The trustworthiness of these results was enhanced as both studies complied with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) and used the Joanna Briggs Institute of Critical Appraisal Instrument to appraise the quality of the studies (Alghamdi et al., 2021; Zhan et al., 2022). In this regard, Zhan et al. reported that the studies had a medium level of quality, and Alghamdi et al. rated the studies medium to high quality. The high heterogeneity across the studies was a concern for both reviewers, and it was recommended that there needed to be consensus agreement on the use of one validated fatigue assessment tool or a standardised methodology used to identify fatigue (Alghamdi et al., 2021; Zhan et al., 2022).

Cognition

Two systematic reviews with very different inclusion criteria have been conducted to analyse the prevalence of cognitive impairment after stroke. Sexton et al. (2019) did not include studies with participants with dementia, cognitive impairment prior to the stroke, those with recurrent stroke, and studies that recruited participants with a specific stroke type. Across 21 studies ($n = 4,152$) published between 1995 and 2017, Sexton et al. (2019) found the prevalence of cognitive impairment was 38% (95%, CI 32%–43%, $p < .01$) within 1 year of stroke. There was some doubt about this finding, as there was a high level of heterogeneity across the studies that was not explained by case mix, follow-up time, age, patient selection, or the definition used for cognitive impairment. On analysis, it was found that six studies with a high-quality score had very low heterogeneity. Using these studies, the prevalence of

cognitive impairment was 39% (95%, CI 35%–42%). As this figure is similar to the prevalence of 38%, this analysis supports the original prevalence level. Several aspects of this systematic review increase confidence in this finding. Studies were only included if participants were representative of the general population with stroke, the two reviewers independently evaluated the studies using the Crowe Critical Appraisal Tool, and the researchers were able to identify and analyse factors that produced heterogeneity across the studies. However, Sexton et al. identified some limitations when doing a meta-analysis of this topic, primarily the lack of a consistent definition of cognitive impairment across the studies and the need for clearer reporting on the processes used for patient selection and data analysis.

The inclusion criteria for Barbay et al.'s (2019) systematic review of 16 studies ($n = 3,087$ participants) published between 1990 and 2017 were designed to represent patients likely to be seen in hospital settings rather than the wider population and included participants with dementia, pre-stroke cognitive impairment, and recurrent strokes. A much greater prevalence of cognitive impairment of 53.4% (95%, CI 46.9%–59.8%) was identified, comprising mild cognitive impairment post-stroke of 36.4% (95%, CI 29.0%–43.8%) and major cognitive impairment of 16.5% (95%, CI 12.1–20.8). The prevalence rate increased with the inclusion of participants with increased age and recurrent strokes. Similar to the systematic review by Sexton et al. (2019), there were high levels of heterogeneity across the studies. This was mainly related to methodological differences and different thresholds used to determine cognitive impairment. This systematic review had several strengths; it followed the guidelines for the Meta-Analysis of Observational Studies in Epidemiology (Stroup et al., 2000) and reported and analysed factors that resulted in heterogeneity. There were limitations, as it did not report on the quality of the studies nor attempted a meta-analysis on studies with low heterogeneity.

In summary, it appears that the prevalence of cognitive impairment after stroke varies depending on whether the person has had cognitive decline prior to the stroke. From the current reviews, cognitive decline was prevalent in 38% of people with no history of cognitive impairment post-stroke, and this increased to 53.4% when people with a past history of cognitive issues were included (Barbay et al., 2019; Sexton et al., 2019). In the group with cognitive impairment, two-thirds had mild impairment and one-third had a major impairment rate (Barbay et al., 2019). Barbay et al. recommended that a more accurate determination of prevalence could be achieved by studies using standardised cognitive impairment assessments with cut-off points that determine mild and major cognitive impairment stroke and a standardised method to combine multiple cognitive scores. Both studies have highlighted the need for a standardised definition and criteria for mild and major cognitive impairment.

Depression

This section presents the prevalence rates for depression based on two systematic reviews with contrasting inclusion criteria. Liu et al. (2023) included articles that used a clinical interview or a rating

scale to diagnose depression, time since stroke, and if participants were representative of the typical population post-stroke. It included 56 studies that used a rating scale and 20 studies that used clinical interviews to diagnose depression. From the pooled data from 77 articles published from inception to 2022 ($n = 27,401$), it was found that the prevalence for depression was 27% (95% CI 25%–30%). From 24 studies that reported the natural progression of depression over 1 year, it was found that most people (71%) were diagnosed with depression in the first 3 months after stroke. Of those diagnosed with depression at 3 months, 53% continued to have depression within 1 year of stroke, and 44% of people recovered in 1 year. The pooled cumulative incidence for 1 year was 38% (95% CI 33%–43%). This study highlighted the importance of depression screening in the first 3 months of stroke and the need for clinical intervention to shorten the duration of the depressive episode.

Several strengths of this study support the validity of the findings. The researchers used the Critical Appraisal Skills Programme Cohort Study tool and found that 33 of the studies had high or very high quality and 35 had adequate quality. Although there was high heterogeneity across studies, the different study settings, the socioeconomic characteristics of the participants, or the time of the depression assessment did not influence the prevalence estimate. The main source of heterogeneity was due to the different depression scales and cut-off points used across the studies.

An earlier study using studies from inception to 2016 investigated the prevalence of mood and emotion disorder post-stroke using 147 studies ($n = 15,573$) based on clinical assessment of depression post-stroke rather than a rating scale (Mitchell et al., 2017). This study is important as it provides information on the severity of mood conditions post-stroke and the risk factors associated with depression. This study followed the guidelines of the Meta-Analysis of Observational Studies in Epidemiology and rated all the studies for quality and risk of bias. Using this tool, it was determined that 24.1% of studies were of low quality and 13.0% had a high risk of bias. Across the 147 studies, the time of diagnosis ranged from 2 days to 7 years, and the mean time of diagnosis was 6.87 months after stroke. Across 128 studies, the prevalence of major depression was 17.7% (95% CI 15.6%–20.0%) and the prevalence of minor depression was 13.1% (95% CI 10.9%–15.8%). Overall, it was found that the prevalence of any type of depression was 33.5% (95% CI 30.3%–36.8%). It was found that people were at higher risk of depression if they had a left hemisphere stroke (26% higher risk, RR = 1.26, 95% CI 1.16–1.37), aphasia (50% higher risk than no stroke with no aphasia, RR = 1.50, 95% CI 1.28–1.75), family history of a mood disorder (RR = 1.44, 95% CI 1.15–1.80) and prior history of a mood disorder (RR = 1.80, 95% CI 1.36–2.38). Based on these findings, the authors recommended that routine screening for mood disorders should be conducted 1 year after stroke, particularly for people who are at high risk.

These studies indicate there are high levels of mood disorders after stroke, but the prevalence level of depression is still unclear. This is because both studies had different inclusion criteria for the reviewed

studies. Lui et al. (2023) included studies diagnosing depression by rating scales and interviews, whereas Mitchell et al. (2017) used only clinical interviews. Lui et al. found depression was prevalent in 27% of people from 1 month to 1 year after stroke, whereas Mitchell et al. found the prevalence to be 33.5% based on a mean time point of 6.87 months (range between 2 days and 7 years).

Participation

In contrast to the other impacts of stroke, there have been few studies indicating the prevalence of participation after stroke. Despite efforts to find systematic reviews on this topic using the terms pre- and post-stroke, participation or social participation or community integration, leisure, and prevalence or incidence, no systematic reviews were found. Consequently, the articles selected to present in this section of the literature review reported studies with large samples conducted in contexts with economic and social conditions similar to NZ.

Four studies evaluated engagement in leisure, housework, social activities, work pre-stroke, and 3, 5, and 12 months after stroke (Adamit et al., 2015; Castagnoli et al., 2023; Reeves et al., 2022; Tse et al., 2019). The studies used different sample sizes and participants came from Ireland and England ($n = 1,988$; Reeves et al., 2022), Israel ($n = 245$; Adamit et al., 2015), Italy ($n = 105$; Castagnoli et al., 2023) and Australia ($n = 92$; Tse et al., 2019). Three studies had participants with mild disability (Adamit et al., 2015; Reeves et al., 2022; Tse et al., 2019) and one study had participants with moderately severe disability (Castagnoli et al., 2023). The studies used different participation measures, one using the Shortened Nottingham Leisure Questionnaire to collect data on leisure activities (Reeves et al., 2022), while the others evaluated social, productive, and leisure activities using the FAI (Castagnoli et al., 2023), the Activity Card Sort (Tse et al., 2019), and the Reintegration into Normal Living Index (Adamit et al., 2015).

All the studies found reductions in the number of activities participants engaged in after stroke, but the degree of loss reported differed across the studies. At 6 months, Reeves et al. (2022) found there was a mean loss of 2.2 leisure activities (95% CI 2.0–2.4, $p < .001$), while Castagnoli et al. (2023) found a mean reduction from 28 activities pre-stroke to 13 activities at 6 months post-stroke. A similar pattern was found by Tse et al. (2019), who showed there was a mean loss of 5.2 activities at 6 months (95% CI 6.8–3.5, $p < .001$) compared to pre-stroke activities. At 12 months, participants started to re-engage in activities and the mean loss of activities had improved to 2.1 activities at 12 months (95% CI 3.7–0.5, $p = .01$) (Tse et al., 2019). Although Adamit et al. (2015) did not measure pre-stroke participation, this study found that at 3 months, 45.2% of participants reported difficulty re-engaging with leisure activities, 23.6% with productivity, 22.4% with mobility outside the home, and 19.2% with social activities.

The frequency of engagement in activities also decreased. Reeves et al. (2022) found that leisure activities reduced from 10%–40%, with an average reduction of 22%. This result was similar to Castagnoli

et al.'s (2023) study, where the frequency of participation in all previous activities was reduced at 6 months. From these studies, it is evident that participation restrictions are common in people with mild to moderate stroke at 3, 6, and 12 months. The evidence in these studies suggests that impaired cognition, depression, limitations in ADL, and stroke severity are all associated with a reduction in participation after stroke. The similarities across the studies support the validity of the combined results despite being in different countries, using different participation measurement tools, and participants with different levels of stroke severity. The diversity of methods is also a limitation as it makes it more difficult to conduct a meta-analysis of studies in the future.

Given the apparent need to provide interventions to address participation restrictions across social, leisure, and productivity activities, CSR services seem to be uniquely positioned as they are provided in the context where such activities naturally occur.

Service gaps in community rehabilitation services in New Zealand

This section will review the literature on service gaps in community rehabilitation in NZ from three perspectives: regional and national service provision, functional outcomes for Māori and Pacifica peoples, and the views of staff and patients on the gaps in CSR.

Five studies have contributed to the knowledge of service provision of community stroke services in NZ. Two are regional studies (Thompson et al., 2019; Yeo et al., 2016), two are national audits of 28 hospitals that provided stroke care and rehabilitation in NZ (McNaughton et al., 2014; Thompson et al., 2020), and one reviewed psychosocial practice for stroke patients in NZ (Bright et al., 2023). Three different methods were used: a retrospective audit of stroke patients receiving inpatient and community rehabilitation (Yeo et al., 2016), a prospective cohort of stroke patients receiving community rehabilitation (Thompson et al., 2019), and an online survey of health managers of inpatient and community stroke services (Bright et al., 2023; McNaughton et al., 2014; Thompson et al., 2020).

From comparing the two national audits, the service delivery model for CSR has changed between 2013 and 2018 (McNaughton et al., 2014; Thompson et al., 2020). Over this time, there was an increase in home-based rehabilitation services from 14–21, and outpatient services from 19–24 services, and a decrease in day hospitals from 14–4 and ESD services from 6–3. Regarding patients' waiting time for CRS, the 2013 national audit reported patients were waiting 13.6 days; however, regional services reported a time delay of 25–29 days in 2014 (Yeo et al., 2016) and 13.9 days in 2019 (Thompson et al., 2020). In the 2018 national audit, no waiting time data was reported. In this audit, the duration of CRS varied between providing a set time for rehabilitation ($n = 12$) and providing care until all goals were met ($n = 13$). Of those with a set duration, 7 provided therapy for 6 weeks, 3 for 3 months, 1 for 6 months and 1 for 1 year (Thompson et al., 2020). From these results, it is evident that over half of community rehabilitation

services are adhering to the NZCGSM 2010 recommendation 1.4.2, which states that “the duration of the formal rehabilitation phase of care should be tailored to the individual patient based on their response to interventions and not an arbitrary time limit” (Stroke Foundation of New Zealand and New Zealand Guidelines Group, 2010, p. 14). Providing rehabilitation based on need is also the intention of the 2017 Australian and New Zealand Living Clinical Guidelines for Stroke Management (Stroke Foundation, 2022).

Regarding the intensity of therapy, the NZCGSM 2010 states that patients should receive as much therapy (physiotherapy and occupational therapy) as possible, but there should be a minimum of 1 hour of practice, 5 days per week. However, the ANZLCGSM (2017) recommends that at least 2 hours of active task practice per day is beneficial for most people with stroke to improve ADL, walking, and arm movements. Despite these strong recommendations, it appears that most NZ community stroke services are achieving the NZCGSM 2010 guidelines but not the ANZLCGSM recommendation. This is supported by the findings of the 2018 audit, which found that the median number of therapy hours varied from 1.5 (1–2) hours for non-urban centres to 2.5 (1–5) hours for urban centres (Thompson et al., 2020). In the 2018 audit, the data for therapy intensity were based on combining therapy sessions from day hospital, outpatient therapy, and community/home-based rehabilitation, so this figure may not accurately reflect the level of intensity provided in home-based community rehabilitation. The Thompson et al. (2019) study may provide a more accurate representation of therapy intensity, as it specifically collected data from a community/home-based rehabilitation service. This study found that the mean number of rehabilitation sessions per week was 1.1 ($SD = 3.4$), and the mean total rehabilitation time per week was 42.2 minutes ($SD = 49.3$).

Limited availability of psychosocial support has been identified in two studies (Bright et al., 2023; Thompson et al., 2020). A 2018 national audit of stroke services found that only 48% (13/28) of hospitals had psychology staff. In contrast, all services reported having physiotherapists, occupational therapists, speech language therapists, and social workers (Thompson et al., 2020). Routine psychological screening was limited in 9/11 community rehabilitation services that completed the online survey. Of this group, 22% ($n = 2$) reported no routine use of a psychosocial screen, 56% ($n = 5$) screened with a discipline-specific or transdisciplinary tool, and 33% ($n = 3$) used a validated tool (Bright et al., 2023). From 32 completed survey responses on how psychosocial support was provided in a specific service or a DHB, 3 reported that no interventions were provided, 24 said referrals were made to a variety of different providers, and 5 reported that members within the team provided psychosocial support and when necessary, referrals were made to specialist services. The available psychological support may be less than reported, as several respondents reported it was hard to access the support as staff worked part-time (Bright et al., 2023). From these studies, it is evident that psychological support is not provided to the same level as other disciplines, and although community services generally assess psychological well-being, few use a validated tool. As staff and patients were not surveyed on patients’ unmet psychological

needs, it is still unclear whether the current resources meet patients' needs across the various stroke services.

Two studies evaluated aspects of CSR for Māori and Pacifica (Thompson et al., 2020; Thompson et al., 2022). The first used an online survey to uncover the national service provision of stroke services in NZ (Thompson et al., 2020) and the other collected observational data on patients ($n = 2,379$) from each region in NZ on functional outcomes and quality of life, 3, 6, and 12 months after stroke (Thompson et al., 2022). These studies found that all DHB services had Māori support services, and 71.4% had Pacific support services (Thompson et al., 2020). Although cultural support services were present, they appear to be underused. This is supported by Thompson et al.'s (2022) finding that only 61.5% of 249 Māori patients were offered Māori/tikanga cultural support services, and 45.7% accessed these services. This same pattern was also apparent for 31 Pacifica patients, as only 30.7% were offered this service and only 16.8% accessed it. Māori appropriate information was routinely provided in 70% of acute and inpatient services, but information in Te Reo Māori (the Māori language) was only provided in 57.1% of acute and 32.1% of inpatient services. Although no data were presented for CSR services on providing culturally appropriate information, the data from acute and inpatient information provision may indicate similar levels of service provision.

Significantly poorer functional outcomes were found for Māori and Pacifica at 3 months (aOR = 0.66, 0.43–0.99 and aOR = 0.49, 0.26–0.95) and 12 months (aOR = 0.59, 0.36–0.96 and aOR = 0.28, 0.11–0.68) (Thompson et al., 2022). The reasons for this result are unclear as the mean number of total community rehabilitation visits was higher for Māori ($n = 5$) and Pacifica ($n = 4.5$) compared to Europeans ($n = 3$), there was no association between ethnicity and arrival to hospital or receiving treatment with intravenous thrombolysis, and no significant differences in stroke reoccurrence. In addition, this study controlled for known confounders, such as age, sex, stroke severity, stroke type and pre-morbid level of function, urban or non-urban hospitals, and differences in baseline characteristics. It is possible that differences in hospital care could have influenced this result as it was found that non-Europeans had poorer access to acute stroke units, swallow assessments, a lower rate of early mobilisation, and a trend towards lower levels of access to 1 hour of inpatient rehabilitation. This result could also be attributed to poorer management of risk factors in non-Europeans compared to Europeans, as non-Europeans had higher rates of diabetes and smoking and lower rates of prescriptions for anticoagulant medication on discharge (Thompson et al., 2022).

Thompson et al.'s study had several strengths that support the validity of the results. There were equal numbers of participants from the 28 hospitals in NZ. The sample size was powered to detect disparities in outcomes for non-Europeans collectively and for Māori. Lastly, the study removed the confounding variables of age, sex, severity of stroke type, and pre-morbid level of function. Although this study found

that Māori were not receiving some hospital interventions, there are still no definitive reasons why Māori stroke patients have worse long-term outcomes than Europeans.

Two studies have examined the perspectives of staff and patients on the barriers to stroke service access (Harwood et al., 2022; Thompson et al., 2022). One study surveyed 51 consumers and 41 staff who worked in various stroke services across NZ (Thompson et al., 2022). The other study conducted 10 focus groups across NZ in urban and non-urban settings. In total, there were 34 people with stroke and 13 family members, of whom 19 were European, 9 Māori, 3 Pacific, and 2 Asian (Harwood et al., 2022).

There were several similar findings from these two studies. The first was the need for more support after discharge. Consumers identified problems with receiving timely follow-up from community rehabilitation services, difficulty accessing speech therapy, not having information on community services and not being able to ask questions related to their stroke recovery (Harwood et al., 2022; Thompson et al., 2022). Staff also agreed that community rehabilitation needed to improve and considered that lack of funding for staff and services was a barrier for patients accessing community rehabilitation (Thompson et al., 2022). The second area discussed in both studies was the need for better services for patients under 65 years who wanted to return to work and driving (Harwood et al., 2022; Thompson et al., 2022). One study identified the lack of Māori and Pacific staff employed in stroke services (Harwood et al., 2022). This was considered important to patients as it was felt their presence would improve their comfort and safety levels.

The strengths of Thompson et al.'s (2022) study were the inclusion of stroke rehabilitation staff and patients with stroke and their families. Similar views from both groups increase the validity of the claims that in some parts of NZ, community rehabilitation is difficult to access, and there are problems with follow-up and a lack of services to return patients to work and driving. The findings may have been biased by having more staff participants who represented inpatient services ($n = 12$ from the acute setting; $n = 5$ from the inpatient setting; $n = 8$ from the community setting) and more consumers who lived in urban settings compared to non-urban settings (Urban, $n = 40$; non-urban, $n = 13$). In contrast, the strength of Harwood et al.'s (2022) study was that the focus groups evenly represented urban and non-urban settings, but the depth of data generated on CSR was limited as participants were asked to comment on all the stroke rehabilitation services they received.

To this point, this section has identified gaps in service provision for CSR in NZ. From the literature on regional and national stroke services, there have been improvements over the years, as the number of CSR services has increased over the country, and most services are meeting the NZCGSM 2010 recommendation of providing 1 hour of therapy per day in acute, inpatient, and community rehabilitation settings. The gaps identified are the possible 13.6 days delay between hospital discharge and starting community rehabilitation (Thompson et al., 2019), with over half of the community rehabilitation

services not following the NZCGSM 2010 guideline to continue to provide services until patients achieve their goals, rather than finish the service at an arbitrary time. Nationally, there are lower staff numbers for psychological support compared to other rehabilitation staff, and it is unclear whether the current levels of psychological staff are sufficient to meet patient needs. In addition, psychological issues may not be identified due to 22% of services not providing routine screening of cognitive impairment and only 33% using a validated cognitive assessment. Māori and Pacifica functional outcomes are significantly poorer than Europeans at 3- and 12-months post-stroke, and the reasons for this continue to be unclear. Staff and patients have identified the following service gaps: inconsistent follow-up at discharge, the lack of services for patients wishing to return to work and driving, low levels of Māori and Pacifica staff, and a lack of services to address information needs.

Stroke intervention gaps found internationally

This next section reviews the international literature regarding the provision of specific interventions in CSR. The four studies reviewed were conducted in Australia, Canada, and the United Kingdom, which have publicly funded health systems similar to NZ. Consequently, the findings of these studies may apply to community rehabilitation in NZ.

Three intervention areas have been studied: upper limb therapy, cognition, and outdoor journeys (Connell et al., 2014; Korner-Bitensky et al., 2008; Korner-Bitensky et al., 2011; McCluskey et al., 2015). Three different methods were used: an online survey of occupational therapists and physiotherapists in hospital and community services (Connell et al., 2014), phone surveys of hospital and community occupational therapists responding to a fictional case study (Korner-Bitensky, Barrett-Bernstein, et al., 2011), and an audit of medical records of patients receiving community rehabilitation from occupational therapists and physiotherapists (McCluskey et al., 2015).

In all the studies, it is evident that therapists were not following stroke guidelines. Prior to the 2014 online survey on upper limb therapy, the Intercollegiate Stroke Working Party (2012) recommended that patients with some arm movement should practice arm activities within their capacity. However, from 295 participants, of which 35.6% were therapists working in community rehabilitation, 64.7% said they would provide upper limb therapy, and of this group, 46.8% would provide range of motion exercises, 21.3% repetitive task practice, and 13.8% strengthening exercises (Connell et al., 2014). It is concerning that one-third of therapists would not offer therapy, and of this group, 46.8% would offer a passive intervention where patients were not using the available movement in the upper limb. Concerning cognition, the *Canadian Best Practice Recommendations for Stroke Care* (Lindsay, 2010) recommended that all stroke patients should be screened with a standardised cognitive assessment, and where indicated, patients with cognitive impairment should be offered treatment. However, from a sample of 227 Canadian community rehabilitation occupational therapists, only 31.3% identified a cognitive issue in

a fictional case study, 80.2% would use a cognitive assessment, but only 44.9% would use a standardised cognitive assessment, and 50% would offer cognitive intervention (Korner-Bitensky et al., 2011). This same pattern of not following stroke guidelines is apparent for outdoor journeys. The *Australian Clinical Guidelines for Stroke Management* (National Stroke Foundation, 2010) recommended that people who have difficulty with mobility or using transport services should be offered multiple tailored escorted outdoor journeys, equipment, and information about transport options. It was found from 76 patient records audited from five community rehabilitation services that the mean outdoor journeys offered to patients was 2.0 ($SD = 2.7$) (McCluskey et al., 2015). Although these studies have highlighted gaps in stroke provision intervention for therapy for upper limb, cognition, and outdoor journeys, they do not identify why these interventions were not conducted. As these studies were based in similar health services to NZ, it is reasonable to assume that recommendations for community rehabilitation from the NZCGSM 2010 and more recently Clinical Guidelines for Stroke Management (Stroke Foundation, 2022) are not being followed.

The review of the literature has found that people continue to have problems after hospital discharge for ADL dependency, fatigue, impaired cognition, and participation loss. Due to the varied health disciplines that comprise a community rehabilitation team, CSR services are uniquely qualified to address these problem areas. Although this review has found gaps in community rehabilitation service provision in NZ and internationally, no studies have evaluated whether patients within a regional community stroke service receive interventions for common stroke problems as identified in the EICSS. In addition, no studies have explored why or why not interventions are provided. Without this information, community stroke services have no feedback on whether they are providing the range of interventions necessary to promote recovery after stroke. Consequently, this study was initiated to identify the frequency of interventions so that managers and staff can take steps to improve services.

Summary

This section has summarised evidence that supports the need for ESD and community stroke services. Early-supported discharge, compared to hospital rehabilitation, reduces the average hospital stay by 6 days and significantly reduces the likelihood of death, institutional care, and dependency for patients with mild or moderate stroke. However, qualitative studies have found that patients and stroke survivors find it difficult to transition to other forms of rehabilitation after the service has finished. There is strong evidence that patients receiving CSR (less or more than 6 months) have greater improvements in physical function compared to outpatients, day hospital, usual care, health education, or no treatment.

From the quantitative and qualitative research, the lives of carers of stroke survivors are significantly impacted by emotional distress, financial burden, and reduced social contact. The degree of impact depends on the level of unmet needs of the stroke survivor, specifically if they have a higher dependency

on ADL, emotional needs, and cognitive impairment. Carers report that they are not prepared for the caring role, and the individual's capacity to care for a stroke survivor is not assessed, nor are they provided with ongoing support.

Patients with either moderate or severe stroke make the most ADL gains in the first 4 months after stroke onset and continue to improve for up to 18 months (Lee et al., 2022). It has been found that the most significant recovery for patients with moderate stroke occurs from onset to 6 months and for severe stroke from onset to 3 months and from 6–18 months. In contrast, it has been found that 16.3% of patients who were independent at dressing, toileting, and indoor mobility at 3 months became dependent at 12 months (Ullberg et al., 2015). These results challenge the traditional view that community stroke services should end at 3 months. Continued or intermittent stroke rehabilitation may increase the rate of ADL independence and prevent deterioration of ADL.

This review has also found that fatigue, cognitive impairment, and depression are highly prevalent 1 year after stroke. From two large systematic reviews, the prevalence rate in studies using the Fatigue Severity Scale at 12 months was 46.79% (Zhan et al., 2022) and 47.44% (Alghamdi et al., 2021). The prevalence of cognitive impairment varied depending on stroke severity. The prevalence rate was 38% when excluding patients with dementia, recurrent stroke, or previous cognitive impairment (Sexton et al., 2019) and increased when these patients were included to 53.4% (Barbay et al., 2019). The prevalence rate for depression is still unclear, with different systematic reviews reporting 27% (Liu et al., 2023) and 33.5% (Mitchell et al., 2017). Factors associated with an emotion or mood disorder are past family history or personal history of depression, aphasia, and a lesion in the left hemisphere.

Lower engagement in participation after a stroke has been associated with impaired cognition, higher stroke severity and depression (Castagnoli et al., 2023; Tse et al., 2019). Four studies found patients with mild and moderate stroke had reduced engagement and loss of leisure, domestic, work, and social activities 1 year after stroke (Adamit et al., 2015; Castagnoli et al., 2023; Reeves et al., 2022; Tse et al., 2019).

Overall, this section has identified that stroke has significant impacts on stroke survivors and carers due to ADL dependence, fatigue, impaired cognition, depression, and loss of participation. These are all areas where CSR has the potential to make a positive difference. Currently, there is no structure or system by which health managers and CSR staff can identify where therapists are providing interventions that align with the current stroke guidelines. Without knowledge of the type and frequency of interventions that are provided, evaluating and continually improving the quality of service provision for patients receiving CSR is difficult.

Chapter 3: Methodology

Introduction

This chapter will explain mixed methods research and how it differs from traditional research methods. Following this, I will discuss how the philosophical ideas of pragmatism developed by John Dewey support the development of the mixed methods approach. After this section, I acknowledge the debate on whether pragmatism is a research paradigm. I also explain how the post-positivist and constructivist paradigms have been used in this research project. I then discuss the characteristics of mixed methods research and the sequential explanatory design that guides the present research. I explain how the strengths of both quantitative and qualitative methods were used to address the research questions and how the data were integrated using the guidelines for sequential explanatory design. I conclude this chapter by explaining the benefits and limitations of mixed methods research as they impact this research project.

Mixed methods research

Mixed methods research occurs when qualitative and quantitative methods are jointly used to answer one or more research questions. This approach is typically chosen when the researcher decides that using both quantitative and qualitative methods can better answer the question than either alone. The research process follows the procedures linked to a chosen quantitative or qualitative method but integrates the research process at various points (Creswell et al., 2011). When using this approach, researchers need to justify how each approach's strengths will help answer the research question (Morgan, 2014a).

A philosophical framework or paradigm usually guides research. This term was first defined by Kuhn (1922–1996) as “an agreed upon theory, worldview or methodology embodied in the beliefs, practices and products of a group of scientists” (Johnson & Gray, 2010, p. 14). The term was further developed by Guba and Lincoln (1994), who said an inquiry paradigm was defined by three fundamental characteristics and interlinking questions: (i) ontology: what is considered reality and what can be known about it? (ii) epistemology: what is the relationship between the inquirer and what can be known? and (iii) methods: how can the inquirer determine what they believe can be known? The answer to any one of these questions constrains how the others are answered.

To understand how the mixed methods paradigm is unique from other paradigms, the next section will outline the post-positivist and constructivist paradigms.

Post-positivist ontology proposes that there is an objective reality that is independent of us. Although it can be observed and experienced, we cannot be completely sure we are correctly representing it. Post-

positivist epistemology posits that natural laws can predict behaviour and can be generalised to other contexts. As knowledge is socially constructed, it is subject to error and bias. Consequently, researchers make efforts to be as neutral as possible throughout the research process. To reduce measurement error, the researchers use techniques that improve the reliability and validity of the results. The method is guided by the development of a hypothesis on the factors that may predict a particular outcome and by testing the hypothesis to show if it is verifiable or false (Appleton & King, 2002).

In contrast, within constructivist ontology, reality is understood to be unique to every person, whereby we create our reality through our social relationships and experiences. Our reality changes depending on our context and the social contacts we have; consequently, many realities can exist simultaneously. Constructivist epistemology holds that knowledge is developed by understanding the meaning of social interactions and the researcher coming to a consensus view of reality, but also acknowledging different views of reality. Greater emphasis is placed on the researcher interpreting the data, which is justified by the belief that knowledge gained from social interaction between the researcher and the participant is considered a “truth” or a valid version of reality (Pryce et al., 2014). Constructivism rejects the idea that there are linear causes for events as it proposes that many influences shape what is occurring. At best, the results represent a “slice of life” at a certain moment in time. Consequently, it is not possible to generalise research findings to other settings. Instead, the researcher provides rich descriptions so the reader can assess whether the findings can be applied to their context (Pryce et al., 2014). Constructivist methods include in-depth interviews, focus groups, and observations. After developing extensive familiarity with the data, the researcher uses inductive analysis to compare, categorise, and generate patterns or themes (Appleton & King, 2002).

Both post-positivism and constructivism ideas are generated from a dualistic view of reality by accepting that objects have their own reality that is separate from us or where reality can only be known subjectively by the individual.

The philosophy that supports mixed methods research

Mixed methods research was first recorded in a methods text in 1935 (Fry, 1934, as cited in Johnson, 2010). Its development can be supported by the pragmatist philosophy developed by James Peirce, William James, John Dewey, Richard Rorty, and Susan Haack (Johnson et al., 2017). The following section will explain the philosophical ideas of John Dewey and how they support mixed methods research. Russel (1872–1970), a contemporary of Dewey, proposed that all ideas start by experiencing the world through our senses, and from here, we develop ideas to explain our sensory experiences. In contrast, Dewey’s definition of experience has multiple dimensions combining emotions, memories, our interactions with the environment, interests, limitations, and thoughts of future projects (Boisvert, 1998). Experience

cannot be separated into objective conditions and subjective feelings. This means that when we analyse a situation, we should start by understanding people's experiences in all their complexity.

In Dewey's definition of experience, the individual (or living organism) transacts with the environment. This occurs when the individual's or organism's actions change the environment, which, in turn, impacts the individual or organism. As a result, "the living creature undergoes, suffers, the consequences of its behaviour" (Dewey, 1988b, p. 129).

Experience is defined as objects interacting and how we experience these interactions, as "things interacting in certain ways are experience; they are what is experienced. Linked in certain other ways with another natural object - the human organism - they are how things are experienced as well" (Dewey, 1929, p. 4). The term "experience" is further defined as what humans do and how they act, and "it includes what men do and suffer, what they strive for, love, believe and endure and also how men act...in short, processes of experiencing" (Dewey, 1929, p. 8).

To prevent the separation of matter (the natural world) and mind (our subjective view of the world), Dewey recommends that we acknowledge that both these elements are our experience and are consequently linked to nature. Dewey (1929) notes that,

"the only way to avoid a sharp separation between the mind which is the centre of the processes of experiencing and the natural world of which is experienced is to acknowledge that all modes of experience are ways in which some genuine traits of nature come to manifest realisation" (p. 24).

The benefits of acknowledging the link between mind and matter means we may have a greater understanding of "how the outer world can affect the inner world" (Dewey, 1929, p. 10). Thus, we would be able to better "regulate" our experience and there would be "enriched meaning and value in things, clarification, increased depth and continuity" (Dewey, 1929, p. 11).

Regarding epistemology, Dewey rejected the idea that knowledge can only be gained by the human mind interpreting the qualities of objects through our senses. Using this practice meant humans could reduce the interference of the subjective mind, distorting what was being observed. Knowledge was considered already present; it just required the observer's deeper powers of observation. Dewey labelled this view of knowledge as a "spectator view of knowledge" where humans are detached spectators of the objects around us (Dewey, 1984, p. 19).

In contrast, Dewey thought of humans as inquirers, whose investigation of subject matter (object of inquiry) was motivated by a specific goal. Using the word "inquirer" meant that the process of knowing is an active process, where humans manipulate and change the "subject matter", resulting in new knowledge. The process of making art and scientific discovery have common elements, where humans

experiment to achieve an objective guided by a hypothesis or imagination (Dewey, 1984). As described by Dewey (1984):

“What science is concerned with is the happening of those experienced things. For its purpose, therefore, they are happenings, events. Its aim is to discover the conditions and consequences of their happening. And this discovery can only take place by modifying the given qualities in such ways that relations become manifest... and when it's accomplished the scientific object becomes the means of control of experienced things” (p. 84).

Dewey (1988b) recognised that knowledge is constantly evolving, and we should always be open to observing the consequences when applying what we have learned, “intelligence is not something possessed once and for all. It is in a constant process of forming, and its retention requires constant alertness in observing consequences, an open-minded will to learn and courage in re-adjustment” (Dewey, 1988b, p. 135). Consistent with the view that knowledge evolves over time, Dewey (1984) maintained that there is no one fundamental description of reality and that alternative views of reality do not have to be translated or reduced to the same reality. As a result, the subject matter under inquiry may be approached in different ways depending on the objectives of the inquiry and the characteristics of the subject matter. Dewey (1984) states, “to use philosophic terminology each type of subject matter is entitled to its own characteristic categories, according to the questions it raises and the operations necessary to answer them” (p. 172).

Dewey's form of inquiry means that objects of inquiry are situations or problems where we are doubtful or puzzled. To resolve the problem, the inquirer thoughtfully does something to alter the conditions around the problem and achieve harmony. This implies that humans think about what to do before doing something, but thinking alone will not solve the problem; we must act (Boisvert, 1998).

Learning about the relationship between our actions and consequences provides us with rules by which we can control our environment. It allows us to plan and organise our lives, “if we start from primary experience, occurring as it does chiefly in modes of action and undergoing... knowledge contributes – namely the possibility of intelligent administration of the elements of doing and suffering” (Dewey, 1929, p. 22). Without accepting that knowledge comes from our actions, we risk using magical thinking to explain the world around us, “and unless we start from knowing as a factor in action and understanding we are inevitably committed to the intrusion of an extra-natural, if not a supernatural, agency and principle” (Dewey, 1929, p. 23).

Dewey proposed a generic five-step process of inquiry that could be applied to all areas of problem-solving: step 1, recognising a situation is problematic; step 2, defining the problem; step 3, developing a

solution to solve the problem; step 4, evaluating the possible consequences of the proposed action; and step 5, implementing and evaluating the action (Johnson et al., 2017; aMorgan, 2014a). From this process, it is apparent that knowledge is gained from action and reflection (Biesta, 2010).

In contrast to other paradigms where truth is considered a fact that is proven or is unique to an individual, Dewey sees the truth as provisional and the result of action (Biesta, 2010). The strength of a truth is determined by the fitness and relevancy of the concepts used to guide the inquiry and the procedures that are used:

“Its ‘truth’, ...is provisional; as near the truth has as yet come, a matter determined not by a guess at some future belief but by the care and pains with which inquiry has been conducted up to the present time”. (Dewey, 1988a, pp. 56–57)

A unifying concept

A major contribution that supports mixed methods research is Dewey’s view that knowledge is created by making links between our actions and the consequences. This challenges the post-positivist view that true knowledge must be objective and is about how objects *really* are or the constructivist view that knowledge can only be subjective. Instead, different types of knowledge result from different experiences, ways of acting, and consequences. Consequently, the pragmatic paradigm recognises the value of methods that are linked to post-positivist and constructivist paradigms (Johnson et al., 2017).

Following on, the pragmatic philosophy can unify many forms of research if they share the following criteria: it addresses problems, uses Dewey’s five-step process of action and reflection to problem solve, understands the impact of context on the research results, and creates knowledge by finding links between human acts and their consequences (Johnson et al., 2017). This viewpoint recognises that knowledge claims are not finite and may change, and findings will be judged on the quality of our processes and procedures and how well they address the research problem (Biesta, 2010; Johnson et al., 2017).

Does pragmatism fit a traditional paradigm?

There are differing views on whether pragmatism is a paradigm that can guide mixed-method research. In the view of Hesse-Biber (2010), mixed-method researchers should follow a “comprehensive approach to mixed methods” (p. 11). This means the researcher should follow a paradigm in which the researcher follows a certain ontology (beliefs about what reality is), which then informs their epistemology (what knowledge is and how knowledge can be known). These beliefs provide the researcher with their methodology or theoretical perspective that links the research problem to a particular set of methods. The chosen methodology influences what type of research questions are asked and what questions are considered the most important to pursue. In the opinion of Hesse-Biber (2010), a methodological

perspective does not dictate the type of method that is used. Consequently, researchers following an interpretative or post-positivist methodology can use qualitative or quantitative methods. Methods are seen simply as tools, but to use them wisely in mixed methods research, the researcher needs to be aware of their methodological standpoint so that they consciously guide the organising framework and ensure they follow the correct procedures for each method that is used (Hesse-Biber, 2010).

However, Morgan (2014b) differs from Hesse-Biber (2010), as he believes pragmatism is “a new paradigm for social research, that replaces the older philosophy of knowledge approach” (p. 1045) and therefore does not require an ontology, epistemology, and methodology. Morgan states that Dewey’s philosophical beliefs underpinning pragmatism reject the traditional philosophy of knowledge, whereby the nature of reality determines what kind of knowledge is possible. Instead, following Dewey’s lead, researchers are interested in people’s experiences that are influenced by a unique context. In doing so, we are finding out about people’s beliefs that drive their actions and the consequences of those actions. To address problems, Dewey proposes an inquiry approach. First, the researcher recognises that a situation is a problem. The researcher then considers the difference it will make to define a problem in a particular way rather than another, and the potential consequences of any action are evaluated. Lastly, an action is taken and then evaluated to see if it addresses the problem. In this process, the researcher considers what beliefs are behind actions and what the impact of our actions is on our beliefs. Dewey sees all modes of research as a form of experience where beliefs inform actions that result in consequences. Taking this overarching viewpoint, both the constructivist and the post-positivist approaches make equally important claims about the nature of different experiences. This is because researchers in each of these research fields have different experiences, which lead to different beliefs and actions. Consequently, a researcher using a pragmatist philosophy is not tied to following a particular ontology and epistemology but sees traditional paradigms as approaches to inquiry used in different contexts and with different standards of inquiry, resulting in different types of knowledge. Researchers who use pragmatism philosophy use an active process of inquiry to examine the relationship between beliefs, actions and their consequences (Morgan, 2014b).

The characteristics of mixed methods research

Mixed methods research is defined as a “type of research in which the researcher combines elements of qualitative and quantitative research approaches (e.g., the use of qualitative and quantitative viewpoints, data collection, analysis, and inference techniques) for the broad purposes of breadth and depth of understanding and corroboration” (Johnson & Onwuegbuzie, 2007, p. 123).

Creswell et al. (2011) state that mixed methods research has the following characteristics: a visible philosophical and theoretical base, the use of multiple methods and the intentional combination of methods that maximise the strengths of each method.

Mixed methods designs are most appropriate for research questions where a quantitative or qualitative approach is inadequate to provide a complete understanding of the issue, when it is important to have an understanding of the real-life context surrounding an issue, and when it is necessary to use diverse strategies to address complex issues (Creswell et al., 2011).

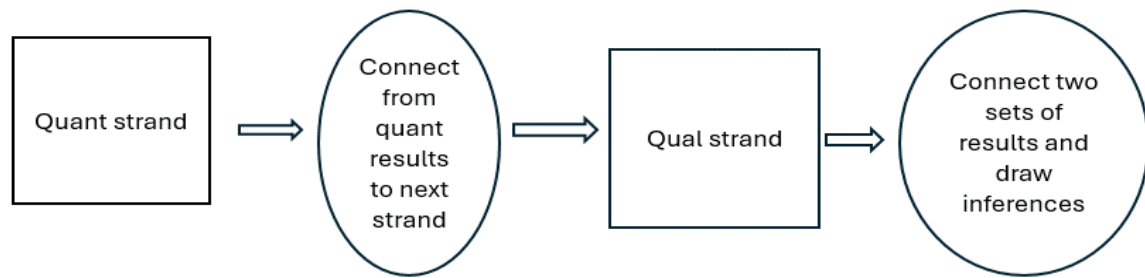
The purpose of mixed methods is to gain a greater understanding of an issue by using the strengths of each contributing research method while minimising their weaknesses (Johnson & Onwuegbuzie, 2004). This is based on the premise that a single quantitative or qualitative study cannot capture all the dimensions that could contribute to answering a research question.

Sequential quantitative to qualitative explanatory design (quant → QUAL)

Sequential quant → QUAL design in mixed methods was defined by Plano Clark and Ivankova (2016) as a “design in which researchers implement the quantitative and qualitative strands in sequence to use the qualitative data to elaborate, explain or confirm initial quantitative results” (p. 3). The notation above indicates that the quantitative study was done before the qualitative study and the capital letters indicate that the qualitative study was the priority study and the quantitative study was the supplementary study. Priority is determined by the importance of each study to the overall purpose of the research. The supplementary study explicitly serves the purpose of the core method (Morgan, 2014a). In this project, the decision to make the qualitative study the core study was taken as it was hoped that the qualitative study would uncover the reasons for any patterns observed in the intervention data, and this information could be used to improve the provision of community stroke interventions. It was hoped that the knowledge gained from this study might influence decisions about staff training, staffing mix, and the organisation of services. It was decided that the quantitative study was the supplementary study as no data had been generated on the frequency and type of interventions provided to patients receiving CSR before this study. The results from the quantitative study would address this knowledge gap and form the basis of the interview questions for the qualitative study. This demonstrates that this project used a strength of the quantitative method as it presumed that the quantitative results would be objective and reliable, and not be influenced by bias.

Figure 1 illustrates the sequential quant → QUAL design by Plano Clark and Ivankova (2016), where by the quantitative results from the first study inform the design of the following qualitative study. The qualitative and quantitative results are then integrated, and inferences are drawn on the meaning of these combined results.

Figure 1 *Sequential quant to Qual mixed methods design*



How the strengths of quantitative research methods were used

Study 1 used quantitative research methods to gather and analyse observational data to address the following research questions:

1. What are the patterns of community stroke rehabilitation interventions in Auckland?
2. Do CSR interventions address the scope of patient problems identified by the EICSS?
3. Are there differences in the type and frequency of interventions provided to Māori and non-Māori?

The numerical data obtained from the study allowed a comparison of DHBs and health discipline interventions provided to Māori and non-Māori interventions. This form of quantitative method can help identify patterns and associations that may otherwise be hidden (Maxwell & Mittapalli, 2010). Due to random sampling techniques and the use of reliable procedures, it is possible to generalise results (Creswell et al., 2011) to other similar health services in NZ and across the world. However, quantitative research may have limited use when a phenomenon has not been researched before, and there are no measures to test or measure the phenomenon (Creswell, 2013). This limitation was present in this study, as no measures or methods had been developed to identify and select rehabilitation interventions from patient notes. Consequently, Study 1 used an untested method to find the type and frequency of interventions from patient notes.

Study 1 was an observational, retrospective, descriptive case series/control study (Talari & Goyal, 2020). It was considered an observational retrospective study, as the intervention target data was collected from patient notes several years after the patient had completed their rehabilitation and had been written by health professionals without any outside influence from myself as the researcher. This was a case series study as intervention targets were extracted from each patient's clinical record from the start to the end of the rehabilitation period with the CSR service. Compared to a study where participants are instructed to record interventions for research, a retrospective study removes the risk of bias when participants,

intentionally or not, may record interventions that were not provided (Mann, 2003). Using a quantitative method to extract intervention targets to see the type and patterns of interventions is a more reliable method than obtaining this information from an interview (McEvoy & Richards, 2006). This is because more recent memories of interventions may impact staff memories of interventions in the past, and staff may not be aware of any shift in intervention patterns over time. Retrospective studies using secondary data have the added benefit of being able to collect data from a high number of cases (or patient files). This means such studies have a better chance of gathering accurate prevalence data and improving the generalisability of the findings (Mann, 2003). A final consideration related to the reliability of data extraction was that having a single person to collect the data, rather than several researchers, was expected to achieve greater consistency in data extraction and coding.

There are several limitations when using a retrospective observational design. Firstly, there may be issues not recorded in the notes that caused differences in stroke interventions across services or individual records. For example, there might have been an underlying condition or emotional issues that made it difficult for the patient to participate in treatment. Also, as the data were not collected using a predesigned template, some data may have been missed (Talari & Goyal, 2020).

When this research was started there was no formally recognised terminology to categorise patient interventions. Consequently, in this observational study, rehabilitation intervention targets documented in 113 patient files were extracted and linked to the EICSS. The linking of intervention targets to the EICSS has an acceptable degree of face validity as it is a recognised system used previously to capture stroke interventions (Evans et al., 2017). Since this time WHO has developed the International Classification of Health Interventions (ICHI) (Fortune et al., 2018).

However, there were several disadvantages to categorising the intervention targets to the EICSS. Firstly, the results depended on my understanding of what comprised an intervention target. and secondly, the linking process of the intervention to the EICSS categories could be influenced by my interpretation of the intervention target and the matching code. Consequently, it was necessary to evaluate the reliability of selecting intervention targets from patient notes and coding them to the EICSS. To address this, a sub-study was conducted to evaluate the reliability of selecting and coding intervention targets to the EICSS.

How the strengths of qualitative research methods were used

A qualitative research method of conducting in-depth interviews with CSR staff was used to answer research question 4: "What are the CSR therapists' explanations for the patterns of interventions found in Study 1?". Qualitative research methods can explore the meaning of human experiences and the processes that underpin actions. The interpretation of observations enables the researcher to develop new theories or hypotheses to explain behaviour and suggest strategies that can change behaviour (Creswell et al., 2011; (Morgan, 2014a). By using in-depth individual interviews it is possible to explore a

range of factors relevant to the topic, and to unpack complex concepts and relationships that are unlikely to be found by standardised quantitative measures (Maxwell & Mittapalli, 2010). Qualitative research cannot test hypotheses, and results cannot be generalised to a larger population due to small sample sizes (Palinkas & Cooper, 2017).

In the case of this research, the quantitative inquiry would help identify clear and consistent patterns of practice, which could then be confirmed and elaborated by the qualitative study.

The interviews allowed me to explore the participants' views about the intervention patterns. It was a strength to use a summary of the quantitative results in the qualitative interviews, as solely relying on the participants' reports could have resulted in participants reflecting on critical incidents or their most recent experience rather than seeing patterns over time. They might also be influenced by the dynamics of the research interview and feel pressured to say "the right sort of things" (McEvoy & Richards, 2006, p. 74). Therefore, participants' comments on the reasons for patterns in the data may have been seen as less trustworthy. In contrast, asking participants to comment on independent data makes it possible to determine whether there is a corroborative link between the data and the participants' comments.

How the studies were integrated

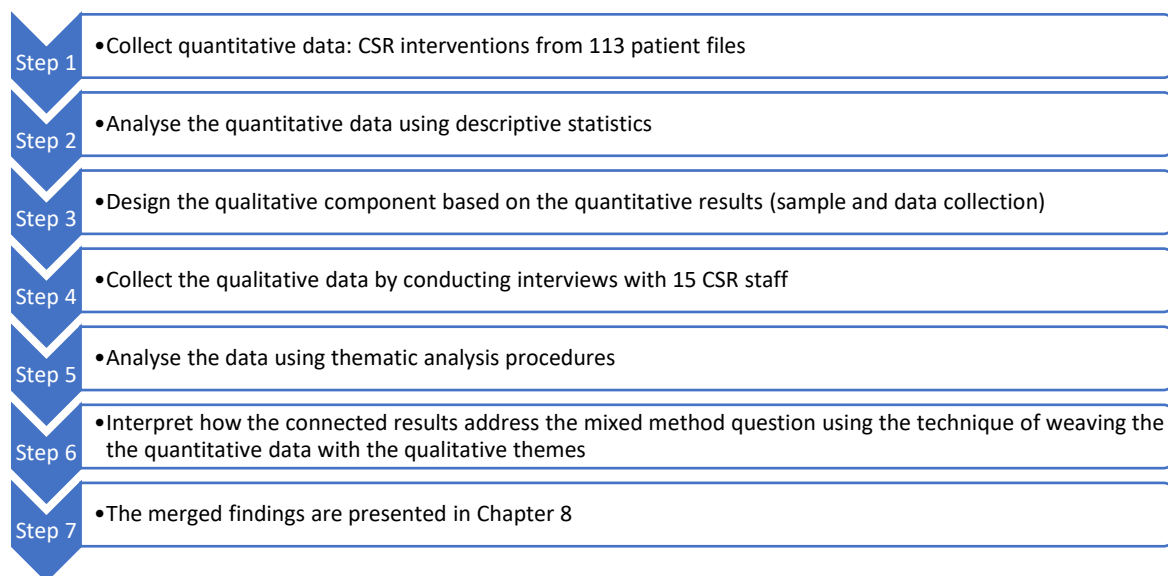
The next section will explain how the data from both studies were to be analysed and integrated. In mixed methods research, various studies can be integrated with the design, methods, and interpretation phases (Fetters et al., 2013). In this study, integration in the methods phase was conducted using the process of "connecting", which means the findings of the initial study can influence the sampling strategy of the second study (Curry & Nunez-Smith, 2015; Fetters et al., 2013). In this case, for Study 2, I recruited a representative sample of CSR staff who provide CSR services and who report their interventions in patient files. The participants for Study 2 represented a range of health disciplines from the three CSR services from which the original data were sourced. True to the constructivist ontology of the qualitative study, participants presented unique perspectives on the accuracy of the results from Study 1 and the reasons why or why not specific interventions were provided. Due to the time that had lapsed between Study 1 and Study 2, only one staff member in Study 2 was present during the period when the data were collected for Study 1. As other factors had remained constant, including the incidence and presentation of stroke, the knowledge base the rehabilitation professions draw on, the professions represented in the community rehabilitation teams, and the structure of services, it was assumed that their interpretation of the findings from Study 1 would have veracity in the context they were generated.

Another form of connecting (known as building) is when the results of one data procedure inform the data collection approach in a subsequent study (Curry & Nunez-Smith, 2015; Fetters et al., 2013). This technique was used as the findings from Study 1 were presented as graphs showing the intervention patterns for each CSR service. The graphs were shown to participants in Study 2 and the general patterns

across the data formed the basis of the interview questions. The last form of integration was in the interpretation phase and was completed after the analysis of both the quantitative and qualitative studies. In this phase, the findings were interpreted as a whole, and comparisons were made across the data set to look for convergence and divergence (agreement or disagreement) and for complementary findings (findings that are unique from one data set) (Curry & Nunez-Smith, 2015; Fetters et al., 2013). This was achieved by merging the findings in a narrative approach (termed weaving), which is defined as “organising the quantitative and qualitative finding according to a unifying or recurrent themes or constructs” (Curry & Nunez-Smith, 2015, p. 14). Consequently, in this study, the findings from Study 1 and Study 2 were merged by reporting how they were convergent, divergent, and complementary to the themes generated in Study 2. A summary of the steps involved in this study is presented in Figure 2.

Figure 2

The mixed methods steps used in this study adapted from Curry and Nunez-Smith (2015, p. 11)



Benefits and limitations of mixed methods

The most important limitation of mixed methods research is the need for the researcher to be familiar with more than one research method and have the knowledge of how to integrate the methods appropriately. In addition, mixed methods research may be more time-consuming and more expensive than a single-method study (Johnson & Onwuegbuzie, 2004). When using sequential designs, it can be difficult to interpret the data from two data sets if unequal emphasis is placed on one data set over the other, when the data are inaccurate, or when there are questions about combining the philosophies related to each qualitative and quantitative method Creswell et al. (2011).

One of the major advantages of mixed methods research is the ability to collect both quantitative and qualitative data and use the strengths of each method to answer the research question (Creswell et al.,

2011). In addition, looking at an issue from multiple perspectives allows the researcher to contextualise the data (Creswell et al., 2011). In this case, it allowed me to ask the reasons for the intervention patterns from the participants who provided interventions in the same community services that provided the quantitative data. Using a quantitative and qualitative study allowed a more complete understanding of why interventions were provided. It also improved the strength of the outcome as only results that were common across both studies were reported.

Chapter 4: Method for Study 1

The study aimed to describe the type and frequency of intervention targets provided to community-living stroke survivors by the CSR services of three Auckland DHBs. Quantitative analysis of the data gathered would then inform data gathering with participants in Study 2.

Study design

Study 1 was designed to answer the following research questions:

1. What are the patterns of community stroke rehabilitation interventions in Auckland?
2. Do CSR interventions address the scope of patient problems identified by the EICSS?
3. Are there differences in the type and frequency of interventions provided to Māori and non-Māori?

To answer these questions, this study used a retrospective observational design where intervention targets were extracted from electronic patient notes written by CSR staff between 2016 and 2017.

An observational descriptive design was chosen as observational research does not evaluate interventions but instead aims to “accurately portray the characteristics of a particular individual, situation, group sample or population and/or to describe processes that operate within a particular milieu”(Palys & Atchison, 2008, p. 40). Descriptive research aims to systematically represent the phenomenon of interest. This may involve identifying how often a variable occurs, its distribution in the population, who is involved, and the processes by which the variable of interest is produced (Palys & Atchison, 2008). Descriptive study designs can establish disease frequency and patterns in a population, and this information can contribute to health policy and planning (DiPietro, 2010). In this study, the data will establish what interventions CSR services provide to inform health service provision.

Sample size

As the study aimed to describe the incidence of intervention rather than analyse the relationship between variables, it was important to select a sample of patient notes representative of the population receiving CSR (Mann, 2003). Inquiries were made to each DHB on the number of people who received CSR from March 1, 2016, to February 29, 2017. Counties Manukau DHB had records for 401 people, Auckland DHB had records for 149, and Waitematā DHB had records for 42, which resulted in a total of 592. Two of the services provided 12 weeks of stroke rehabilitation for patients with mild, moderate or severe stroke (Counties Manukau and Auckland DHB) and one service provided 6 weeks of intensive rehabilitation for patients with mild to moderate stroke severity (Waitemata DHB). Audit research examining adherence to stroke guidelines in the acute setting has previously used a sample of 17%

(Johnston et al., 2013) and 16% of the total number receiving an inpatient service (Luker & Grimmer-Somers, 2009). Based on these figures and using the previous studies as a guideline, the sample size chosen was 17% of the total number who received CSR in Auckland over the target period. This meant the total sample size should be 100 patient files selected proportionally from each of the three DHBs. The final number of patient files selected was 113 (19% of the total yearly number of CSR patients).

Sample criteria

Before selecting a random sample from each DHB, I asked the DHB hospital statistician to identify potential patient files based on the following criteria: over 55 years old with a primary diagnosis of stroke who received CSR from a 12-week CSR service or a 6-week ESD service in Auckland from March 1, 2016, to the end of March 2017. A criterion of primary diagnosis of stroke was chosen to ensure all the interventions were related to stroke rehabilitation. Patient files were excluded if the patient only received outpatient stroke rehabilitation or was discharged to residential care.

To address research question 3, the principle of equal explanatory power informed the sampling method (Wellington School of Medicine and Health Sciences, 2002). This meant that I aimed to have an equal number of Māori and non-Māori participants rather than a sample size based on the proportional numbers of Māori in the population. This is because a sample based on the proportion of people living in a country produces research outcomes that reflect the impact of a variable on the largest ethnic group and not the impact on minority ethnic groups. In this research, there were insufficient Māori patient files to achieve equal numbers of non-Māori in each DHB. Consequently, it was decided to compare Māori and non-Māori data in the DHB with the highest number of Māori patient files. To maximise this data source, all the available Māori patient files in the specified period were used for the research.

The patient record staff member within each DHB provided a list of anonymised patient file records that met the criteria of the study. I randomly selected the patients for the study by selecting every third patient file from this list until the desired number of files was reached for each DHB. Each patient file was then given a number.

Ethics

Study 1 involved collecting retrospective patient data from potentially identifiable medical records from three CSR services in Auckland without the patient's knowledge or consent. According to the National Ethics Advisory Committee (2012), this is permitted under certain criteria. This next section highlights the criteria in italics and the actions that were taken to meet these criteria.

1. *Access to medical records should be restricted to appropriately qualified investigators and their associates.* As an occupational therapist who has worked in CSR, I understand the rationale for the stroke interventions being written in patients' notes. In addition, I was very familiar with the process of

extracting intervention targets as it was the method used in a prior research study I had conducted. To protect the privacy and confidentiality of patients, digital patient files could only be accessed by accessing the files from a computer situated within the hospital of each DHB. In addition, I was not permitted to take a digital or hard copy of any patient file off-site. For the inter-rater reliability study, I gained amended ethical approval to take a copy of 10 patient files, and after the study, these files were destroyed in a paper shredder.

2. Confidentiality and privacy requirements are met. Research supervisors, the ICF expert who assisted with the inter-rater reliability, and I signed a confidentiality agreement stating that patient information would only be discussed during supervision sessions and research meetings and that no patient or staff names would be used.

3. When using Māori patient files, a kaitiaki group should be consulted. The researcher gained approval from the Māori ethics group at Waitematā DHB to ensure the use of Māori health data would be of benefit to Māori (Appendix A).

4. Using potentially identifiable patient data without the patient's consent will pose no risk to the patient. Patient names and patient files were stored on a password-protected USB drive. The USB drive was stored in a locked cupboard at my place of work. Once the study was completed, the USB drive was destroyed. Each patient's name and file number were replaced with a unique code in all outputs. As all the data produced from this study was numerical, no patient or staff member will be identifiable in any future publication or presentation.

5. It may be ethical to collect patient information without consent when research auditing clinical practice has the intention of improving health delivery.

From the research results, it will be possible to determine if people are receiving the full range of stroke interventions and whether there are differences in intervention targets for Māori and non-Māori. At the completion of the research, relevant findings will be communicated to the service managers of the participating DHBs. This information may be used to review services to better meet the needs of people with stroke and may generate more ongoing education for staff members employed in CSR.

Ethical approval for this study was gained from the Health and Disability Ethics Committee on December 11, 2017, reference number 17/CEN/244 (Appendix B). The ethics application was amended so that 10 patient records could be copied and shared with another researcher for the inter-rater reliability study. This amendment was approved on February 18, 2019, reference number 17/CEN/244/AM03 (Appendix B).

Selecting intervention targets from patient notes

I considered an intervention to be any activity in the home or community conducted with the patient or any administrative activity to access equipment funding for the patient carried out by a health professional or student in the CSR team. The following activities were not considered interventions: assessments, meetings, referrals, and phone conversations with the patient, family, or another health professional. The selected interventions from each patient's digital notes were copied and pasted into an Excel spreadsheet that had the following column headings: the patient's allocated number, the treatment session number, the date of the session, the health professional providing the intervention, and intervention target (indicated by the heading RH). Each new intervention target was added to the spreadsheet and numbered by the column titles of RH1, RH2, and RH3. Each RH column had two associated columns titled standard name and ICF code. The standard name column and the ICF code column had preprogrammed information with the target functions of the extended ICF and the ICF codes. This column was designed to improve the speed and consistency of coding as I used the drop-down menu and scroll function to select the standard name that best described the intervention target, and this automatically populated the next column with the ICF code. The list of standard-name interventions and the linked code had been developed before the research started and was based on the findings of an earlier study (Evans et al., 2017). It was possible to change and add to the standard terms and linked codes if mistakes in coding were identified or if new intervention targets needed to be added to the standard term list (see the complete list in Appendix C).

As the main intent of the research was to identify the type and frequency of intervention targets, I decided not to code interventions to other classification categories in the ICF (World Health Organization, 2001), such as body structures, qualifiers indicating performance and capacity, or environmental factor barriers and facilitators. As personal factors have not yet been fully incorporated into the ICF, interventions linked to the patient's personal factors were not selected and coded.

Processes to improve reliability

Extracting intervention targets and linking them to the EICSS is not a standardised process. The quality of intervention extraction and linking the intervention to an ICF code is influenced by the researcher's ability to accurately execute the following steps: identify an intervention, interpret the targeted outcome of the intervention accurately, and consistently link the target of the intervention to an ICF code. The following section will review the reliability of these steps.

The coding guideline (Appendix D) guided difficult coding decisions and was continually updated with new coding decisions throughout the coding process. Changes were made to this document based on the feedback from an expert coder, intra-rater reliability checks, feedback from CSR staff, and an inter-rater

reliability study (reported in Chapter 5). The coding document improved the coding consistency as it was used to review the data on the Excel spreadsheet, and any linked intervention codes that did not match the coding guideline were corrected. The following sections outline the various methods used to improve reliability: an initial check of coding from five patient files, CSR physiotherapy staff checked coding of physiotherapy interventions, an intra-rater reliability check of eight patient files, and an inter-rater reliability study of 10 patient files.

After the initial coding of five patient files, an expert coder familiar with the ICF checked the accuracy of linking the intervention target to an ICF code in a sample of interventions and coding. The aim was to check the accuracy of the ICF codes linked to the extracted intervention targets. The data were sequenced by ICF code, which effectively grouped all interventions linked to a specific ICF code. There were 18 body function codes, 24 activity and participation codes, and 15 environment codes. The expert reviewed this list and identified the codes that differed from her coding, and the expert and I agreed on how these linked codes should be coded. The changes were recorded using the coding guideline, and the full data set was checked for consistency with the consensus decisions.

To check the target function of some physiotherapy interventions, I asked two physiotherapists employed by CSR services to indicate the functional target of 18 interventions taken from patient files. This feedback was added to the coding guideline, and these physiotherapy interventions were reviewed in the data set to align with the coding guideline.

An intra-rater reliability check was completed by repeating the extraction and coding of eight patient files that had previously been extracted and coded. I then compared the two sets of extracted intervention targets and coding for similarities and differences. This analysis found poor intra-rater reliability, as only 46.55% of interventions and codes were the same. Mismatches in coding were attributed to adding or missing interventions, meaning the two data sets had unmatched ICF codes. Mistakes were also caused by selecting the same intervention target but providing a different ICF code. Each error was analysed, and new rules were added to the coding guideline on what was considered an intervention target and how interventions should be coded. The original data set was modified to reflect these changes.

For the inter-rater reliability study, an Australian ICF expert (Catherine Sykes) was asked to independently code 10 patient files I had previously coded. The results were compared and written up in an article that was subsequently published in *Disability and Rehabilitation* on December 6, 2021. The post print version of the article was accepted for publication in *Disability and Rehabilitation* is presented in Chapter 5.

Data cleaning

Before the data were statistically analysed, the Excel spreadsheet was reviewed so that the dates, labels for health professionals, and codes were consistent, and the values and empty spaces were removed. The

Excel spreadsheet was imported into a program written in Python to enable data counting. This transposed the data so interventions were displayed vertically rather than horizontally. Figure 3 shows a sample of the new format for patient files A22 and A23. This example shows that each intervention could be coded to two ICF codes. The intervention “trialled foot pedals for 20 mins, to add to ex prog 10 mins” was subsequently coded to *b7308 exercise* and *e115 product for daily living*.

Figure 3

Screenshot of RH delimiter copy of the data before data analysis

A	B	C	D	E	F	G	H	I	J	K	L	M	N	O
ID	Ethnicity	DHB	th	date	HP	intervention wording	standard term	ICF code	Intervention number	ICF domain	ICF chapter	ICF category 1	ICF category 2	ICF category 3
A22	NM	A	1	24/11/2016	PT	Trialed foot pedals for 20 mins, to add to ex prog 10 mins a c	exercise (strength, endurance, control)-b730	b730	RH1	b	b7	c3	cc0	8
A22	NM	A	1	24/11/2016	PT	Trialed foot pedals for 20 mins, to add to ex prog 10 mins a c	exercise (strength, endurance, control)-b730	e115	RH1	e	e1	c1	cc5	
A23	NM	A	6	19/09/2016	SW	Advanced care planning book provided	making decisions-d177	d177	RH1	d	d1	c1	cc7	
A23	NM	A	6	19/09/2016	SW	Advanced care planning book provided	making decisions-d177	e125	RH1	e	e1	c2	cc5	
A23	NM	A	1	7/09/2016	OT	Advised about fatigue management	mental fatigue, energy and drive functions-b130	b130	RH1	b	b1	c3	cc0	
A23	NM	A	8	20/09/2016	OT	advised on coping strategies (for stress	providing support to decrease stress-d240	d240	RH2	d	d2	c4	cc0	
A23	NM	A	8	20/09/2016	OT	advised to choose a day no one at work	advice on how to return to work-d845	d845	RH4	d	d8	c4	cc5	
A23	NM	A	3	14/09/2016	OT	advised to make all hot drinks	meal making/cooking-d630	d630	RH4	d	d6	c3	cc0	
A23	NM	A	8	20/09/2016	OT	advised to put name tags on cages and recall through day	memory fuction-b144	b144	RH5	b	b1	c4	cc4	
A23	NM	A	#	22/09/2016	OT	advised to remember items on shopping list	memory fuction-b144	b144	RH4	b	b1	c4	cc4	
A23	NM	A	3	14/09/2016	OT	advised to use an alarm on his watch to remind re medicatio	providing a health advice/advice on personal safety,	d570	RH2	d	d5	c7	cc0	
A23	NM	A	3	14/09/2016	OT	advised to use an alarm on his watch to remind re medicatio	providing a health advice/advice on personal safety,	e125	RH2	e	e1	c2	cc5	
A23	NM	A	2	13/09/2016	SP	attempted functional reading, with prompting	reading-d166	d166	RH2	d	d1	c6	cc6	

Note. The column headings signify the following: A = Anonymised patient file code; B = Ethnicity; C = DHB; D = Number of treatment sessions; E = Date of treatment session; F = Health professional providing the intervention; G = Intervention wording from the patient file; H = The standard term to describe the intervention target; I = ICF code; J = Intervention number in that session; K = ICF domain; L = ICF chapter; M, N, and O = ICF category.

Data analysis

Demographic information was extracted and summarised into a table under seven columns and headings: patient age in eight age bands, gender, ethnicity, living circumstances, stroke timing (average days between referral and treatment, average weeks of rehabilitation), stroke type, patients per DHB and number of Māori patients per DHB. The primary outcome was to determine the type and frequency of interventions provided to Māori and non-Māori who received CSR. This was achieved by using the pivot table function in Excel. This function allows the user to separate parts of the data set and combine them in various ways (Katz, 2011). Consequently, this allowed me to select and count different data types from the same data set. For example, it was possible to separate and count the interventions by ICF code, health discipline, Māori and non-Māori, and by service. Following this calculation, counts were turned into percentages and graphs. Chi-square statistics were used to determine whether there were statistically significant differences in the interventions provided to Māori and non-Māori (Domholdt, 2005). As only two DHBs had Māori patients, this calculation used the combined data from Māori and non-Māori patients from these two DHBs. The interventions were amalgamated under the twenty chapter headings of the ICF. The sum and percentage of interventions per chapter were calculated for Māori and non-Māori. The chi-square test of association ($\alpha = .05$) was used to determine whether interventions were equally distributed between the Māori and non-Māori. The chi-square result was compared to the number of people who received these interventions to verify whether it was a significant result.

This study used a retrospective observational design to identify the type and frequency of interventions provided to patients receiving CSR in a random sample of 113 patient files. This figure represented 19% of all the people who had received CSR in Auckland between March 1, 2016, and February 29, 2017. Patient files were chosen if patients were over 55 years old and had a primary diagnosis of stroke. The number of patient files selected from each DHB was based on the proportion of patients who had received CSR from each DHB service from March 2016 to February 2017. To determine if there were differences in the type of interventions provided to Māori and non-Māori, it was originally planned to compare interventions with equal numbers of Māori and non-Māori patient files. However, this was not possible as there was not an even spread of Māori patients across all the DHBs. Consequently, I used all the Māori patient files from one DHB and compared them to non-Māori in a similar 12-week service in another DHB. The exact wording for each intervention was extracted from patient files, and the target function was matched with the intervention and coded to the ICF code. As I was the sole researcher, it was not possible to analyse the reliability of coding; as a result, the following steps were taken to improve reliability: a coding protocol was developed for ambiguous coding decisions, feedback was obtained from an expert ICF coder and physiotherapy staff on a selection of coding and an inter-rater reliability study was conducted with 10 patient files. When there were errors in coding or intervention selection, the whole data set was

reviewed and amended. The intervention frequencies were analysed using Excel pivot tables to extract and sum different parts of the data. Chi-square statistics were used to evaluate the significance of the difference in interventions and the number of people receiving an intervention for Māori and non-Māori. The results were then transformed into graphs showing the total frequency and type of interventions for the 113 patient files, by ICF component, Māori and non-Māori, health discipline and each participating DHB.

The next chapter presents the post-print version of a manuscript describing the processes used to evaluate the inter-rater reliability of intervention selection and coding to the ICF of 10 patient files.

Chapter 5: Reliability of linking data in patient files to the EICSS

Prelude: This chapter is included because it provides an in-depth analysis of the reasons for poor inter-rater reliability when selecting and coding intervention to the ICF for 10 patient files randomly selected from the 113 patient files used for Study 1. In most studies where researchers link interventions to the ICF, two researchers independently code the data and then agree on codes. When there is a disagreement in coding, a third expert coder decides the coding outcome (Jeglinsky et al., 2021; Kohler et al., 2013; Tetzlaff et al., 2020). Although this is the preferable method, it is costly, and this method does not identify areas of poor reliability and how researchers can improve their reliability when coding patient data to the ICF. The analysis of the errors in coding from this study was used to amend and improve the coding of the interventions in Study 1 and, therefore, contributes to the reliability method used in Study 1. It was also hoped that the recommendations from this study will help other solo researchers who wish to use the same methods. The full reference for this publication is:

Evans, M., Sykes, C., Hocking, C., Siegert, R., & Garratt, N. (2022). Inter-rater agreement when linking stroke interventions to the extended international classification of functioning, disability and health core set for stroke. *Disability and Rehabilitation*, 44(25), 8022–8028.
<https://doi.org/10.1080/09638288.2021.2008525>

Abstract

Purpose: To uncover the factors that influence inter-rater agreement when extracting stroke interventions from patient records and linking them to the relevant categories in the EICSS.

Method: Using 10 patient files, two linkers independently extracted interventions and linked the target of the intervention to relevant functions in the ICF. The percentage agreement of extracted interventions and the ICF codes was calculated. Non-matching interventions and codes were further analysed to determine the reasons for poor agreement.

Results: 518 interventions were extracted, with 44.01% agreement between the two linkers. Of the non-agree codes and interventions, 43.79% were due to mismatched ICF codes and 56.20% were due to mismatched interventions. Differences were due to linkers: a) extracting interventions from different parts of the patient note; b) differences in interpreting the target of the intervention; and c) choosing a different code with a similar meaning.

Conclusion: Greater reliability when linking interventions to ICF codes can be achieved by health services using a consistent progress note that uses ICF language, recording the intervention aim,

linkers knowing the aims of each discipline's interventions, and using multiple reliability checks and analyses to inform the linking method.

Introduction

The ICF is the WHO classification system to describe human functioning and relevant environmental factors. It provides a comprehensive coverage of the functions associated with health conditions and definitions for each function and environmental factor. Relating interventions to a common reference framework identifies the health and health-related domains that are addressed by the intervention and enables different interventions to be compared across research studies and rehabilitation facilities (Cieza et al., 2005). This allows services to determine the quality and equity of rehabilitation and identify whether a service is meeting the needs of specific patient groups (Fortune et al., 2018).

Linking rehabilitation intervention targets to the ICF is not common in the literature, and only five studies have used the ICF in this way (Boldt et al., 2005; Evans et al., 2017; Fitinghoff et al., 2011; Klang Ibragimova et al., 2011; Tantilipikorn et al., 2012). In the future, this method will become redundant as researchers will be able to classify interventions according to the International Classification of Health Interventions (ICHI) (Fortune et al., 2018). The development of the ICHI and the digital browser will "support the production of consistently coded data" (World Health Organization, 2020, p. 8). However, there will be a time lag before countries and services adopt the ICHI to record and classify interventions in patient notes. In the interim, researchers can select interventions from free text in patient notes and classify the target function of the intervention using the ICHI browser. Both these processes can cause poor reliability as researchers are required to interpret an intervention from the patient record and select the most appropriate target of the intervention.

The study reported here involved two independent linkers who used the linking rules developed by Cieza et al. (2005) to extract interventions from 10 digital patient records provided by CSR services. The linkers used their knowledge of the ICF and interventions for stroke to link the target function of the intervention to one or more of the 166 categories in the EICSS. The EICSS is validated by physicians, occupational therapists, and physiotherapists and represents the problems most commonly addressed by these professions (Glässer et al., 2011; Glässer et al., 2010; Lemberg et al., 2010). The primary aim of this research was to investigate the inter-rater agreement between two independent linkers when extracting interventions from patient digital records and when linking the target of the intervention to an ICF code. The secondary aims were to analyse factors that reduce inter-rater reliability and make recommendations to improve inter-rater reliability in similar studies. Catherine Sykes was acknowledged as the second author, and her role included coding the patient files and meeting with me after the data analysis stage to come to a consensus on coding for the non-agree interventions and codes found in the study. The third and fourth authors of the article, Clare Hocking and Richard Siegert, gave guidance on the study design

and feedback on drafts of the article. The fifth author, Nick Garratt, provided guidance on the study design and advice on analysing the data.

Methods

Overview

The primary researcher (ME) randomly selected 10 patient records from 113 patient records used in a larger study that explored the provision of CSR to patients living in Auckland, NZ, between 2016 and 2017. The hospital staff removed the patients' names and addresses from the records before the researchers accessed the data. Ethical approval for the study was granted by the New Zealand Health and Disability Ethics Committee and the three DHBs that held the patient records.

The rehabilitation team at each DHB consisted of a social worker, physiotherapist, speech language therapist, dietician, occupational therapist, nurse and rehabilitation assistants (student health professionals also contributed to the records). The 10 records were from people aged 62–89 years (*M* age 73) and five were male. In this group, there were four Māori, four NZ Europeans, one Samoan, and one record where demographic data were not recorded.

Data collection

Two researchers (or linkers) involved in the study were ME, a New Zealand-educated occupational therapist (40 years since qualifying) who has worked in the stroke rehabilitation area and has had prior experience linking stroke interventions to the ICF, and CS, a UK educated physiotherapist (45 years since qualifying) who has been involved in the development and maintenance of the ICF but has limited recent experience of stroke rehabilitation.

Interventions were defined as activities in the home or community that were prescribed and supervised by a health professional or student health professional and administrative activities to access funding for equipment and home modifications. The following activities are excluded in this definition: patient assessments, meetings, referrals, and phone conversations with the patient, family, and health professionals.

Data extraction and coding

Both linkers worked independently, following the same data extraction and coding process, and only met to discuss the non-agree codes after the results had been calculated. For each patient file, each linker extracted the date of each therapy session, the health discipline providing the intervention, and the actual words from the patient record describing the intervention and transferred that information to an Excel spreadsheet. Linkers then selected the target of the intervention from a drop-down list in the Excel spreadsheet. The action of selecting an intervention target automatically selected an EICSS code. The list of intervention targets and pre-determined ICF codes were drawn from an earlier study by ME and

colleagues that investigated interventions and targets of intervention in a similar community stroke service (Evans et al., 2017). There could be more than one target function per intervention.

For difficult or ambiguous concepts, linkers were provided with a protocol showing typical interventions and their assigned codes to improve the consistency of coding. This protocol was developed based on feedback from an independent ICF expert (CH) on samples of coding provided by ME. The use of a protocol for concepts that could be coded to two or more different codes was recommended by Cieza et al. (2019) and has previously been used by researchers to improve the reliability of coding (Granberg et al., 2014; Osborne & Kauvar, 2019; Van Leeuwen et al., 2017). As the 2005 linking rules were used, linkers could assign one or more targets and, therefore, one or more codes to an intervention. An example of extracted interventions, targets, and linked ICF codes is presented in Table 1.

Table 1

Example of extracted intervention, target and linked ICF code

Day	Date	Therapist	Intervention extracted from record	Intervention target	ICF code
1	8/07/2016	TA	Home exercise programme completed	<ul style="list-style-type: none"> • Strength • Endurance • Control of voluntary movement 	b730 b740 b760
1	8/07/2016	OT	Hot drink preparation	<ul style="list-style-type: none"> • Meal making 	d630
2	11/07/2016	OT	Practiced functional activities that involved scanning	<ul style="list-style-type: none"> • Undertaking a task • Vision 	d210 b210

Note. TA = Therapy assistant; OT = Occupational therapist.

Data analysis

Data were analysed in four stages. Stage 1 organised the data into four categories based on when linkers recorded the same intervention and code; interventions and codes did not agree; same intervention and same ICF chapter, but the ICF code did not agree (less specific); and same intervention but did not agree at ICF chapter and code (Table 2). The data from each patient record were summed and then combined for all 10 patient records. An overall percentage agreement was calculated for the same interventions and codes (including chapter codes) recorded by both linkers. The criteria for acceptable percentage agreement between the two linkers was 70% (Stemler & Tsai, 2008).

In stage 2, using the extracted interventions from both linkers, the average number was calculated for the interventions per day, the targets per ICF component (body function, activities and participation, and environmental factors), and the targets per ICF chapters (sub-headings under each component). This information described the density of concepts that needed to be extracted by the linker. It was assumed

that with a higher density of concepts, there would be a higher risk of mismatched interventions between the two linkers.

In stage 3, a consensus list of interventions and codes was developed based on a consensus agreement with the other linker (CS). Following this, each linker's extracted interventions and coding were compared to the consensus list. This analysis revealed the number of times: a) each linker had an intervention and code different to the consensus list, b) the number of times when both linkers selected the same intervention and code as the consensus list, and c) the discrepancies in coding and whether this was due to the linker choosing an incorrect code or intervention. In stage 4, the discrepancies for each patient file and the whole data set were identified and problematic interventions and codes were analysed (Tables 3–6).

Results

Across the 10 patient records, patients received on average 17.8 days of rehabilitation. The linkers extracted 518 interventions, with an average of three interventions per day from between one and six disciplines. In each treatment session, interventions, on average, were related to 1.59 components of the ICF and linked to two or more chapters in that component ($M = 2.27$).

In comparing the results of linking interventions to ICF codes, the linkers identified the same intervention and code 228 times, resulting in a percentage agreement of 44.01%. The percentage agreement increased to 51.93% when including interventions matched to the same ICF chapter, but where the specific ICF code did not agree. Of the 290 non-agree codes and interventions, 43.79% ($n = 127$) were due to mismatched codes and 56.20% ($n = 163$) were due to mismatched interventions. Of the mismatched codes, 32.28% ($n = 41$) matched at the less specific chapter level and 67.71% ($n = 86$) were mismatched. Of the mismatched interventions ($n = 163$), 85 were from linker 1 and 78 from linker 2 (Table 2).

Table 2*Numbers of agree and non-agree codes and interventions from the two linkers*

Patient record	Intervention	Same intervention & same code	Non-agree codes & intervention	Same intervention & same chapter, non-agree ICF code	Same intervention & non-agree at chapter and ICF code	Non-agree intervention	New intervention CS	New intervention ME
1	58	25	33	4	14	15	11	4
2	69	31	38	1	6	31	22	9
3	84	42	42	8	8	26	15	11
4	60	38	22	4	8	10	5	5
5	44	11	33	9	11	13	4	9
6	13	5	8	1	2	5	5	0
7	34	21	13	0	3	10	5	5
8	34	12	22	2	7	13	2	11
9	75	21	54	11	13	30	3	27
10	47	22	25	1	14	10	6	4
Total	518	228	290	41	86	163	78	85

Note. CS = Catherine Sykes; ME = Melissa Evans.

After reviewing the differences between the two linkers, ME and CS came to a consensus agreement on a selection of interventions and targets that were consistently mismatched. Following this, all the patient records were recoded based on the consensus agreement for mismatched codes and recommendations in the coding protocol. Coding that was the same between the two linkers was retained. Following this, the extracted interventions and coding of each linker were compared to the consensus coding for each extracted intervention. Across the 518 codes, ME had 359 (67.91%) and CS had 360 (68.43%) codes that were the same as the consensus coding. The close alignment of the overall accuracy of the linkers indicates that no one linker was more proficient than the other. Both linkers had a similar proportion of codes that did not match the consensus coding, which indicates that the linkers had different perceptions of how to code the interventions.

Analysis of the differences in linking

An analysis of the differences in the linkers' coding to the consensus coding list revealed that inconsistent extraction of interventions was caused by extracting interventions from different parts of the patient note (Table 3), linker professional bias (Table 4), and not coding the target function of the intervention (Table 5). Non-agree codes were caused by errors in coding and linkers not having clear information on the target of the intervention. This was particularly evident for interventions that had more than one target (Table 6).

Table 3

Example of extracted interventions from different clinical note headings

Text from clinical record	Intervention extracted	
	Linker 1	Linker 2
<p>S: Patient was in back bedroom sitting in sun, said she'd been out already as daughter had to go to WINZ.</p> <p>O – Alert & agreed to participate</p> <p>T – <i>Left arm exercises</i></p> <p>A – Whilst sitting in chair patient was able to reach to <i>pick up water bottle</i> from various positions on floor to her left side but didn't fully extend her elbow</p> <p>When she went to pick bottle up & place it on table she was unable to lift it far as her upper arm was too sore</p> <p>Putting <i>a pill packet on floor was more successful</i> as patient had to reach further thereby extending her elbow more until it was almost straight</p> <p><i>Shoulder shrugs & shoulder retractions</i> were same as last time and needed prompting to raise left shoulder more</p>	<p>Interventions under the A letter:</p> <ul style="list-style-type: none"> <i>picking up water bottle and pill packet (d440 fine hand use)</i> <i>shoulder shrugs and shoulder retractions (b710 range of motion)</i> 	<p>Intervention under the T letter:</p> <ul style="list-style-type: none"> <i>left arm exercises (d445 arm and hand use).</i>

Note. S = Subjective; O = Objective; T = Treatment; A = Assessment; *Italics* = Extracted interventions and linked ICF codes.

Table 4

Example of patient note showing linker bias impacting on extracted interventions

Text from clinical record	Interventions extracted
<p>S. Pt seen at home, daughter present. Plan discussed and consent gained</p> <p>O. Notable left sided inattention</p> <p>T. <i>Standing symmetry and scapular stability work at the bench, elbow extension work in weight-bearing, functional upper limb tasks; stroking the cat, turning pages of magazine and bimanual, tying shoelaces.</i></p> <p>A. Low tone upper arm, some pain reported, requires ongoing scapular stability work and trunk rotation work.</p> <p>P. Review tomorrow for Saturday high intensive visit</p>	<p>Both linkers extracted the interventions <i>“standing symmetry, scapular stability and elbow extension work in weight bearing”</i>.</p> <p><i>b730 muscle power functions</i></p> <p>In addition, linker 2 (occupational therapist) coded <i>“Functional upper limb tasks stroking the cat, turning pages of magazine and bimanual tying shoelaces”</i>.</p> <p><i>d445 hand and arm use</i></p> <p><i>d540 dressing</i></p>

Note. S = Subjective; O = Objective; T = Treatment; A = Assessment; P = Plan; *Italics* = Extracted interventions and linked ICF codes.

Table 5*Differences in coding*

Extracted intervention from clinical record	Linker 1 identified the environment	Linker 2 identified the functional aim of the intervention
1. Set up permanent shower chair	<i>Interpreted aim: Equipment so the patient could shower</i> Coded: e115 products for personal use in daily living	<i>Interpreted aim: Provide chair to help with sitting</i> Coded: d410 changing basic body position
2. Provided education to family on correct use of walking frame and demonstrated use	<i>Interpreted aim: Support to the family to assist the patient with walking</i> Coded: e310 immediate family	<i>Interpreted aim: The patient walking with frame</i> Coded: d465 walking with equipment
3. Brief and short warfarin education	<i>Interpreted aim: Education to the person on how to take medication</i> Coded: e110 products and substances for personal consumption	<i>Interpreted aim: Patient to look after health</i> Coded: d570 looking after one's health

Note. Italics indicate the different aims of the intervention given by the linkers for the same extracted intervention.

Table 6*Interventions coded to two or more ICF codes*

Interventions	Possible codes that were assigned to this intervention
Fatigue management	b130 energy and drive functions d240 handling stress d570 looking after one's health
Tandem stance held heel to toe for 60 sec L leg leading, 30 sec on R	b755 balance reactions d410 standing
Walking on A and B levels with eyes open and closed	b760 control of voluntary movement b755 involuntary movement reaction functions d450 walking
Gardening	d6505 taking care of plants indoors and outdoors d920 recreation and leisure

Discussion

Interventions

This study found poor inter-rater reliability (44.01%) when linking 518 CSR interventions to the relevant target functions in the ICF by two independent linkers. This was unexpected as both linkers had experience linking health data to the ICF. In addition, efforts were made to increase reliability by using a linking protocol and a drop-down list of intervention targets with pre-linked ICF codes. It appears that poor inter-rater reliability was largely due to linkers extracting different interventions. This was due to the following reasons:

1. On average, there were 3.5 interventions per treatment day, and of these, two were linked to a different chapter and, consequently, a different target function. This figure is higher than the concept density of 2.8 which was reported by Osborne and Kauvar (2019). The high number of interventions per treatment day increased the density of information for coding and may have caused linkers to miss interventions. In addition, extracting interventions was made more difficult by the presence of unfamiliar acronyms and duplicated interventions in different parts of the record.
2. The method used to record patient notes was not consistent across professional groups, and consequently, the linkers had difficulty determining what part of the clinical note represented the intervention. Physiotherapists and occupational therapists used the Subjective, Objective (includes interventions), Assessment/Analysis and Plan (SOAP) format (Sullivan, 2018). Other formats were the "Subjective, Objective, Treatment, Assessment and Plan" (SOTAP) (*Treatment notes and progress notes using a modified SOAP format*, 2016) and "Presentation, Client's perspective, Assessment, Intervention, Outcome and Plan". Confusion for linkers arose when the interventions were placed under headings other than objective, treatment and intervention headings. This confusion is evident in Table 3, where one linker extracted information from the objective part of the patient note and the other linker extracted interventions under objective and assessment. This may have occurred because the instructions in the study protocol stated that assessments are not considered an intervention. Nurses and social workers used a narrative approach with no clear headings. Overall, the linkers were more likely to extract the same intervention when it was written under the objective, treatment, or intervention headings.
3. Professional bias was clearly seen when the linkers identified and extracted more interventions from their own discipline than from other disciplines. Although this contributed to poor inter-rater reliability, having multiple perspectives is beneficial. Professional bias can be identified by examining all non-agree codes due to linkers coding different interventions and using a consensus process to determine which interventions should be linked.
4. When the aim of the intervention was not provided, linkers had to interpret the target based on their knowledge of the health discipline's scope of practice and the range of stroke interventions. It was not possible to clarify the target of interventions by reading the patient's initial assessments as this was not provided to linkers. The finding that poor inter-rater reliability is related to poor clarity of the text is also supported by Soberg et al. (2008).
5. Non-agree interventions and coding occurred when linker 1 coded the intervention to an environmental factor code and linker 2 coded the same intervention to a code that reflected the functional target of the intervention (Table 5). Linker 1 may have intended to capture

environmental factor interventions and, in doing so, did not follow the 2019 linking rules, which state the linker should “identify the purpose of the information to be linked by answering the question: What is this information about? Or what is this item about? The answer to these questions will help identify the main concept(s)” (Cieza et al., 2019, p. 577). This type of issue would not have occurred if linkers had discussed how to interpret the aim of the intervention before coding or if linkers had regular meetings to compare coding of the same patient file.

6. The Excel spreadsheet used to record the intervention and select the target of the intervention from a drop-down list may have increased the complexity of coding. This is because the wording in the drop-down list was written in natural language rather than ICF terminology. In future, it is recommended linkers use their own words to describe the target of the intervention and then select a code using the ICF browser in a separate column. This process would assist researchers to monitor consistency in coding and the use of the ICF browser would ensure that both linkers were using a consistent reference point.

Codes

Despite the low percentage of agreement found in this study, if the non-agree interventions (163) are removed from the total number of interventions, the percentage of agreement to specific codes increases to 64.50%.

Coding reliability was reduced when the target of the intervention could be linked to two different codes (Table 6). For example, in this research, education on fatigue management was coded by one linker to *b130 energy and drive functions*, as the intervention target was to change the person’s energy level. The other linker coded this intervention to *d570 looking after one’s health*, as it was thought that the outcome of education would assist the person to manage fatigue. The first linker had the view that the intervention aim was to address the body’s capacity for energy; the second linker had the view that the intervention aim was for the person to do an action that will impact their energy use. In this example and others in Table 6, it is evident that linkers had a different view on whether an intervention target was a body function or activity and participation life area. Mismatching of codes could also be due to linkers having a different view on whether the target of the intervention relates to an immediate target, such as body function, or an ultimate target in a life area. These types of coding disagreements could be reduced if therapists providing the intervention recorded the primary aim of the intervention in the patient notes.

Recommendations

To encourage consistency and identify differences in coding between two linkers, it is recommended that linkers use an Excel spreadsheet to extract the actual words for the intervention from the text, the primary target function of the intervention, and the linked ICF code using the ICF browser. To improve inter-rater reliability for extracting and linking interventions to relevant ICF codes, it is recommended that

researchers conduct inter-rater reliability checks at the beginning of data collection until reliability reaches an acceptable level for interventions and codes (Lustenberger et al., 2019). After each inter-rater reliability check, differences in coding should be analysed. Researchers should check for the following causes of low reliability: interventions not being extracted from the same part of the patient note, the influence of professional bias, linkers having different views on how to interpret the target of the intervention, linkers selecting similar but different codes for the same intervention, and whether research protocols are clear to linkers. When linkers have identified different targets for the same intervention, it is recommended linkers meet with the clinician and clarify the intervention target. This process may provide further insights into what wording or types of interventions cause confusion for linkers. When linkers have chosen a different but similar code for the same intervention, researchers should decide on a consistent code to be used throughout the linking process. It is natural that professional bias will be present, and researchers may consider this an asset, as different health disciplines and work experience means the data are seen through a variety of perspectives and there is a greater chance that all relevant interventions will be extracted.

The ICHI browser tool will now become the preferred method to classify interventions. Although this is the case, the quality of the classification process still depends on the researcher selecting the intervention from the patient's hospital records and having a sound understanding of the target of the intervention. The reliability of classifying interventions would be improved if all health disciplines used the ICF language in patient records. Where the ICF language is not used, consistency in reporting would be improved by asking services participating in the research to use a common method to record interventions that avoid the use of abbreviations and acronyms and clearly signals the target function(s) of the intervention. An example of a possible template for recording interventions is presented in Table 7. Prior to classifying interventions from a health team, it may benefit the researcher to meet with each discipline and identify common interventions and the target functions of interventions.

Table 7*Intervention template for health professional session notes*

Intervention type	Meaning of term
Patient problem or issue:	
Patient goal:	
Subjective:	The subjective experience of the patient
Objective:	The clinician's objective observations and measurements
Assessment:	The clinician's interpretation of the objective section
Intervention:	
The aim/target of the intervention for the patient.	Identify if the primary aim is to improve a body function, the person's ability to do a task or participate with others or to change the environment
Refer to the ICHI to identify the target of the intervention	
Outcome of the intervention:	Was the intervention useful? Has the person's performance changed since the last session? How did the client/family member respond?
Plan for the next session:	

Limitations of this study

As extracting and coding targets depends on the linker interpreting what is written, mistakes may have been due to the linker's inattention or lack of knowledge of the purpose of interventions a discipline provides. Linking was constrained to the 166 categories in the EICSS rather than all the categories of the ICF. This may have forced linkers to use EICSS codes where another ICF code would have been more appropriate. This may have caused inconsistent coding, as linkers selected the code they considered to be the best fit with the intervention target. In future studies, it is recommended that linkers use ICF codes that are not included in the EICSS when the codes within it do not fully describe the intervention. No intra-rater reliability statistics were developed for this study, so it was not possible to determine whether each linker was coding the data in a consistent way. It is important to recognise that the data collected by the linkers was constrained by the composition of the rehabilitation team and the current ICF framework. In this study, the lack of psychological staff in the rehabilitation team may have impacted the provision of interventions for emotion, stress, and interpersonal and family relationships. In addition, the lack of codes for personal factors means that interventions directed at improving the lived experience of health were not comprehensively documented (Geyh et al., 2019). This situation may soon be resolved as two recent publications have developed the definition of personal factors and provided codes that align with the ICF coding structure and philosophy (Geyh et al., 2019; Grotkamp et al., 2020).

Conclusion

This study found that there was poor inter-rater agreement (44.01%) when extracting and coding interventions from 10 patient files for the EICSS. Linking interventions to target functions is a complex process requiring multiple steps, which include identifying an intervention in the health record, interpreting the aim of the intervention when this is not recorded, and selecting the EICSS code(s) that best represents the intervention aim. Each step may contribute to the level of reliability between linkers. For greater reliability when using data in health records for service evaluation and planning, it is recommended that health professionals use a consistent method to record interventions and the functional target of the intervention using ICF terminology. To eliminate factors that could cause poor inter-rater reliability, it is recommended that researchers conduct early robust reliability checks of extracted interventions and linked codes.

This chapter has described the processes used to determine inter-rater agreement for selecting and coding interventions used for 10 patient files that were randomly selected from the 113 patient files used for Study 1. The errors in coding from this study were used to review and amend the ICF coding for the whole data set.

The next chapter describes the methods used in Study 2. This study was a qualitative study that interviewed 15 CSR staff members about the patterns of interventions found in Study 1.

Chapter 6: Method for Study 2

Introduction

Study 2 was designed to answer research question 4: “What are the CSR staff explanations for the pattern of interventions found in Study 1?”. This project was guided by the mixed methods explanatory sequential design, and the principle of “connecting” was applied by using the Study 1 results of the intervention frequencies and patterns to form the basis of the interview questions.

Rationale for data collection methods

Study 2 used in-depth interviews to gather data as it was thought the interviews would be the best medium to address the research question. Interviews are used by researchers “to learn about people’s beliefs, perspectives, opinions, lived experiences and meaning making” (Roulston & Halpin, 2022, p. 668). Using interviews to answer the research question had several advantages: it allowed me to discuss the reasons for the intervention patterns with the staff with the most knowledge on this topic, and the flexibility of interviews made it possible to ask specific questions that were linked to quantitative data results and in-depth follow-up questions. The disadvantages of using interviews are that interviewees may misrepresent their experience; misunderstandings between the interviewer and interviewee can lead to off-topic answers; overly long interviews can be a burden on the interviewee; lack of rapport can cause the interviewee to lack trust in the interviewer resulting in superficial answers to the research questions; the interviewer may miss follow-up questions; and the interviewer may ask leading questions (Roulston & Halpin, 2022). To address these risks, I used a consistent set of questions with each participant (Appendix E). The initial questions were used to develop rapport and to establish the participants’ experience in CSR. These questions covered the participants’ roles, when they graduated, and how long they had worked in stroke rehabilitation. To ensure that the participant felt at ease and safe sharing this information, participants were given the choice of the interview being conducted outside of their work premises. I addressed the issue of missing follow-up questions and asking leading questions by reflecting on my interviewing style after each interview and whether the information generated from my questions matched the study aims. My interviewing technique also improved after my supervisor provided feedback on the initial interview transcripts. Three of the interviews were conducted via Zoom, which gave greater flexibility about when the interview could be scheduled and offered participants greater privacy if conducted at home. Online interviews can lack social connection; therefore, the interviewee may not be as open to sharing their perspectives. This can occur because the researcher may not be able to pick up body language cues as easily and due to technological difficulties such as poor internet and lack of battery power on devices (Roulston & Halpin, 2022). On reflection, interviewing using Zoom was more difficult than face-to-face interviews. This was because I had no control over the

participant's connectivity, how people had set their screens up, and how far the person was from the screen. As a result, the Zoom interviews were longer than the face-to-face interviews as I attempted to compensate for these communication barriers.

Data collection tool

Ten (five each from two of the DHBs involved in the study) participants were presented with graphs showing the ranked frequencies of interventions linked to the EICSS categories of body function, activities and participation and environmental factors for their DHB. Participants were provided with examples of the interventions linked to each category to understand the type of interventions that could be categorised under an EICSS code. In addition, they were presented with the list of missing interventions from the whole data set, as well as a figure showing the ranked frequencies of interventions for their profession from their DHB. For five participants, who were staff members from the DHB with the most Māori patients, the focus of the interview was to understand the reason for the different intervention frequencies between Māori and non-Māori. Consequently, these participants received a one-page summary figure of interventions comparing the interventions for Māori and non-Māori for their DHB. To reduce the time spent looking at graphs, the figure showed selected interventions with clear differences between Māori and non-Māori. Participants also received examples of codes with a linked intervention to help understand the type of interventions that could be categorised under a particular code. An example of the graphs presented to the participants from the three DHBs can be seen in Appendix F.

Data collection procedures

Participant criteria

The types of participants required for Study 2 were guided by research question 1: What are the patterns of community stroke rehabilitation interventions in Auckland? It was decided to have 15 participants who were currently working as allied health professionals in CSR in the three Auckland DHBs. The decision on the number of participants was guided by Terry et al. (2017), who recommended between 15 and 20 participants when a thematic analysis is one part of a doctoral research project. To reflect the possibility that unique differences between the DHBs may impact the provision of interventions, it was decided that five participants would be required from each DHB. As the study aimed for participants to comment on the rationale for the intervention patterns, it would have been preferable to have participants who were staff members at the time the patients' notes were written (between 2016 and 2017). Due to staff attrition and the time that Study 2 was conducted (2021), it was decided that selecting staff employed between 2016 and 2017 was unrealistic.

Participant recruitment

I initially liaised with the manager of each of the CSR services to conduct a 5-minute presentation on the research aims to staff members. At this meeting, I could answer questions and distribute research and participant information sheets. Staff interested in participating were asked to contact me by email or phone. To help recruitment, I explained that the participant input would be confidential, interviews could be held by Zoom or face-to-face during work hours, interviews would be held in a private office space some distance from their usual work office, and participants would receive a \$30 koha to thank them for their time.

To encourage the recruitment of the last four participants, the interview duration of the last four interviews was reduced from 40–20 minutes. The manager of the CSR service was asked to circulate an email I had written to staff, explaining the need for more participants and the reduced interview time. The shorter interviews were all for staff from the CSR service with equal numbers of Māori and non-Māori. It was decided to narrow the interview questions to this topic to fully understand the differences in the data between the two groups.

Ethical approval and ethical issues

AUTEC granted ethics approval for Study 2 on December 8, 2020: reference number 20/378, and amendments were approved on January 21, 2021 (see Appendix A).

Due to the small number of people employed in CSR in Auckland, it was identified that despite participants' names being removed, their comments may still be identifiable in the thesis. To address this issue, it was decided that the participant's profession and place of work would be removed from the thesis and any publications generated from the study. In addition, I sent a transcript of each interview back to the participants to check if the content was correct and whether they would like any content removed from the transcripts. In response, all participants said the transcript was accurate and no participants indicated they would like to modify the transcript.

Data collection, management, and analysis process

Eleven interviews were 40 minutes in duration and four were 20 minutes. Three interviews were conducted via Zoom, 11 at the participant's place of work and one at my workplace. Each interview started with an introduction about the purpose of the research, questions about their work history, and an overview of the questions covered in the interview. Following this, participants had 5 minutes to view the data linked to their DHB. The interviews were recorded and transcribed by a professional transcriber. Once transcribed, each transcript was checked against the recorded interview and sent to the participant for checking. If required, changes were made to the transcription. Following this process, the recordings

were deleted. All the transcripts were then imported into NVivo. This data management tool was used to store and code the concepts and after analysis helped me transfer the coded concepts into initial themes.

This study used reflexive thematic analysis to analyse the interview data (Braun & Clarke, 2019). Reflexive thematic analysis is a process that assists the researcher to “develop patterns of meaning (themes) across a data set that address a research question” (Braun & Clarke, n.d.-bpara.2). The following features distinguish it from other thematic analysis approaches:

- The researcher develops codes and themes after deep engagement and reflection on the data.
- A theme is defined as “patterns of shared meaning underpinned by a central meaning-based concept” (Braun & Clarke, 2019, p. 593).
- The researcher engages in an active and creative process to interpret and construct the themes from the data.
- There is a recognition that the researcher’s background, knowledge, and research question will impact the research findings.
- The process requires the researcher to revise interpretations of coding and themes to ensure that themes reflect the data and the research question.
- The researcher is aware of the philosophical assumptions informing the use of reflexive thematic analysis (Braun & Clarke, 2019).

The participants’ language was analysed at the semantic level, meaning that I focused on the explicit meanings communicated by the participants. This analysis method means the researcher seeks to stay close to what the participants say, but also realises that the researcher’s perspectives may impact the interpretation of the data (Clarke et al., 2015).

As explained in Chapter 3, the philosophy of pragmatism outlined by Dewey proposes that our transactions with the environment result in action and consequences. Dewey and other pragmatic philosophers asserted that the value of any knowledge claim is how well it works in practice to enable us to live good lives (Brinkmann, 2017). Using this pragmatic viewpoint, I viewed the participants’ data as knowledge gained from their day-to-day practice from their actions and the resulting consequences of what worked and did not work with patients.

I used an inductive approach to produce codes, which means the codes were developed based on the content of the data rather than a pre-determined framework (Byrne, 2022). Semantic codes were used to identify and summarise the data. This meant codes described the explicit meaning of what the participants said, and there were no attempts to uncover hidden meanings or assumptions (Byrne, 2022).

The analysis process followed the six phases of analysis developed by (Braun & Clarke, n.d.-a). This included:

- a) Familiarisation with the whole data set: All the data were imported into NVivo, and I became familiar with the whole data set by reading the content many times and taking notes.
- b) Coding: To provide initial guidance on this process, my primary supervisor and I read one transcript together and discussed the potential codes that could be used to describe the participants' comments. The feedback gained from this session informed how to code the remaining data set. All the data with the same codes were collated together.
- c) Generating initial themes: I examined all the codes and collated data for broader patterns of meaning. The codes and data set were grouped together to form potential themes.
- d) Developing and reviewing themes: To establish if themes were distinct from each other and whether the codes could be combined under a theme, a table was developed showing the themes and coded text attributed to each theme. Once I was satisfied that the codes were consistent with the themes, I used NVivo to incorporate all the codes and the linked text under a particular theme.
- e) Refining, defining, and naming themes: The data set under each theme was checked for consistency. Following this, I read over the original transcripts to check if all the meaningful text had been coded correctly and if any remaining ideas had not been coded. The themes and sub-themes were placed on a mind map, and using this, conceptual links and relationships between themes and sub-themes were made. Further insights on themes and codes were assisted by regular discussions with my research supervisors.
- f) Writing up: The analytic narrative and the data extracts were woven together into a narrative form. Throughout this process, I compared the findings from Study 2 to the results from Study 1.

Steps to improve rigour

Four criteria can be used to appraise the quality of a qualitative study: credibility, dependability, transferability, and confirmability (Curry & Nunez-Smith, 2015). In qualitative research, credibility refers to whether the result accurately represents participants' views and whether they concur with what is already known about the topic. Two techniques enhance credibility: triangulation and member checking. Triangulation evaluates the congruence of data across different data sources, and member checking asks the participants if the results are consistent with their experience (Curry & Nunez-Smith, 2015). Triangulation was part of the method in this research as only data consistent across both studies is reported in the findings for Study 2. To evaluate, I presented the findings to the staff members of the three CSR services who participated in the study and asked for confidential feedback on whether the

results reflected current practice. To assess whether the findings accurately portrayed the provision of CSR to Māori patients, I met with a Māori health representative to discuss their perspective on the findings. Both the Māori health representative and staff viewpoints on the results are incorporated in the Study 2 findings in Chapter 8.

Dependability refers to whether the research process is described sufficiently so that another researcher could repeat it. Any variations in the process or findings should be explained by the researcher. Consistency is usually evaluated by an external audit of the research process and results by an independent external researcher (Curry & Nunez-Smith, 2015). This process was not followed because this was doctoral research, but consistency can be evaluated by the level of detail provided in the methods and analysis chapters.

The transferability of a study is whether the findings of the study could be used in another setting or population. This can be determined by the clarity of the research aims, the rationale for the research methods, a description of the context most relevant to the research question, and the study procedures (Curry & Nunez-Smith, 2015). It is hoped that Chapter 1 has provided the reader with the aims and rationale of the study and a detailed description of the context from which the data were sourced.

Confirmability refers to when the researcher takes steps to prevent personal bias and assumptions from impacting the interpretation of the data and being open about how their perspectives impacted the research process (Terry, 2021). This is achieved by the researcher writing a reflective statement outlining their relationship to the topic and the participants and how this may have impacted the design, data collection, data analysis, and results. I chose this option and wrote a reflexive statement in Chapter 1.

This chapter describes the method used in Study 2 to collect data that would contribute to research question 4: What are the staff explanations for the pattern of interventions and Study 1? There were 15, 20 to 40-minute individual interviews with CSR staff members. Of this group, there were five staff from each DHB. Of these, 10 participants from two DHBs were asked to explain the reasons for the differences in the frequency of interventions from a figure showing the type and frequency of interventions for their DHB. Five staff from the DHB where the Māori data was sourced were asked to comment on the reasons for the different patterns of interventions provided to Māori and non-Māori patients. The data was organised using NVivo and analysed using reflexive thematic analysis. Dewey's pragmatic philosophy guided my assumptions based on the client's data. Using this philosophy, I assumed that the participants were reflecting on their actions when providing CSR and the consequences of their actions. As a result, these staff members could provide unique knowledge to explain the reasons for intervention provision. An inductive approach was taken to analyse the participants' words at a semantic level. Triangulation of the data from Study 2 was conducted by only reporting data in the findings that were consistent in Study

1 and 2. In addition, feedback was gained on the findings from the CSR staff in each DHB and from a Māori health professional and is reported in Chapter 8.

The following chapter presents the results of Study One and addresses the research questions 1, 2 and 3:

1) What are the patterns of community stroke rehabilitation interventions in Auckland? 2) Do CSR interventions address the scope of patient problems identified by the EICSS? 3) Are there differences in the type and frequency of interventions provided to Māori and non-Māori?

Chapter 7: Results for Study 1

Introduction

This chapter presents the overall results for Study 1 in three sections. It opens with an outline of the demographic characteristics of the patients whose clinical records were analysed and the number of patient files selected from each stroke rehabilitation service.

The results are then presented under each of the four research questions. The first section presents the results for research question 1: What are the patterns of community stroke rehabilitation interventions in Auckland. Figures summarise the data by linking intervention frequency to chapters and categories of the EICSS. Tables present the number and percentage of people who received an intervention and the average number of treatment sessions per intervention.

It is necessary to understand whether differences in the DHB patient population, organisational structure and staffing personal may have impacted the provision of interventions. Consequently, this section uses figures to compare the frequency pattern of interventions for each DHB. The interventions from each DHB are compared first by chapter level and then by category-level headings for body function, activities and participation, and environmental factors. Following this, the frequency of interventions per allied health discipline are compared across the whole data set and then separately for each DHB.

The second section answers research question 2: “Do CSR services address the scope of the patient problems identified by EICSS?”. The interventions are then compared to the 166 EICSS categories to identify any missing interventions. To determine the relevance of the missing categories, the results are compared to two ICF validation studies and the recommendations for stroke interventions in the NZCGSM 2010.

The third section presents the results for research question 3: “Are there differences in the type and frequency of interventions provided to Māori and non-Māori?”. Figures present the frequency of interventions provided to Māori and non-Māori compared at the chapter level, and chi-square statistics identify chapters with significant differences between the two groups.

Demographics

A total of 113 patient files were used from three CSR services and demographic characteristics of the group are described in Table 8. In total, there were 34 Māori and 79 non-Māori patients, the mean age was 73 years, and the majority had a left cerebral vascular accident. Men slightly outnumbered women,

and over 80% lived with a spouse or family member. On average, there was a 24.9-day time gap between referral to CSR and the first visit from a CSR staff member. There were no appreciable differences in the average number of weeks of rehabilitation for Māori and non-Māori.

Table 8

Demographics and clinical characteristics

Variable	n	%	Missing data
Age			
54–59	7		
60–64	13		
65–69	17		
70–74	23		
75–79	22		
80–84	16		
85–89	10		
90–95	5		
Total	113		
<i>M age</i>	73		
Gender			
Female	54	47	
Male	59	52	
Ethnicity			
Māori	34	30	
Non-Māori	79	69	
Living circumstances			
Living with family	92	81	
Living alone	20	17	
Not reported	1		
Stroke timing			
Average days between stroke and referral to community stroke rehabilitation	24.9		10
Average weeks of rehab for all	13.3		
Average weeks of rehab for non-Māori	13.5		
Average weeks of rehab for Māori	13		
Stroke type			
Right cerebral vascular accident	45	39	2
Left cerebral vascular accident	64	56	
Cerebellar stroke	2	2	
Patients per district health board			
Auckland	26	23	3
Counties Manukau	48	42	31
Waitematā	39	34	

Research question 1: What are the patterns of community stroke rehabilitation interventions in Auckland?

As seen in Table 9, there were a total of 4,353 interventions, with the highest percentage of interventions coded to activities and participation (51.2%), followed by body function (39.7%) and environmental factors (7.9%). No code in the EICSS fully represented the intervention of providing education, so this was recorded separately (1.3%). Waitemata District Health Board (WDHB) had the highest frequency of intervention (44.2%) from 39 patient files, followed by Counties Manukau District Health Board (CMDHB) (29.0%) from 48 patient files and Auckland District Health Board (ADHB) (26.9%) from 26 patient files. The finding that WDHB had the highest frequency of interventions despite not having the highest number of patient files indicates that this service provided higher rates of interventions than the other two DHBs. This is expected as WDHB was an EDS organised to provide intensive daily treatment sessions for 6 weeks.

Table 9

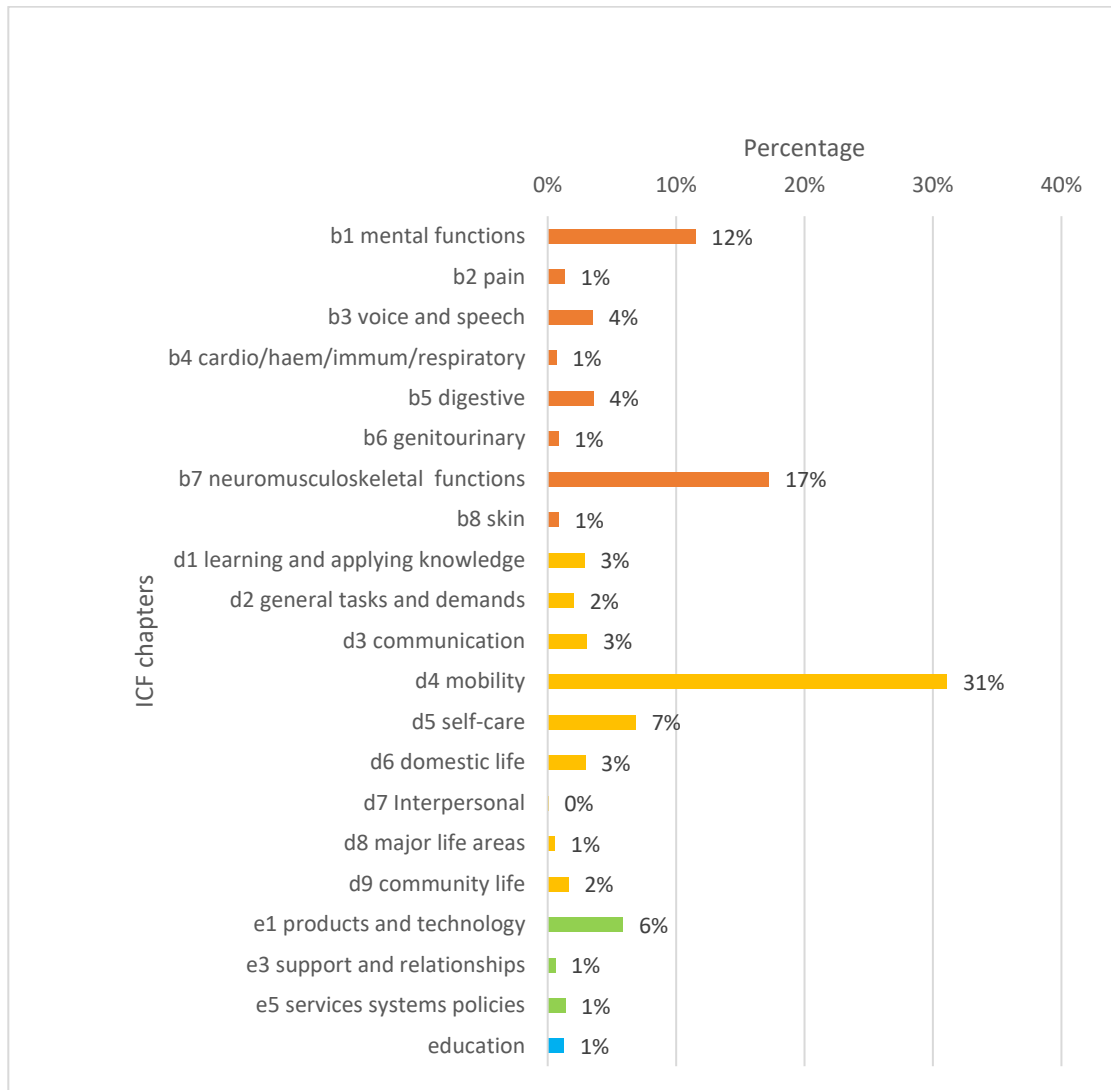
The total frequency of interventions per EICSS component and district health board

ICF components	CSR services							
	ADHB		CMDHB		WDHB		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Body function	409	23.7	474	27.4	844	48.9	1,727	39.7
Activities and participation	618	27.7	663	29.8	947	42.5	2,228	51.2
Environmental factors	125	36.5	108	31.6	109	31.9	342	7.9
Education	17	30.4	17	30.4	22	39.3	56	1.3
Total	1,169	26.9	1,262	29.0	1,922	44.2	4,353	100

Figure 4 summarises the frequencies of interventions provided under the EICSS chapter-level headings for the whole data set. In each component, there were several chapters with a greater proportion of interventions than other chapters. The chapters with the highest frequency of interventions were *d4 mobility* (31%), followed by *b7 neuromuscular and movement functions* (17%) and *b1 mental functions* (12%). The chapters with the lowest frequency of interventions were *d9 community life* (2%) and *d8 major life areas* (1%). The only chapter with no interventions was *d7 interpersonal functions*.

Figure 4

Total interventions linked to ICF chapters



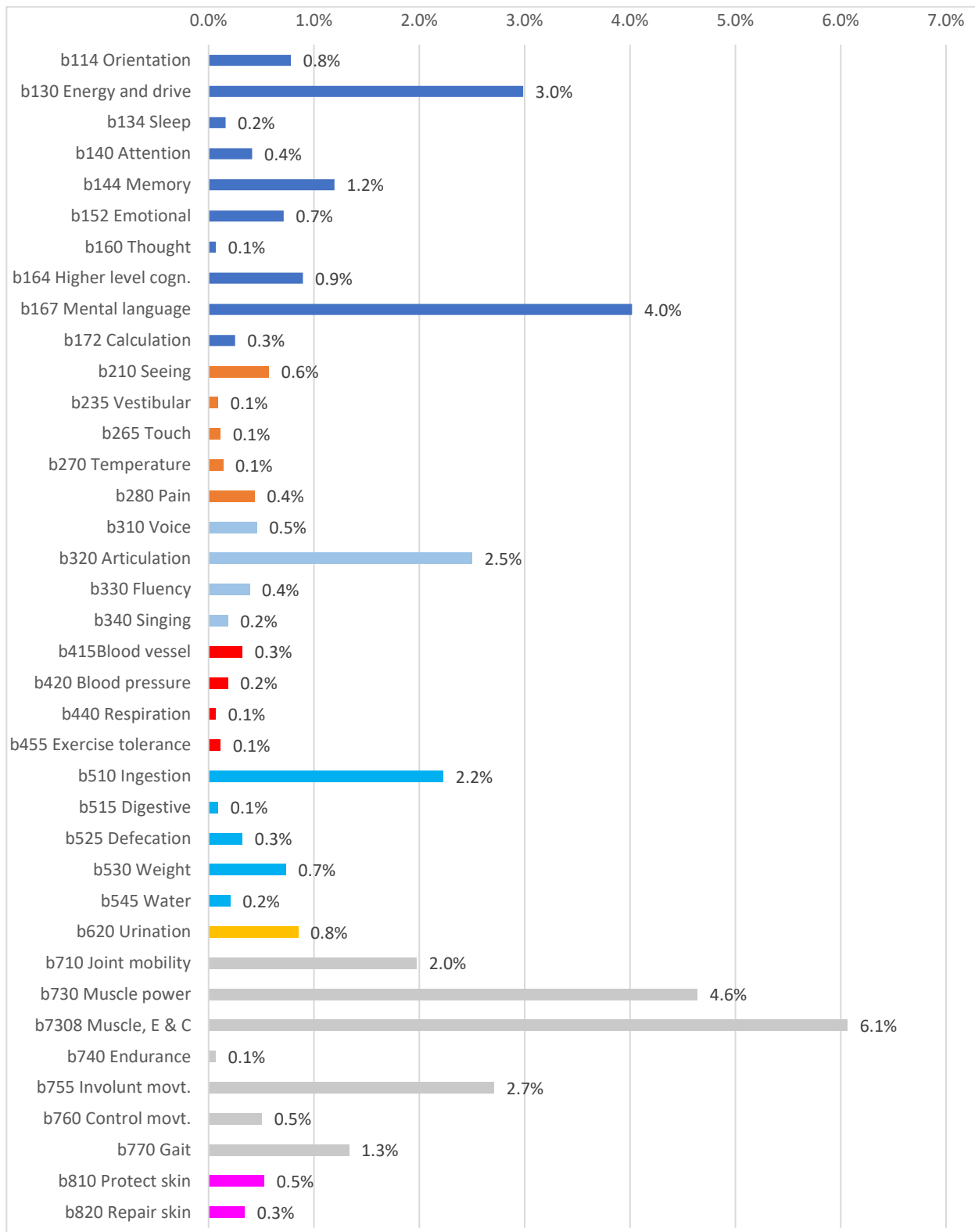
Key. The colours represent the ICF component under which the chapters belong: Body function = orange; Activities and participation = gold; Environmental factors = green; Education is not a chapter of the ICF.

Body function interventions

Figure 5 presents the percentage of interventions linked to the categories in the body function component. The highest frequency intervention was *b7308 muscle E and C* (6.1%). This code represented an exercise intervention, and to reflect that exercise has multiple functional targets, exercise was linked to three separate codes: *b730 muscle power*, *b740 muscle endurance*, and *b760 muscle control*. This was the only intervention that was coded with more than one code. The next two most frequent interventions were *b730 muscle power* (4.6%) and *b167 mental functions of language* (4.0%). Education is not an ICF code, but it was used in this research when therapists educate the patient about the condition.

Figure 5

Percentage of body function interventions



Key. Colours represent interventions linked to the same chapter of the ICS; 1 global mental = orange; 2 sensory and pain = yellow; 3 voice and speech = light blue; 4 cardiovascular haematology, immunological and respiratory = red; 5 digestive = blue; 6 genitourinary = gold; 7 neuromusculoskeletal = bright green; 8 skin and skin repair = pink.

Patients who received a body function intervention

Table 10 presents the number and percentage data for body function interventions, the number and the percentage of patients who received an intervention, and the average number of intervention sessions per intervention type. The interventions provided to most people were *b130 energy and drive* (55%), *b3708 exercise* (52%), *b730 muscle power* (40%), and *b755 involuntary movement* (31%). Three interventions averaged eight treatment sessions: *b167 mental language*, *b320 articulation*, and *b510 ingestion*. The 19 interventions provided twice or less per person are highlighted in yellow in Table 10. For this group, the frequency of each intervention ranged from 0.1–0.4%.

Table 10

Number and percentage of body function interventions and people receiving a body function intervention

Body function categories	Intervention		Patient		Interventions per person (M)
	n	%	n	%	
b7308 exercise	264	6.1	59	52	4
b730 muscle power	202	4.6	45	40	4
b167 mental language	175	4.0	21	19	8
b130 energy and drive	130	3.0	62	55	2
b755 involuntary movement	118	2.7	35	31	3
b320 articulation	109	2.5	14	12	8
b510 ingestion	97	2.2	12	11	8
b710 joint mobility	86	2.0	25	22	3
b770 gait	58	1.3	26	23	2
b144 memory	52	1.2	19	17	3
b164 higher level cognition	39	0.9	10	9	4
b620 urination	37	0.8	12	11	3
b114 orientation	34	0.8	13	12	3
b530 weight	32	0.7	15	13	2
b152 emotional	31	0.7	18	16	2
b210 seeing	25	0.6	8	7	3
b810 protect skin	23	0.5	6	5	4
b760 control movement	22	0.5	17	15	1
b310 voice	20	0.5	4	4	5
b280 pain	19	0.4	9	8	2
b140 attention	18	0.4	9	8	2
b330 fluency	17	0.4	7	6	2
b820 repair skin	15	0.3	3	3	5
b415 blood vessel	14	0.3	9	8	2
Continued...					

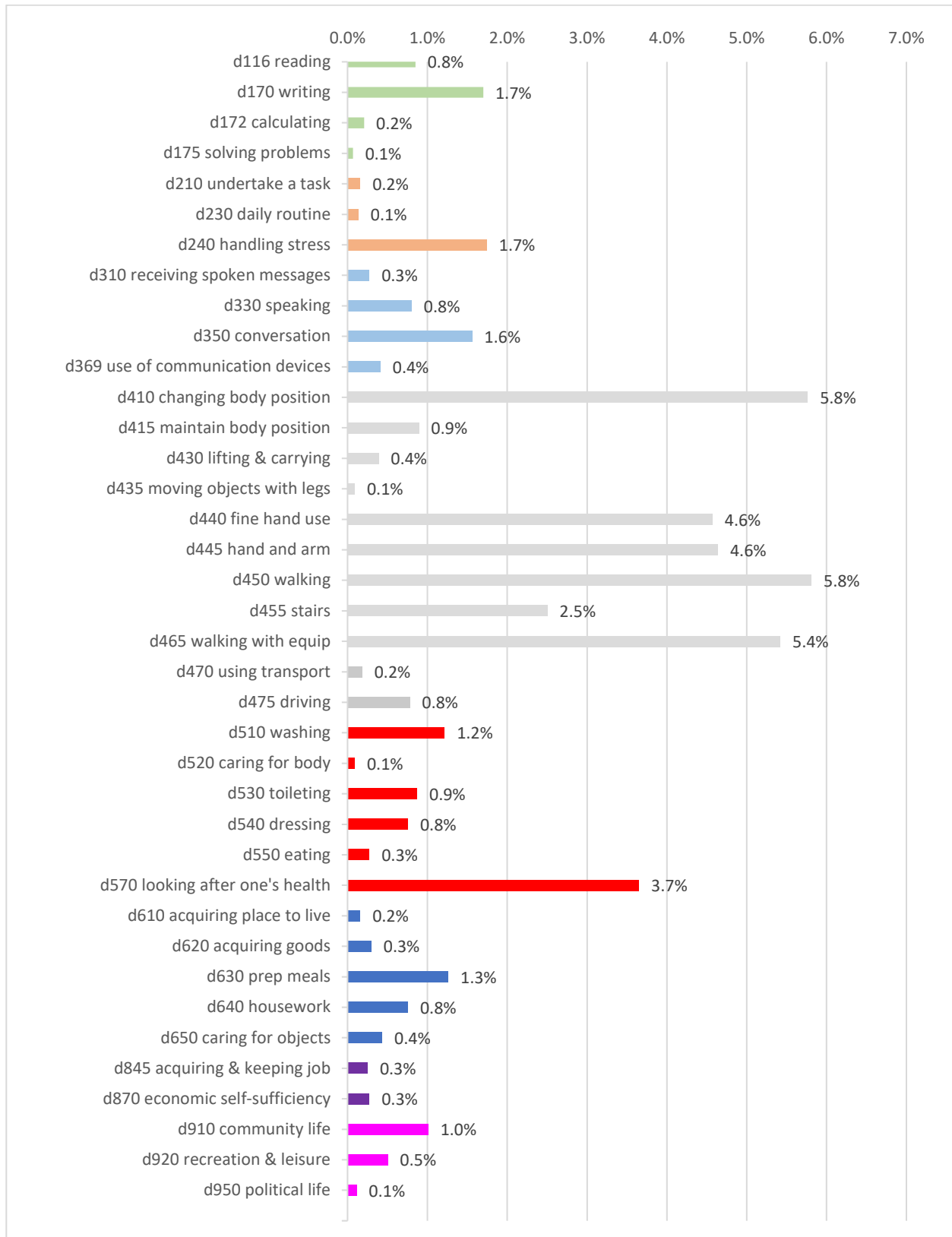
Body function categories	Intervention		Patient		Interventions per person (M)
	n	%	n	%	
b525 defecation	14	0.3	10	9	1
b172 calculation	11	0.3	2	2	6
b545 water	9	0.2	4	4	2
b340 alternative vocalisation	8	0.2	2	2	4
b420 blood pressure	8	0.2	7	6	1
b134 sleep	7	0.2	7	6	1
b270 temperature	6	0.1	5	4	1
b265 touch	5	0.1	3	3	2
b455 exercise tolerance	5	0.1	5	4	1
b235 vestibular	4	0.1	2	2	2
b515 digestive	4	0.1	1	1	4
b160 thought	3	0.1	3	3	1
b440 respiration	3	0.1	3	3	1
b740 endurance	3	0.1	3	3	1

Activities and participation interventions

Figure 6 presents the frequency of interventions linked to the activities and participation component of the ICF. The highest frequency interventions were *d450 walking* (5.8%), *d410 changing position* (5.8%), and *d465 walking with equipment* (5.4%). The seven categories with less than two interventions have been removed from this figure. These categories are noted in Table 11.

Figure 6

Percentage of interventions coded to activity and participation categories



Key. The colours are linked to EICSS chapters; 1 = Learning and applying knowledge = olive green; 2 General task demands = yellow; 3 Communication = blue; 4 Mobility = bright green; 5 Self-care = red; 6 Domestic life = orange 8; Major life areas = purple; 9 Community social and civic life = pink.

Patients who received an activities and participation intervention

Table 11 presents the activities and participation data for the number and percentage of interventions, the number and percentage of patients who received an intervention, and the average number of intervention sessions per intervention. The activity and participation interventions that were provided to the most patients were: *d570 looking after one's health* (60%), *d450 walking* (50%), *d410 changing body position* (46%), and *d465 walking with equipment* (41%). *D440 fine hand use* had the highest average number of treatment sessions ($n = 7$), followed by *d410 changing body position*, *d465 walking with equipment*, and *d445 hand and arm use* ($n = 5$). The frequency of 24 interventions ranged from 0.1–0.4%. These interventions are highlighted in yellow in Table 15.

Table 11

Number and percentage of interventions and people who received activity and participation interventions and average number of interventions per person

Activities and participation categories	Interventions		Patients		Interventions per person (M)
	<i>n</i>	%	<i>n</i>	%	
d450 walking	253	5.8	57	50	4
d410 changing body position	251	5.8	52	46	5
d465 walking with equipment	236	5.4	46	41	5
d445 hand and arm use	202	4.6	39	35	5
d440 fine hand use	199	4.6	30	27	7
d570 looking after one's health	159	3.7	68	60	2
d455 stairs	109	2.5	40	35	3
d240 handling stress	76	1.7	29	26	3
d170 writing	74	1.7	22	19	3
d350 conversations	68	1.6	14	12	5
d630 meals	55	1.3	24	21	2
d510 washing	53	1.2	22	19	2
d910 community life	44	1.0	25	22	2
d415 maintain body position	39	0.9	21	19	2
d530 toileting	38	0.9	13	12	3
d166 reading	37	0.8	12	11	3
d330 speaking	35	0.8	14	12	3
d475 driving	34	0.8	26	23	1
d540 dressing	33	0.8	9	8	4
d640 housework	33	0.8	16	14	2
d920 recreation & leisure	22	0.5	17	15	1
d650 caring household objects	19	0.4	8	7	2
d360 communication devices	18	0.4	10	9	2
d430 lifting & carrying	17	0.4	12	11	1
d620 acquiring goods& services	13	0.3	9	8	1
d310 receiving spoken messages	12	0.3	6	5	2
d550 eating	12	0.3	8	7	2
d870 economic self-sufficiency	12	0.3	8	7	2
d845 acquiring job	11	0.3	8	7	1
d172 calculating	9	0.2	2	2	5
d470 using transport	8	0.2	6	5	1
d210 single task	7	0.2	7	6	1
Continued...					

d610 acquiring a place to live	7	0.2	6	5	1
d230 daily routine	6	0.1	5	4	1
d950 political life	5	0.1	5	4	1
d435 moving objects with the legs	4	0.1	3	3	1
d520 caring for body	4	0.1	3	3	1
d175 solving problems	3	0.1	3	3	1
d177 making decisions	2	0.0	2	2	1
d420 transferring	2	0.0	2	2	1
d770 intimate relationships	2	0.0	2	2	1
d860 economic transactions	2	0.0	2	2	1
d335 produce non-verbal messages	1	0.0	1	1	1
d660 assisting others	1	0.0	1	1	1
d760 family relationships	1	0.0	1	1	1

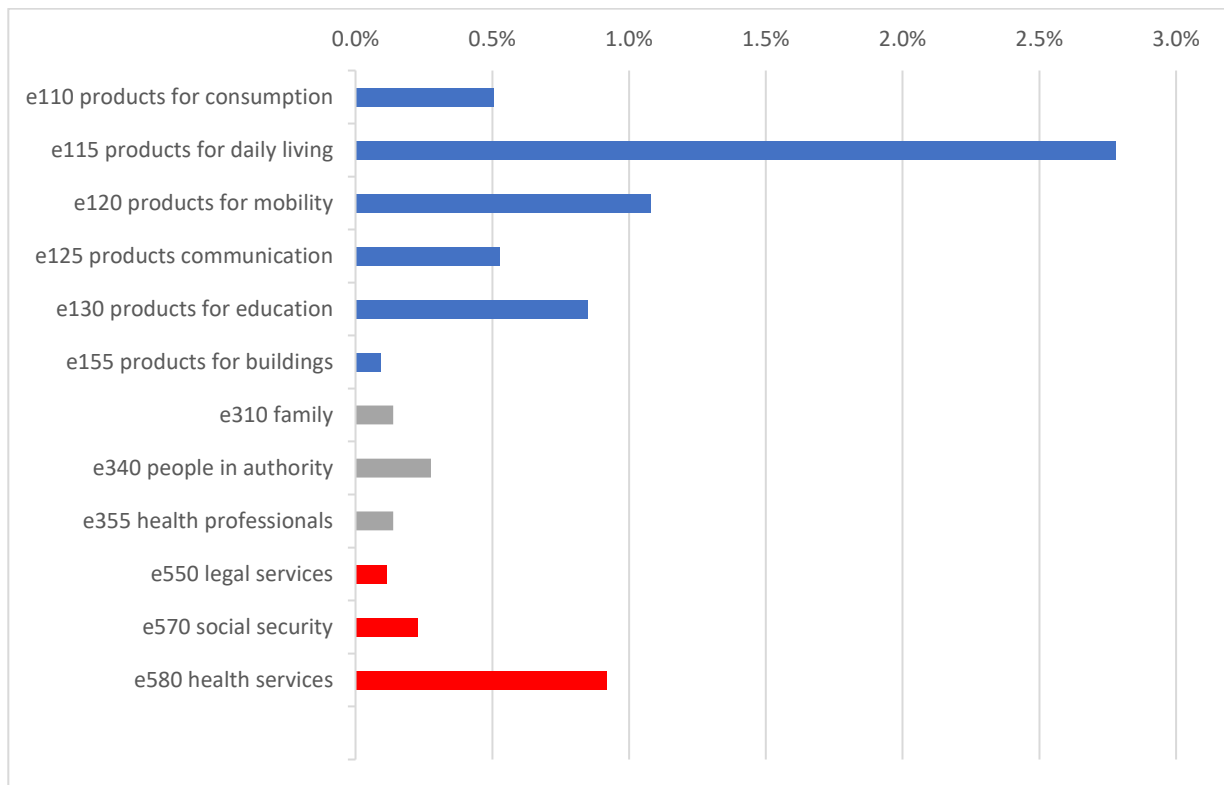
Note. The last seven interventions in this table were not included in Figure 6.

Environmental factor interventions

Figure 7 presents the frequency of interventions linked to environmental factors. Environmental factor codes were used to describe the means used to achieve a primary target, which was either a body function or an activities and participation code. The highest frequency interventions were: *e115 products for daily living* (2.8%), *e120 products for mobility* (1.1%), *e580 health services, systems, and policy* (0.9%) and *e130 products for education* (0.8%). Eleven low-frequency interventions ranged from 0.1–0.4% in frequency, and these interventions are highlighted in yellow in Table 12. There were no interventions linked to Chapter 2 Natural Environment and human-made changes, and Chapter 4 Attitudes.

Figure 7

Frequency of environmental factor interventions



Key: The colours are linked to EICSS chapters; 1 Products of technology = orange; 3 Support and relationships = green; 5 Services, systems and policies = red.

Patients who received an environmental factor intervention

Table 12 presents the environmental factor intervention data for the number and percentage of interventions, the number and percentage of patients who received an intervention, and the average number of intervention sessions per intervention. The environmental factor interventions that were provided to most patients were: *e115 products of daily living* (45%), *e580 health services* (23%), and *e120 products for mobility* (22%), and the average number of treatment sessions ranged from 1–2. The interventions that averaged two treatment sessions were: *e115 products for daily living*, *e120 products for mobility*, *e580 health services*, *e125 products for communication* and *e110 products for consumption*. There were 11 less frequent interventions that ranged from 0.1–0.3%, and these interventions are highlighted in yellow in Table 12. Five environmental categories did not have any recorded interventions.

Table 12

Number and percentage of people who received environmental factor interventions and average number of interventions per person

Environmental factor categories	Interventions		Patients		Interventions per person (M)
	n	%	n	%	
e115 products daily living	121	2.8	51	45	2
e120 products mobility	47	1.1	25	22	2
e580 health services	40	0.9	26	23	2
e130 products education	37	0.8	17	15	2
e125 products communication	23	0.5	11	10	2
e110 products for consumption	22	0.5	12	11	2
e340 personal care assistants	12	0.3	7	6	2
e570 social security	10	0.2	7	6	1
e310 immediate family	6	0.1	4	4	2
e355 health professionals	6	0.1	6	5	1
e550 legal services	5	0.1	5	4	1
e155 buildings private use	4	0.1	3	3	1
e165 assets	2	0.0	1	1	2
e360 other professions	2	0.0	2	2	1
e555 associations	2	0.0	2	2	1
e575 general social support	2	0.0	2	2	1
e540 transportation service	1	0.0	1	1	1

A comparison of interventions across district health boards

Quantitative information on the percentage of interventions per DHB and health professional may indicate whether patient population, organisational practices and staff differences may have contributed to different intervention patterns. As a result the next section compares the percentage of interventions provided in each DHB, and across the allied health disciplines employed in each of the three community stroke rehabilitation services.

Figure 8 compares the frequency of interventions by chapter level per DHB. From this, it is evident that all DHBs had the highest frequency interventions for chapters: *b1 mental functions, b8 neuromusculoskeletal functions, d4 mobility* and *e1 products and technology*. There were also clear variations in interventions per chapter level across the DHBs. The chapter with the highest frequency of interventions for each DHB was:

- WDHB: *b8 neuromusculoskeletal functions* (21%, compared to 19% ADHB and 10% CMDHB).
- CMDHB: *b1 mental functions* (16%, compared to 10.0% WDHB and 9.0% ADHB).

- ADHB: *d4 mobility* (34%, compared to 32% WDHB and 26% CMDHB).

The chapter *d7* has been removed from this figure as no interventions were recorded for this.

Figure 8

Comparison of interventions for ICF chapters for each District Health Board

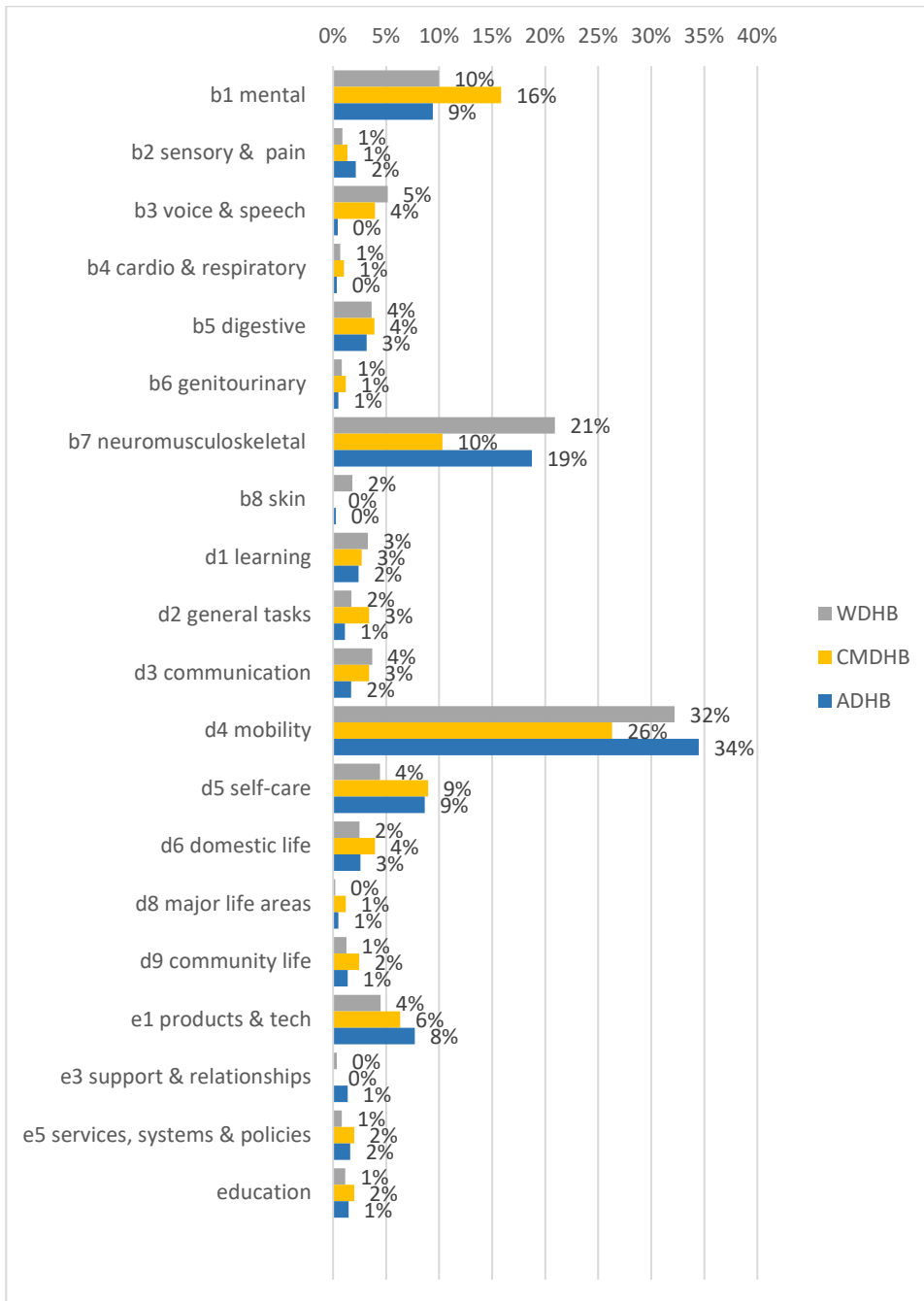


Figure 9 compares the frequency of body function interventions across the three DHBs. This figure shows there is wide variation between the DHBs for the following interventions: *b130 energy* (CMDHB: 10.5%, ADHB: 6.8%, WDHB: 6.2%), *b114 memory* (CMDHB: 4.4%, ADHB: 4.2%, WDHB: 1.7%), *b164 higher cognition* (ADHB: 4.2%, WDHB: 2.3%, CMDHB: 0.6%), *b167 mental language* (CMDHB: 17.1%, ADHB: 8.6%, WDHB: 7.0%), *b320 articulation* (WDHB: 9.5%, CMDHB: 9.0%, A: 0.2%), *b730 muscle power* (WDHB: 15.0%, ADHB: 12.2%, CMDHB: 5.3%) and *b7308 muscle power, endurance and control (exercise)* (ADHB: 21.8%, WDHB: 17.4%, CMDHB: 6.1%).

The following interventions were below 0.5% and were removed from this figure: *b160 thought*, *b265 touch*, *b310 voice*, *b440 respiration*, and *b515 digestion*.

Figure 9

Comparison of body function interventions across each District Health Board

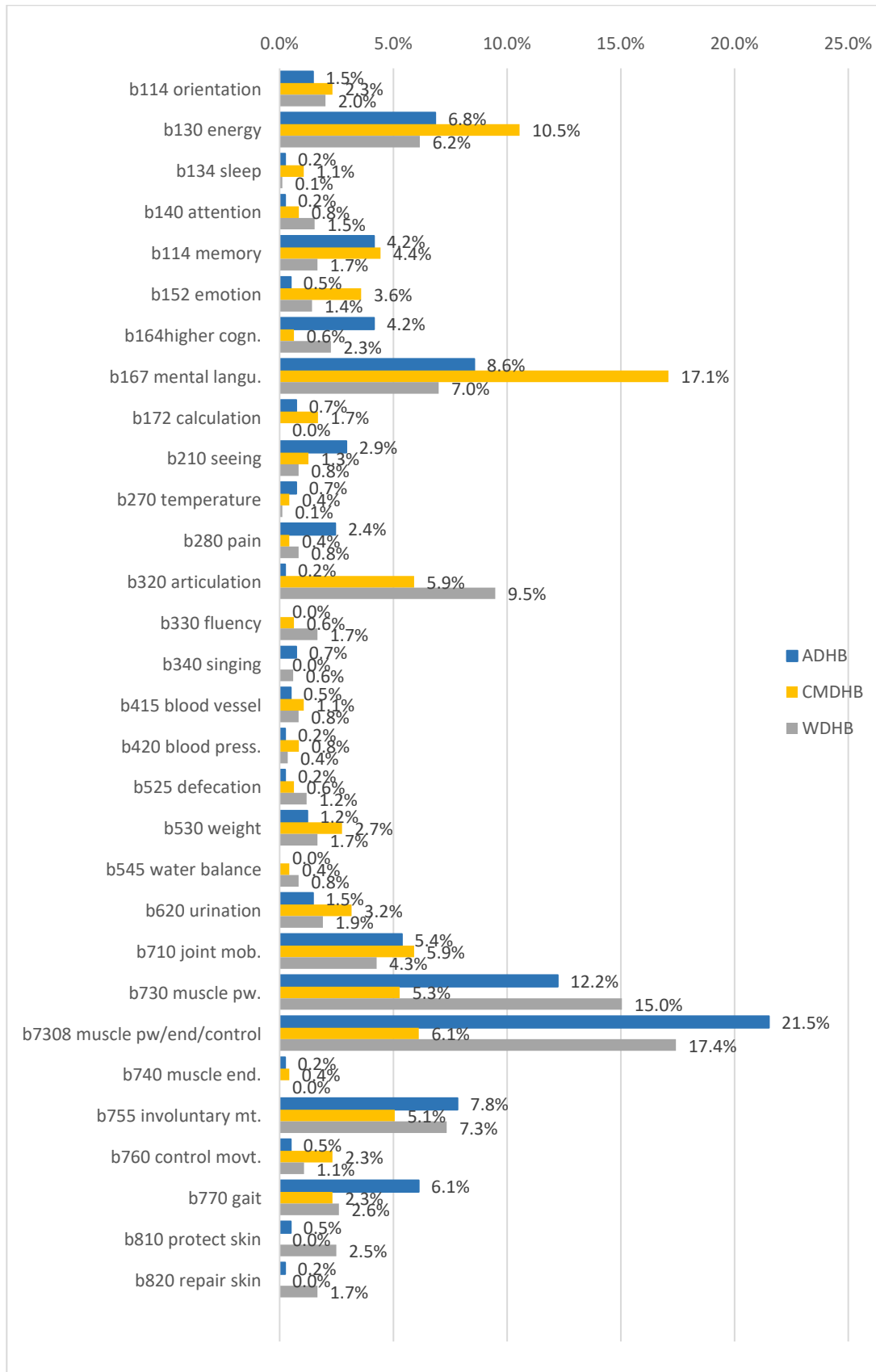


Figure 10 compares the frequency of activity and participation interventions across the three DHBs. The following 11 intervention categories with five or fewer interventions were removed from the figure: *d175 solving problems*, *d177 making decisions*, *d335 non-verbal messages*, *d140 transferring*, *d435 moving objects with the legs*, *d520 caring for body parts*, *d660 assisting others*, *d760 family relationships*, *d770 intimate relationships*, *d860 economic transactions* and *d950 political life*. Figure 15 shows there is wide variation between the DHBs for the following interventions: *d410 changing body position* (ADHB: 18.4%, CMDHB: 9.5%, WDHB: 7.8%), *d440 fine hand use* (WHDB: 13.1%, ADHB: 8.1%, CMDHB 3.8%), *d445 hand and arm use* (ADHB: 12.6%, CMDHB: 9.8%, WDHB: 6.2%), *d450 walking* (WDHB: 15.2%, CMDHB: 9.7%, ADHB: 7.3%) and *d570 looking after one's health* (CMDHB: 13.3%, WDHB: 5.0%, ADHB: 3.9%).

Figure 10

Comparisons of activity and participation interventions for each District Health Board

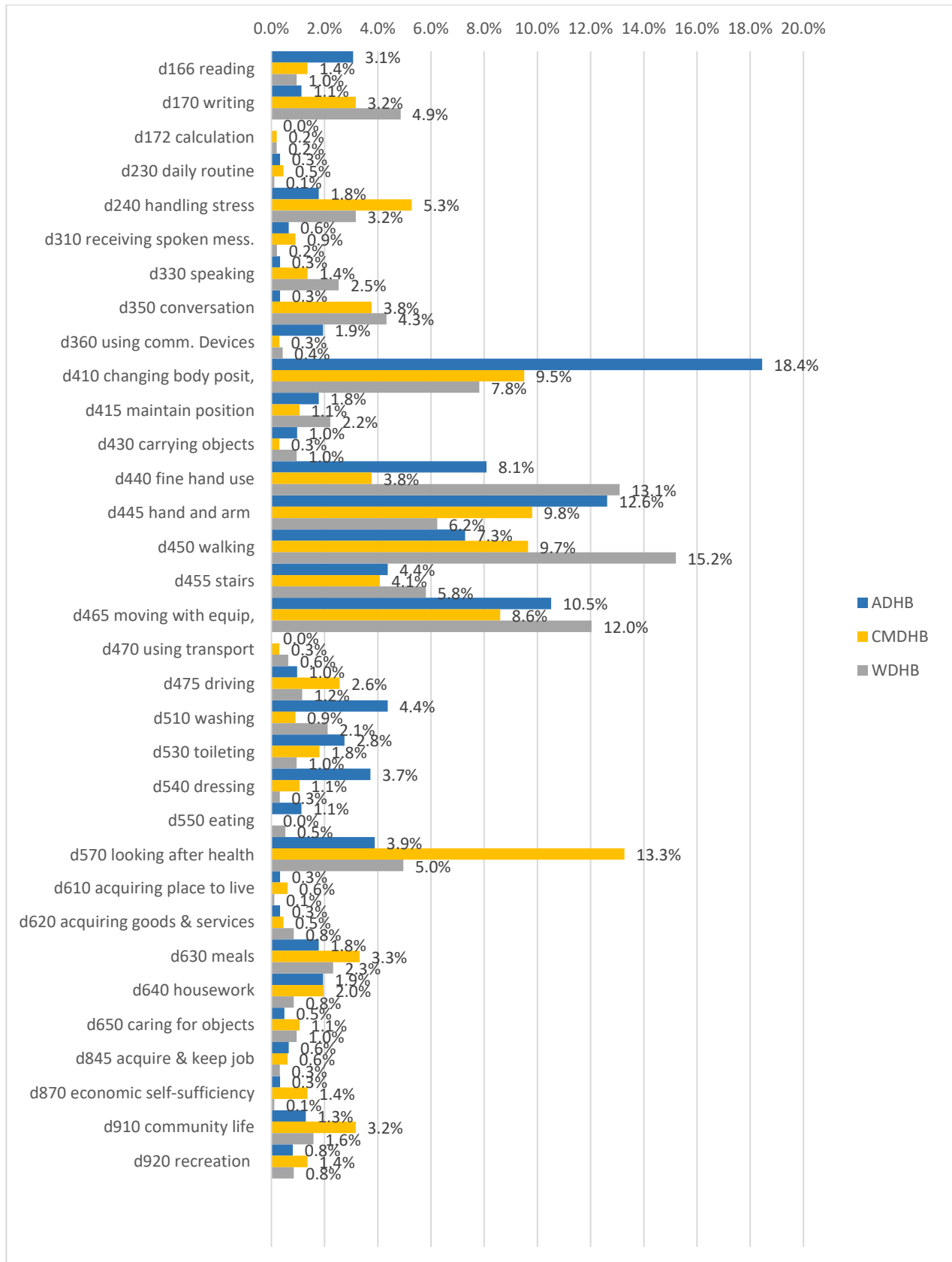
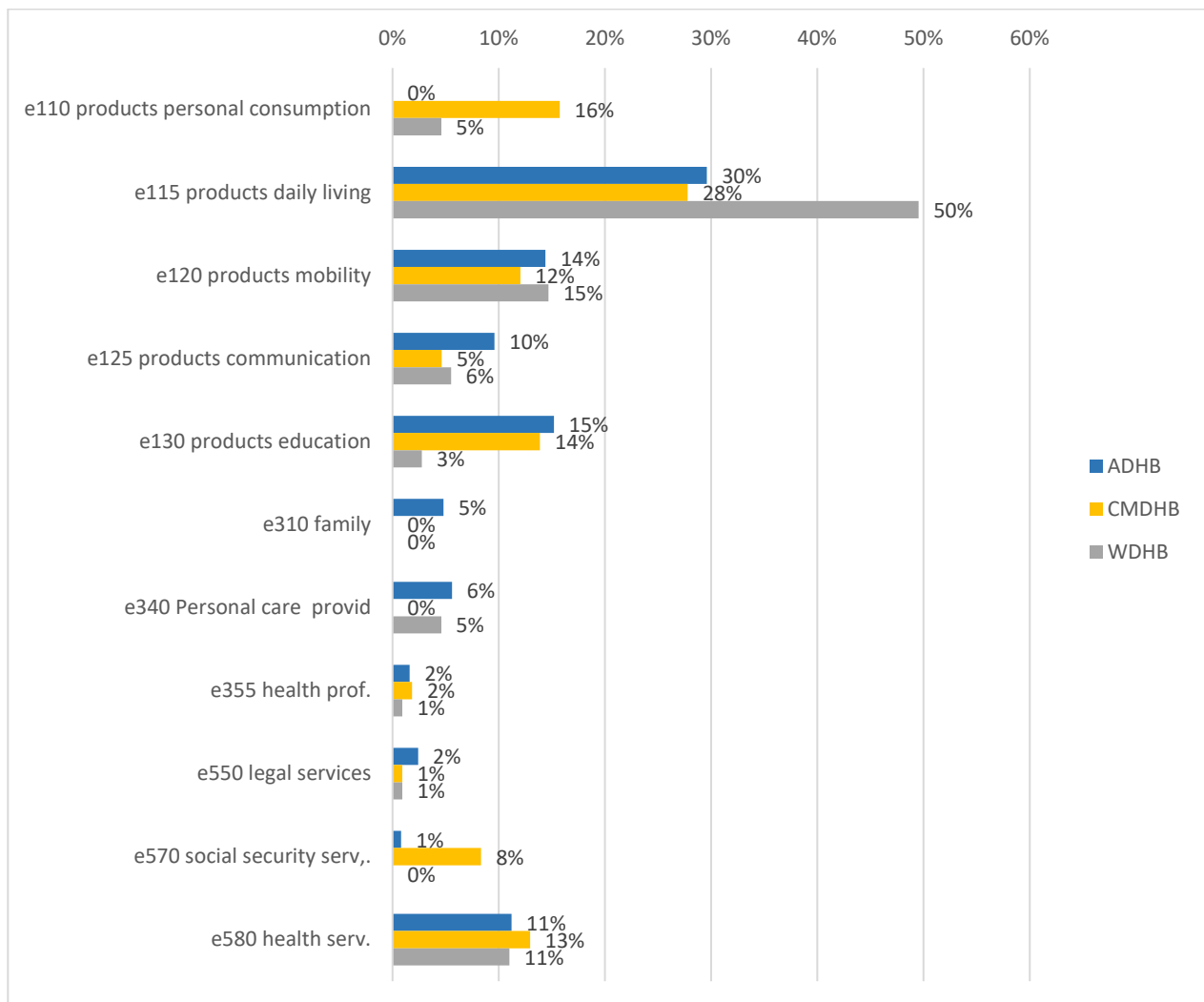


Figure 11 compares the frequency of environmental factor interventions across the three DHBS. The following intervention categories with five or fewer interventions were removed from the figure: *e155 building*, *e165 assets*, *e355 health professionals*, *e360 health-related professionals*, *e540 transportation services*, *e550 legal services*, *e555 associations* and *e575 social support services*. This figure shows there is wide variation between the DHBs for the following interventions: *e115 products for personal consumption* (CMDHB: 15.7%, WDHB: 4.6%, ADHB: 0%), *e115 products for daily living* (WDHB: 49.5%, ADHB: 29.6%, CMDHB: 27.8%) and *e130 products for education* (ADHB: 15.2%, CMDHB: 13.9%, WDHB: 2.8%).

Figure 11

Comparisons of Environmental factor interventions across each District Health board



A comparison of interventions provided by health professionals

Table 13 shows that the highest frequency of interventions was provided by physiotherapists (33.2%) and occupational therapists (25.9%), and the lowest was provided by psychologists (0.1%).

Table 13 *Interventions for each health professional*

Health professional	Interventions (n)	%
District nurse	153	3.50
Dietician	72	1.70
Occupational therapist	1,127	25.90
Psychologist	5	0.10
Physiotherapist	1,446	33.20
Speech language therapist	482	11.10
Social worker	94	2.20
Therapy assistant	974	22.40

Table 14 shows the frequency of interventions by health professionals in each DHB. There is a marked variation in the frequency of interventions per health professional. Compared to the other DHBs, ADHB did not provide a dietician, but it was the only DHB that provided a psychologist. ADHB had the highest frequency of physiotherapy interventions (42.9% compared to 35.4% for WDHB and 20.9% for CMDHB). CMDHB had the highest frequency of occupational therapy interventions (31.3% compared to 30.2% for ADHB and 19.7% for WDHB) and speech therapy interventions (14.3% compared to 11.2% for ADHB and 8.9% for WDHB). WDHB had the highest frequency of therapy assistant interventions (28.4% compared to 22.8% for CMDHB and 12.0% for ADHB).

Table 14 Interventions for each health professional in each District Health Board

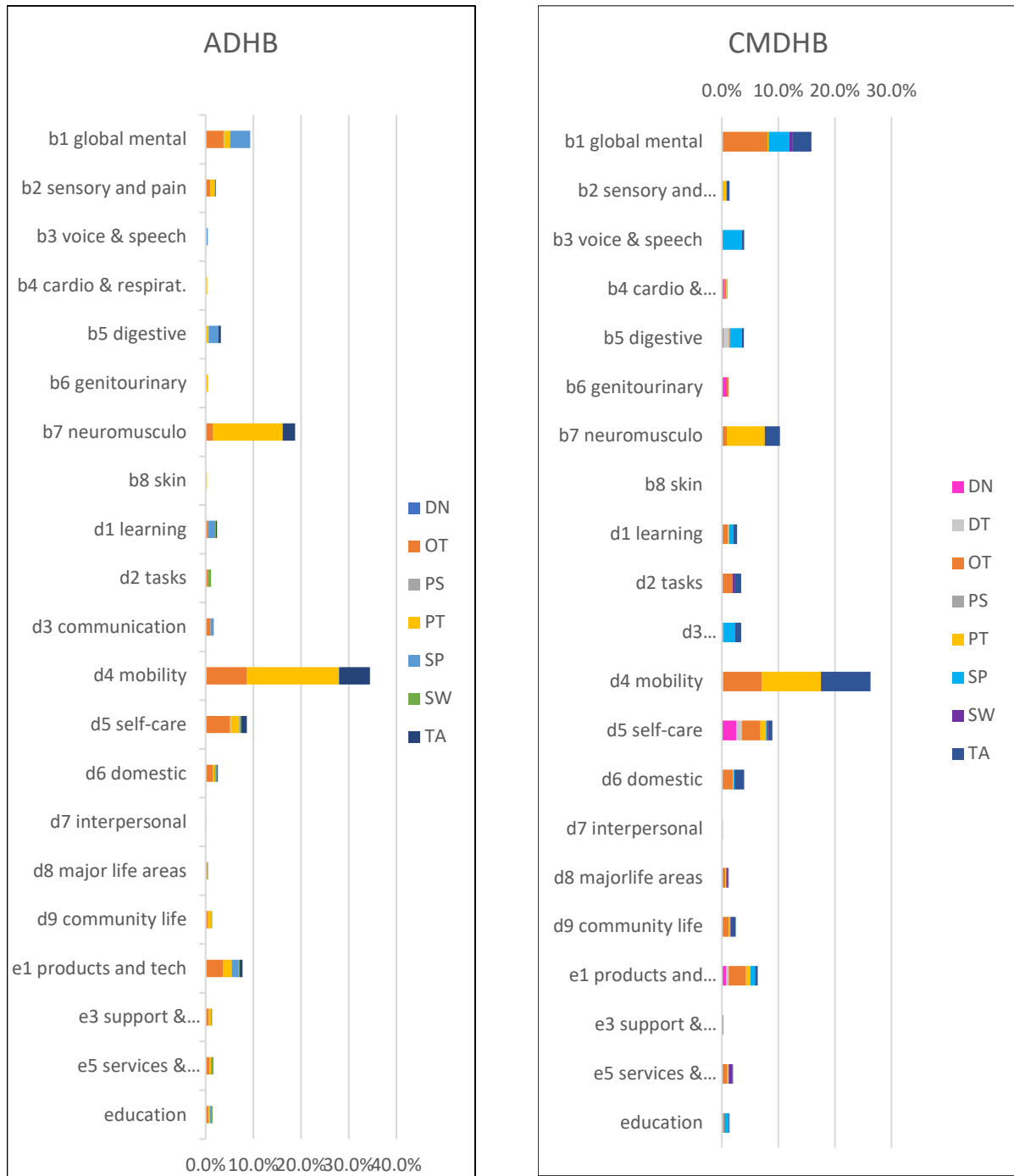
District health board	Nurse	Dietetics	Occupational therapy	Psychology	Physiotherapy	Speech therapy	Social worker	Therapy assistant
ADHB (<i>n</i> = 1,169)	0.4%	-	30.2%	0.4%	42.9%	11.2%	2.8%	12.0%
CMDHB (<i>n</i> = 1,262)	5.3%	2.7%	31.3%	-	20.9%	14.3%	2.7%	22.8%
WDHB (<i>n</i> = 1,922)	4.2%	2.0%	19.7%	-	35.4%	8.9%	1.4%	28.4%

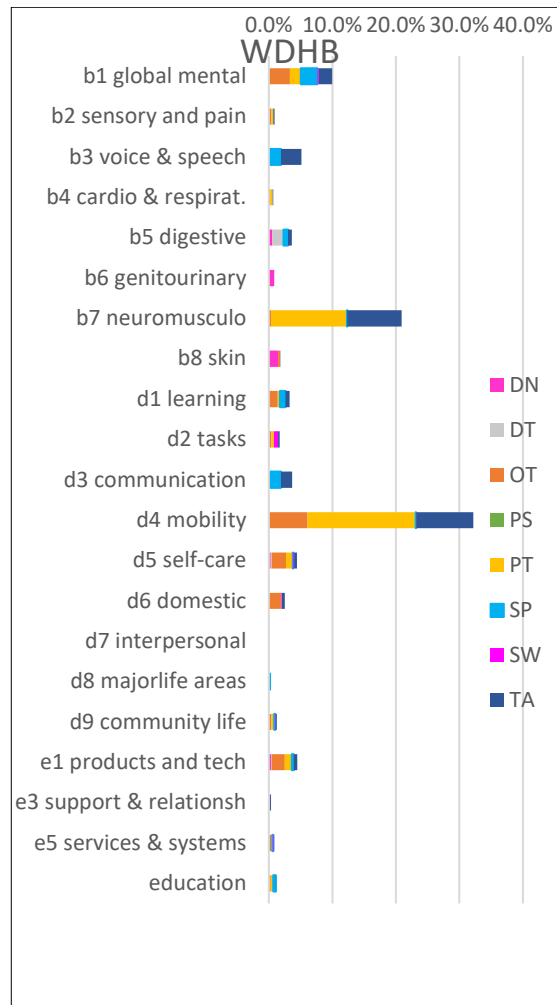
Note. ADHB = Auckland District Health Board; CMDHB = Counties Manukau District Health Board; WDHB = Waitematā District Health Board.

Figure 12 compares the interventions provided by health professionals in each of the three DHBs to the chapter levels of the EICSS. This figure shows that some chapter levels have interventions provided by more than one profession. The chapter levels with the most interventions provided by different health professionals are *b1 global mental functions*, *b7 neuromusculoskeletal*, *d4 mobility*, and *d5 products and technology*. Occupational therapy provides interventions in more chapters than other professions. Therapy assistants provide a high proportion of interventions for chapters *b7 neuromusculoskeletal* and *d4 mobility* in all DHBs and contribute to speech interventions *b3 voice and speech* and *d3 communication* in CMDHB and WDHB.

Figure 12

Comparison of interventions per Health professional in each DHB





Research question 2: Do CSR interventions address the scope of patient problems identified by the EICSS?

Missing body function interventions

Table 15 compares the interventions recorded in the data to the EICSS body function categories. Twenty-three EICSS categories could not be linked to interventions in the data. To understand if the missing categories had been validated from the patient perspective, they were compared to a study that used individual interviews to validate the Comprehensive ICF Core Set (Paanalahti et al., 2014) and another that used focus groups (Glässer et al., 2012) to validate the EICSS. This comparison found that *b450 additional respiratory functions* and *b540 general metabolic functions* were non-validated categories across the two studies and were missing in the data from this study. Consequently, these categories may not be common functional problems experienced by community stroke patients. Of the remaining 21 missing EICSS body function categories, seven are present in the NZCGSM (2010) and 14 are not present. Based on this process, the seven missing interventions considered important for CSR are ***b126 temperament and personality functions***, ***b156 perceptual functions***, ***b176 mental functions of sequencing complex movements***, ***b260 proprioceptive functions***, ***b640 sexual functions***, ***b715 stability of joint functions*** and ***b735 muscle tone functions***. These categories are presented in bold in Table 13.

Table 15

Comparison of the missing interventions to EICSS body function codes and NZCGSM 2010

Not in data but present in the EICSS	Not in the data but recommended by NZGSM 2010 chapter and page number
b110 consciousness functions	
b117 intellectual functions	
b126 temperament and personality functions	8.8 Carer support (p. 229)
b147 psychomotor functions	6.6.6 Cognition (p. 199)
b156 perceptual functions	
b176 mental functions of sequencing complex movements	6.6.5 Cognition (p. 191)
b180 experience of self and time	
b215 functions of structures adjoining the eye	
b230 sensations associated with hearing	
b240 sensations associated with hearing and vestibular function	
b260 proprioceptive functions	6.2.3 Sensorimotor impairments (p. 171)
b410 heart functions	
b430 haematological system functions	
b435 immunological system functions	
b450 additional respiratory functions	
b535 sensations associated with the digestive system	
b540 general metabolic functions	
b550 thermoregulatory functions	
b630 sensations associated with urinary functions	
b640 sexual functions	8.5 Intimacy and sexuality (p. 227)
b715 stability of joint functions	7.5 Subluxation (p. 201)
b735 muscle tone functions	7.3 Spasticity (p. 198)
b750 muscle reflex functions	

Note. Missing categories that were not validated in two validation studies are highlighted in yellow and the seven categories missing in the data but present in the NZCGSM are in bold.

Missing and additional activities and participation interventions

Table 16 compares the interventions present in the data for the activities and participation categories in the EICSS. It is important to note that there were no interventions assigned to Chapter 7 Interpersonal interactions and relationships, which covers interventions for interpersonal interactions and interpersonal relationships. Twenty EICSS categories could not be linked to interventions in the data. The missing interventions were compared to two validation studies (Glässel et al., 2012; Paanalahti et al., 2014). This analysis found that six interventions were not present in the two validation studies and were missing in the data from this study: *d110 watching*, *d115 listening*, *d120 other purposeful sensing*, *d130 copying*,

d315 receiving non-verbal messages, and d940 human rights. Consequently, these categories may not be common functional problems experienced by community stroke patients.

Nine categories were not present in the NZCGSM 2010 and five categories were present. These five are considered relevant for stroke rehabilitation. Two interventions linked to the process of learning: *d135 rehearsing, d155 acquiring skills*, one linked to mental functions: *d160 focusing attention*, one linked to communication: *d325 receiving written messages*, and one linked to employment: *d850 remunerative employment*.

There were four additional interventions present in the data and the ICF but were not part of the EICSS: *d435 moving objects with lower extremities, d650 caring for household objects, d660 assisting others, and d950 political life*.

Table 16

Comparison of missing interventions to the EICSS activity and participation codes and NZCGSM 2010

Not in data but present in the EICSS	Not in the data but recommended by NZGSM 2010 chapter and page number
d110 watching	
d115 listening	
d120 purposeful sensing	
d130 copying	
d135 rehearsing	6.6.4 Executive function (p. 191)
d155 acquiring skills	6.6.4 Executive function (p. 191)
d160 focusing attention	6.6.2 Attention (p. 181)
d220 undertaking multiple tasks	
d315 receiving non-verbal messages	
d320 receiving formal sign messages	
d325 receiving written messages	6.5.1 Communication (p. 182)
d345 producing messages using sign language	
d460 moving around in different locations	
d710 interpersonal interactions	
d750 informal social relationships	
d850 remunerative employment	8.4 Return to work (p. 227)
d855 non-remunerative employment	
d870 economic self-sufficiency	
d930 religion and spirituality	
d940 human rights	

Note. Missing categories that were not validated in two validation studies are highlighted in yellow and the five categories missing in the data but present in the NZCGSM are in bold.

Missing environmental factor interventions

Table 17 compares the interventions present in the data for the environmental factor categories in the EICSS. Twenty-one missing EICSS categories could not be linked to interventions in the data. To understand if the missing categories had been validated from the patient perspective, they were compared to two validation studies, one that validated the Comprehensive ICF Core Set (Paanalahti et al., 2014) and the other, the EICSS (Glässer et al., 2012). Four interventions were not present in validation studies and were missing in the data from this study: *e315 products for employment*, *e440 attitudes of personal carers*, *e455 attitudes of health-related professions*, and *e465 social norms*. Consequently, these categories may not be common functional problems experienced by community stroke patients.

To understand if the missing categories were relevant in the NZ context, the remaining missing EICSS categories were compared to the NZCGSM 2010. Three missing categories were present in the NZCGSM 2010, and consequently, these three categories are considered relevant for stroke rehabilitation: *e410 individual attitudes of family*, *e515 architecture and construction services* and *e590 labour and employment services, systems, and policies*. Fourteen categories were not present in the NZCGSM 2010.

Table 17

Interventions missing in the data but present in the EICSS and NZCGSM 2010

Not in data but present in the EICSS	Not in the data but recommended by NZGSM 2010 chapter and page number
e 135 products for employment	
e150 products public buildings	
e210 physical geography	
e240 light	
e250 sound	
e315 extended family	
e320 friends	
e325 acquaintances, peers, colleagues, and neighbours	
e410 individual attitudes of family	Part two: Pacific people and stroke- valuing family (p. 58) 8.1 Self-management (p. 222) 8.8 Carer support (p. 229)
e415 individual attitudes of extended family members	
e420 individual attitudes of friends	
e425 individual attitudes of acquaintances	
e440 individual attitudes of care providers	
e450 individual attitudes of health professionals	
e455 individual attitudes of health-related professionals	
e460 societal attitudes	
e465 social norms	
e515 architecture and construction services	6.4 Linked to activities of daily living (p. 231)
e525 housing services, systems, and policies	
e530 utilities services, systems, and policies	
e590 labour and employment services, systems, and policies	8.4 Return to work (p. 226)

Note. Missing categories that were not validated in two validation studies are highlighted in yellow and the three categories missing in the data but present in the NZCGSM are in bold.

Table 18 is an overview of the information presented in all ICF domains as captured in Tables 15, 16, and 17.

Table 18

Comparison of the EICSS categories not in the data with the ICF validation studies and NZCGSM 2010

ICF components	Total missing	Considered not relevant to CSR		Considered relevant to CSR
	Total missing	Not in validated studies (n)	Not in the NZCGSM 2010 (n)	Present in the NZCGSM 2010 (n)
Body function	23	2	14	7
Activities and participation	20	6	9	5
Environmental factors	21	4	14	3
Total	64	12	37	15

Research question 3: Are there differences in the type and frequency of interventions provided to Māori and non-Māori?

Data extracted from 74 Māori and non-Māori patient files were analysed based on the combined data from ADHB and CMDHB. This decision was taken because there was a low number of Māori patients in ADHB, no Māori in WDHB, and a high number of Māori in CMDHB. As a result, it was decided to prioritise data collection of Māori files over non-Māori in CMDHB. As there were unequal numbers of Māori and non-Māori files in CMDHB to do a comparison of interventions, it was decided to source the extra non-Māori files from ADHB, as both services provided a 12-week rehabilitation period and consequently had similar treatment intensity.

As seen in Table 19, this analysis used 34 Māori patient files (31 from CMDHB and 3 from ADHB) and 40 non-Māori patient files (23 from ADHB and 17 from CMDHB).

Table 19 *Number of Māori and non-Māori patient files for each District Health Board*

CSR service	Non-Māori (n)	Māori (n)	Total
ADHB	23	3	26
CMDHB	17	31	48
Total	40	34	74

Patient file selection used the following method: for the Māori patients, all the available Māori patients' files were used from CMDHB (n = 31) and ADHB (n = 3), and for the non-Māori patients, all the ADHB files

($n = 23$) were used and the first 11 non-Māori patients from CMDHB. There were a total of 1,081 interventions for Māori and 1,350 interventions for non-Māori. The average number of interventions for Māori was 31.79 ($SD = 33.36$) and 33.75 ($SD = 35.13$) for non-Māori, and the median number of sessions for Māori was 16.5 and 22.5 for non-Māori.

Figure 13 compares the interventions given to Māori and non-Māori at the EICSS chapter level. The chapters where Māori received more interventions than non-Māori were *b1 global mental functions* (39% vs 33%), *b3 voice and speech* (12% vs 2%), *b4 cardio and respiratory* (3% vs 1%), *d5 self-care* (22% vs 12%), *d6 domestic* (7% vs 6%), and *e5 services and systems* (25% vs 14%). The chapters where non-Māori received more interventions than Māori were: *b5 digestive* (11% vs 8%), *b7 neuromusculoskeletal function* (46% vs 30%), *d4 mobility* (65% vs 51%), and *e1 products and technology* (77% vs 69%).

Figure 13

Comparison of total interventions for Māori and non-Māori

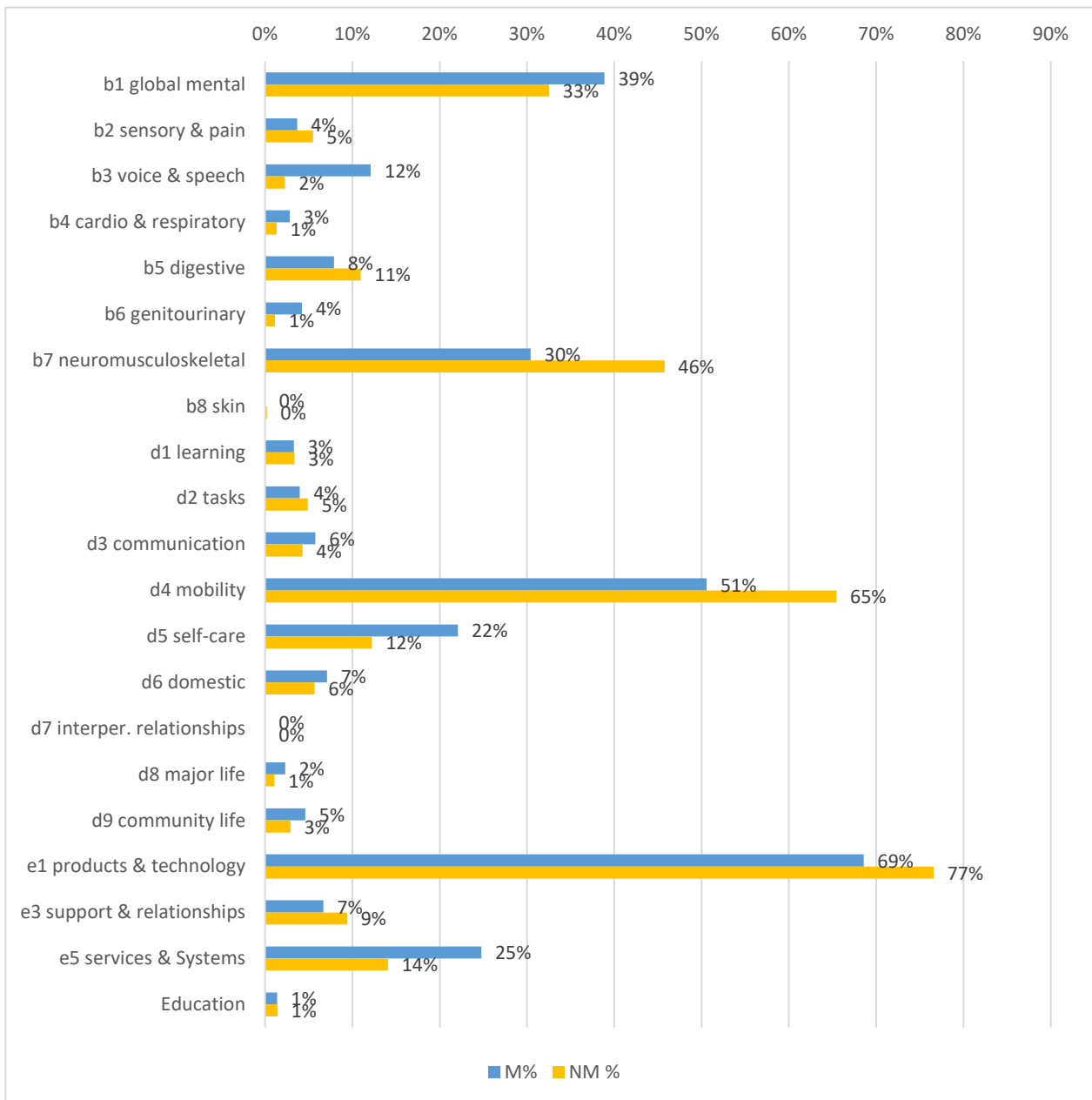


Table 20 compares the frequency of interventions and the number of people receiving an intervention for Māori and non-Māori. A chi-square analysis identified statistically significant results ($p < .05$). This analysis found Māori received significantly more interventions for *d5 self-care* ($p = .00$), *d9 community life* ($p = .03$) and *e5 services and system* ($p = .04$). The *e5 services and systems* result is strengthened by the finding that significantly more Māori patients than non-Māori patients ($p = .01$) received this intervention. Although Māori received significantly more interventions for *b3 voice and speech* ($p = .00$), *b6 genitourinary* ($p = .01$), *d8 major life areas* ($p = .03$), and *d9 community life* ($p = .03$), relatively small numbers of people received these interventions (*b3 voice and speech*: Māori 8, non-Māori 8; *b6*

genitourinary: Māori 5, non-Māori 2; *d8 major life areas*: Māori 3, non-Māori 5; and *d9 community life*: Māori 3, non-Māori 16), which suggests these differences should be interpreted cautiously.

Non-Māori received significantly more interventions for *b7 neuromusculoskeletal functions* ($p = .00$). The number of non-Māori who received this intervention was significantly more than the number of Māori ($p = .01$), which supports the finding that non-Māori received more interventions for this category.

Table 20 Comparison of Māori and non-Māori for number of interventions and number of people receiving interventions

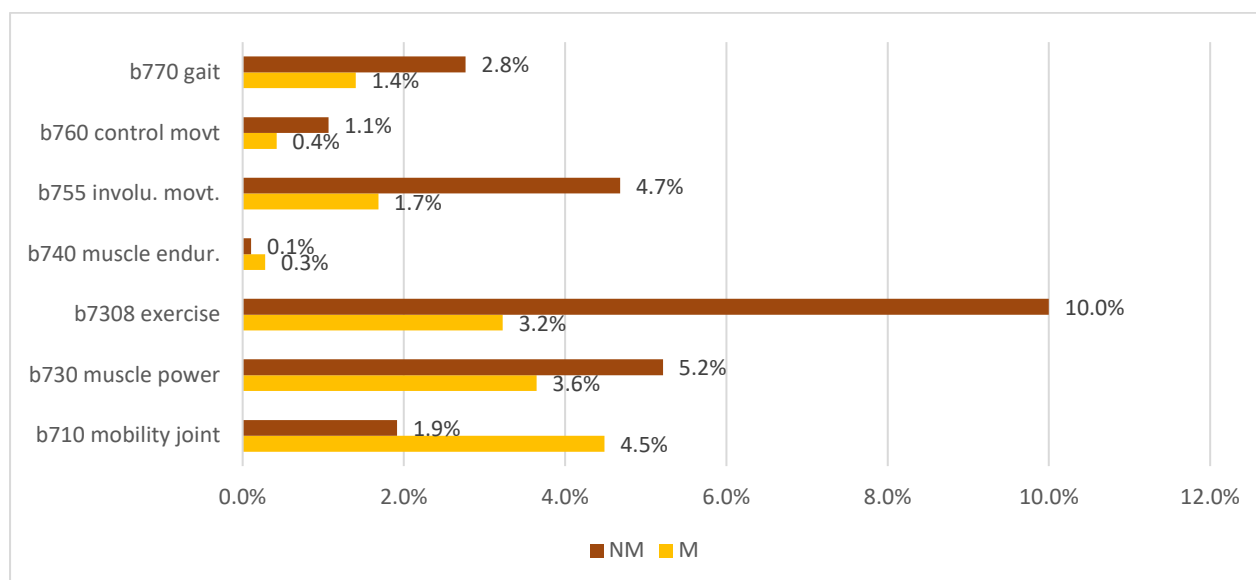
EICSS chapter	Interventions			People receiving interventions				
	<i>n</i>		<i>p</i> -value	%		<i>n</i>		<i>p</i> -value
	Māori	Non-Māori		Māori	Non-Māori	Māori	Non-Māori	
b1 global mental	138	172	.98	39%	33%	47	56	.95
b2 sensory & pain	13	29	.07	4%	5%	10	8	.73
b3 voice & speech	43	12	.00	12%	2%	8	8	.48
b4 cardio & respiratory	10	7	.23	3%	1%	9	7	.35
b5 digestive	28	58	.02	8%	11%	10	14	.69
b6 genitourinary	15	6	.01	4%	1%	5	2	.31
b7 neuromusculoskeletal	108	242	.00*	30%	46%	33	84	.01*
b8 skin	0	3	.12	0%	0%		3	.10
d1 learning	20	22	.05	3%	3%	9	12	.84
d2 tasks	24	32	.80	4%	5%	12	15	.77
d3 communication	35	28	.07	6%	4%	16	10	.35
d4 mobility	307	428	.07	51%	65%	70	111	.44
d5 self-care	134	80	.00*	22%	12%	37	22	.31
d6 domestic	43	37	.08	7%	6%	22	17	.31
d7 interpersonal relationships	2	1	.43	0%	0%	2	1	.46
d8 major life	14	7	.03	2%	1%	3	5	.07
d9 community life	28	19	.03	5%	3%	3	16	.98
e1 products & technology	72	98	.56	69%	77%	36	44	.74
e3 support & relationships	7	12	.50	7%	9%	6	8	.97
e5 services & systems	26	18	.04*	25%	14%	18	10	.01*
Education	15	19	.96	1%	1%	9	11	.92

Note. Significant differences for interventions and numbers of people receiving interventions are indicated with an asterisk.

Figures 14, 15 and 16 display the categories in the chapters where there were significant differences between Māori and non-Māori. In Figure 14, for neuromuscular functions, non-Māori received more interventions in 5/7 categories, and *b7308 exercise* was the most frequent intervention. In Figure 14, *d5 self-care*, Māori received more interventions than non-Māori, and the most frequent intervention was *d570 looking after one's health*. In Figure 16, *e5 services and systems*, Māori received more interventions in 5/6 categories and the most frequent intervention was *e580 health services and systems*.

Figure 14

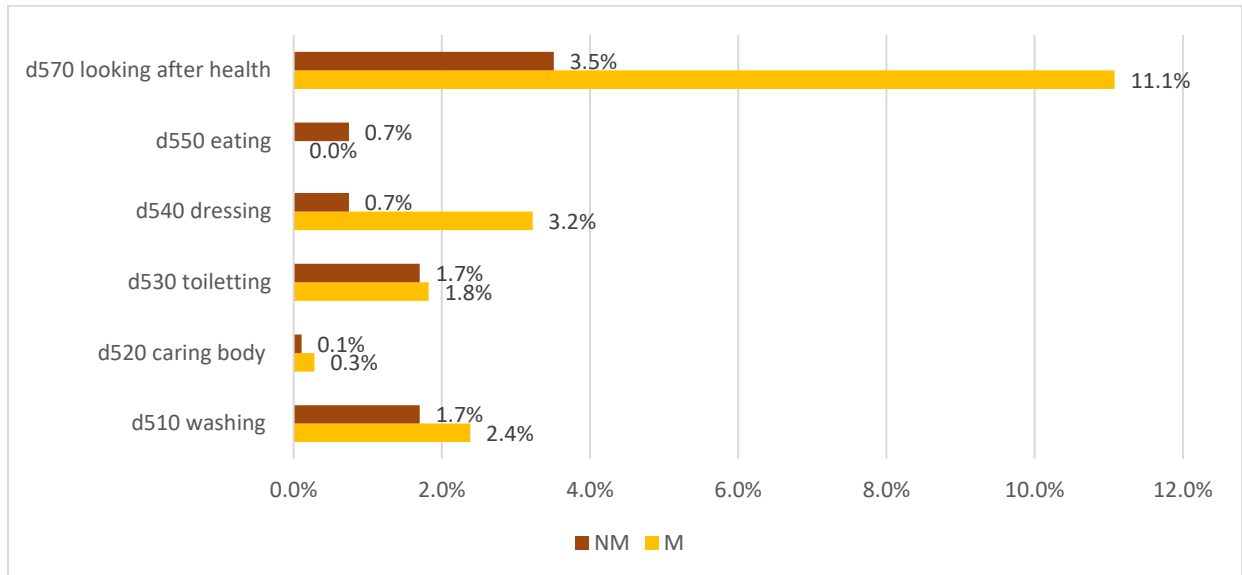
Comparison of interventions for b7 neuromusculoskeletal interventions for Māori and non-Māori



Note. NM = non-Māori; M = Māori.

Figure 15

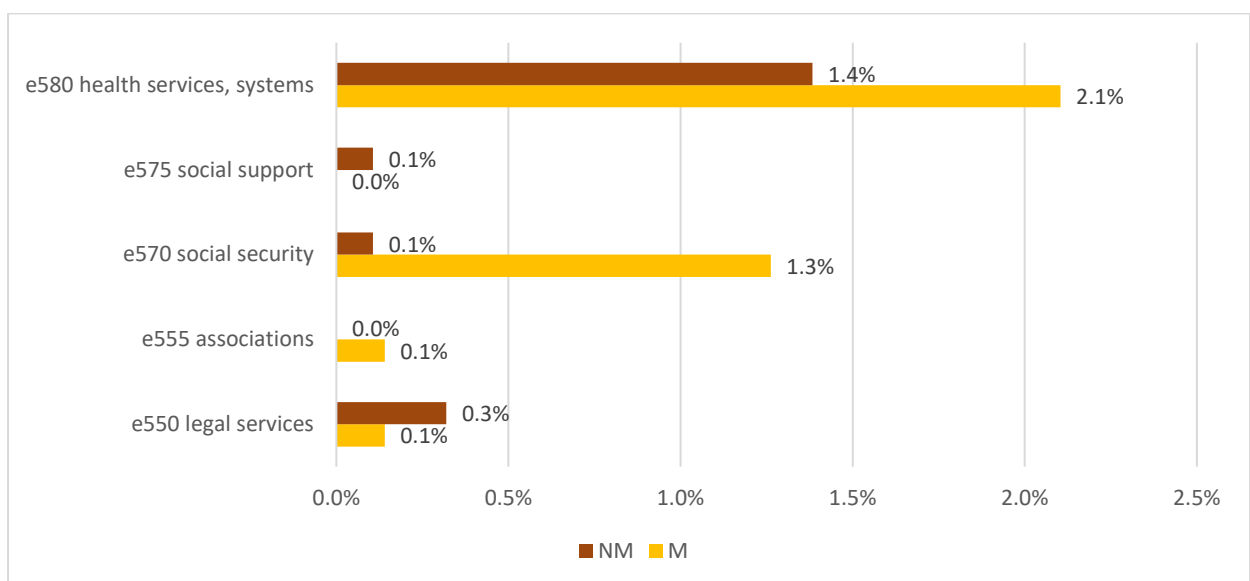
Comparison of d5 self-care interventions for Māori and non-Māori



Note. NM = non-Māori; M = Māori.

Figure 16

Comparison of e5 services and systems interventions for Māori and non-Māori

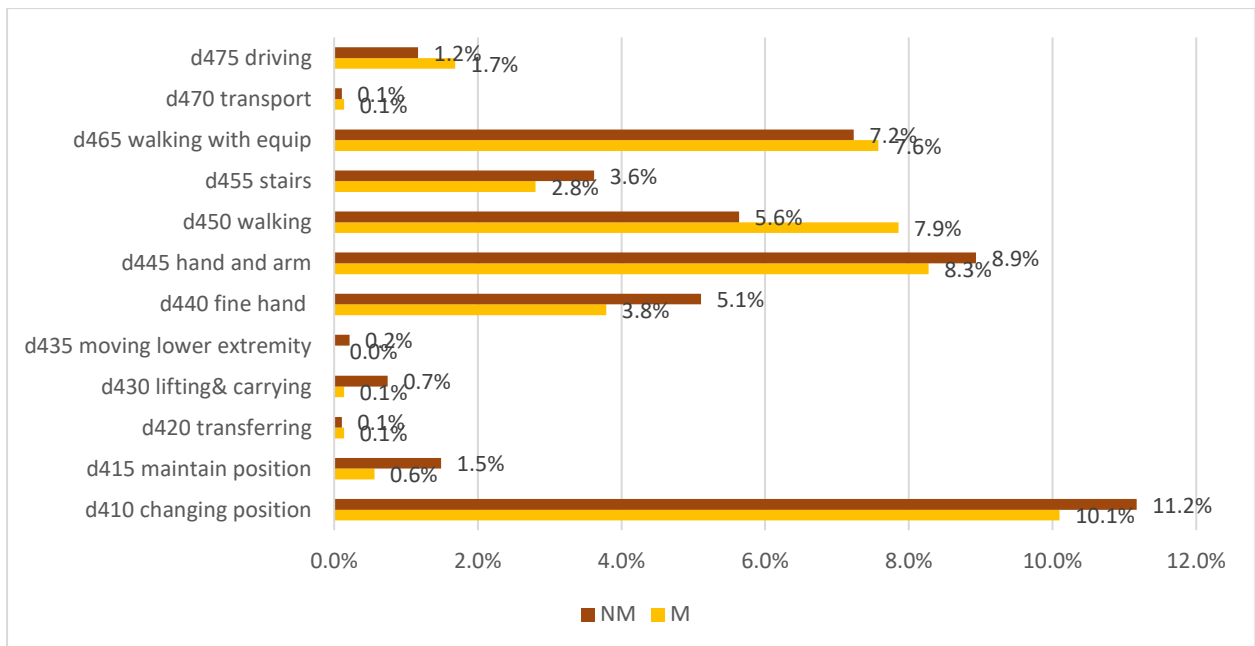


Note. NM = non-Māori; M = Māori.

Although the differences in interventions were not significant for *d4 mobility*, Figure 17 shows non-Māori received slightly more interventions than Māori for 6/9 categories. This resulted in Māori receiving fewer interventions for *d445 hand and arm* (8.3% vs 8.9%), *d440 fine hand use* (3.8% vs 5.1%) and *d410 changing body position* (10.1% vs 11.2%), but more interventions for *d450 walking* (5.6% vs 7.9%).

Figure 17

Comparison of d4 mobility interventions for Māori and non-Māori



This chapter has presented the results for the following three research questions that have guided this thesis: 1) What are the patterns of community stroke rehabilitation interventions in Auckland, 2) Do CSR services address the scope of patient problems identified by the EICSS? and 3) Are there differences in the type and frequency of interventions provided to Māori and non-Māori?

For research question 1, it was found that CSR services provided interventions across most chapters of the EICSS. The chapters without interventions were *d7 interpersonal interactions and relationships*, *e2 natural environment* and *e4 attitudes*. The chapters with the highest frequency of interventions were *d4 mobility* (31%), *b7 neuromusculoskeletal functions* (17%) and *b1 mental functions* (12%). The most frequent interventions from each ICF domain were *b7308 exercise* (combination of improving muscle strength endurance and coordination) (6.1%), *d410 changing body position* (5/8%), *d450 walking* (5.8%) and *115 products of daily living* (2.8%). From each domain of the ICF, people received the most interventions for *b130 energy and drive* (55%), *d570 looking after one's health* (60%), and *e115 products for daily living* (2.8%). There were 11 body functions, 24 activities and participation and 11 environmental factors categories with 0.4% or fewer interventions.

To understand whether organisational differences across each DHB were impacting these results, this chapter compared the DHB's provision of interventions against the broad chapters of EICSS and, in more detail, by comparing the interventions to the categories to the ICF domains (body function, activities and participation and the environmental factors). This comparison found that all DHBs had their highest frequency interventions in the following chapters: *b1 mental functions*, *b8 neuromusculoskeletal functions*, *d4 mobility*, and *e1 products and technology*. However, there were wide variations in the number of interventions provided by each DHB at the chapter and category levels. Comparing the frequency of interventions by health professionals, it was found that there were varying levels of interventions across the DHBs for each profession. The most notable difference was the absence of psychological interventions in two-thirds of the DHBs. While *b1 global mental functions*, *b7 neuromusculoskeletal* and *d4 mobility* had high-frequency interventions, it was evident that two or more different health disciplines were providing interventions for this ICF category.

For research question 2, the missing interventions were compared to two validated studies and the New Zealand Stroke Guidelines 2010 recommendations. This comparison found that patients were not receiving 15 interventions that were considered important in CSR. In the body function domain, these categories were *b126 temperament and personality functions*, *b156 perceptual functions*, *b176 mental functions of sequencing complex movements*, *b260 proprioceptive functions*, *b640 sexual functions*, *b715 stability of joint functions*, and *b735 muscle tone functions*. In the activities and

participation domain, these categories were: *d135 rehearsing*, *d155 acquiring skills*, *d160 focusing attention*, *d325 receiving written messages*, and *d850 remunerative employment*. Lastly, the missing environmental factor categories were *e410 individual attitudes of family*, *e515 architecture and construction services* and *e590 labour and employment services, systems, and policies*.

Research question 3 compared the interventions for Māori and non-Māori, using all the Māori patient files in CMDHB and ADHB ($n = 34$) and a random sample of non-Māori from these DHBs ($n = 40$). This comparison found that Māori received significantly more interventions than non-Māori for *d5 self-care* and *e5 services and systems*, and non-Māori received significantly more interventions than Māori for *b7 neuromusculoskeletal functions*.

Based on interviews with 15 CSR staff on the reasons for the intervention patterns in Study One, the next chapter presents the findings for research question 4 “What are the CSR therapists’ explanations for the patterns of interventions found in Study 1?”

Chapter 8: Findings from Study 2

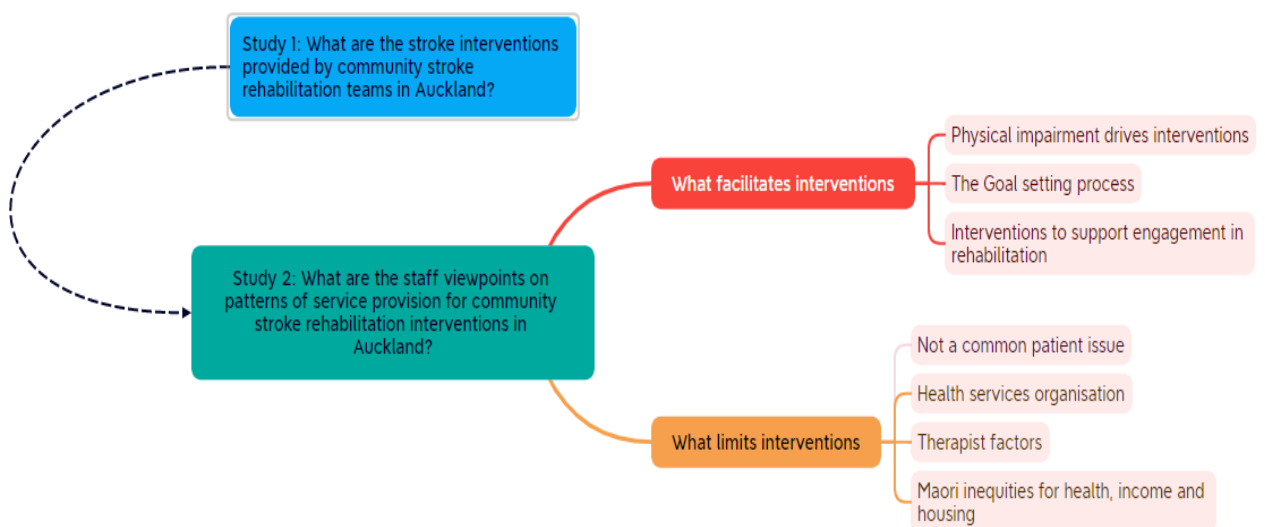
Introduction

In Study 1, I selected the interventions from digital patient records from CSR services provided by three DHBs in Auckland and coded them to the EICSS (Starrost et al., 2008). For Study 2, my research question was to explore the reasons for the pattern of interventions found in Study 1. As described earlier, data to address this qualitative inquiry were generated from 15 individual interviews; 10 staff were recruited from two DHBs who responded to summaries of intervention frequencies generated from Study 1, and five staff were recruited from the DHB that supplied the Māori data. This second group were explicitly asked about observed differences in the patterns of interventions for Māori and non-Māori.

The themes generated from the data were organised according to what facilitated and what limited interventions. Interventions were facilitated by the common patient experience of physical impairment, patient goals, and the need to provide interventions that enabled the patient to engage in rehabilitation. Interventions were limited by the issue being uncommon in this patient group, the impact of the health service organisation, therapist factors, Māori presenting with poor health, low income, and housing issues. The interrelationship of these themes is illustrated in Figure 18.

Figure 18

Main themes from Study Two



In the following sections, each theme (coloured pink in Figure 18) will be discussed in detail. To provide context, this next section presents a demographic description of the participants' disciplines and the number of years since qualifying.

Participants

There were 15 female participants, 7 were physiotherapists, 4 were occupational therapists, 2 were speech language therapists, 1 was a social worker, and 1 was a dietician. Six staff had been working in the CSR service for 1 year or less, 5 had been working there for 1–2 years, 3 for 2–4 years and 1 person had worked in the service for 10 years. The views and practices discussed by this group of staff may differ from those whose interventions were investigated in Study 1, as only three staff members interviewed in Study 2 were working for the community stroke services when the Study 1 data was collected in 2017. Direct participant quotes are used to illustrate the findings, and pseudonyms have been used.

What facilitates interventions?

As outlined above, participant accounts elucidated three key issues that support frequent provision of interventions. These issues will be presented in this order: most patients present with physical impairment; the interventions are guided by patient-led goals and most patients require interventions to support their engagement in rehabilitation.

Theme 1: Physical impairment drives interventions

Physical impairment is a common symptom after stroke and appeared to be the primary reason for the most high-frequency interventions found in Study 1 for ICF chapters *b7 neuromusculoskeletal functions* (17%) and *d4 mobility* (31%) (Figure 4, Chapter 7). Therapists reported that when patients started CSR, patients selected walking as the most important goal to achieve. *“Walking and mobility, independence and mobility, is one of the top goals for generally everyone”* (Jill). The goal of walking was linked to the ability to do functional activities and to access the community, and *“the majority of the stroke patients would like to be able to walk again or to transfer to, or to access the community. It’s all about mobility and, physical work”* (Lucy). The high focus on physical abilities was because patients were *“very quick to recognise their physical impairments and what they can’t do... rather than things they might be able to kind of compensate for”* (Carol). Patients were also concerned about how their physical appearance might be perceived by others, and *“for a lot of stroke clients, that physical picture and potentially what they look like to people, that’s important to them”* (Carol).

Following walking, fine hand use appeared to be the next most pressing goal. *“Fine hand use also doesn’t surprise me, after walking. The next thing they want to [do is to] be able to use their hands to*

do things for themselves" (Linda). To improve upper limb functioning and walking, it was thought therapists *"have to work at the impairment level to build their [patients'] strength and their range of motion before you can take them forward to the functional side of tasks"* (Jill). The participants' viewpoints were supported by the intervention frequency data at the category level. The highest frequency body function interventions were *b7308 exercise* (6.1%) and *b730 muscle power* (4.6%). This trend continued for the activities and participation categories, with the highest frequency interventions for *d410 changing body positions* (5.8%), *d450 walking* (5.8%), *d465 walking with equipment* (5.4%), *d445 hand and arm use* and *d440 fine hand use* (both at 4.6% frequency) (Figures 5 & 6, Chapter 7).

One therapist reported there was evidence showing it takes 6 weeks to improve muscle strength and suggested this was the reason for the high frequency of physical impairment interventions, *"for muscle to gain strength significantly it takes about 6 weeks and we're only there for 6 weeks so, I think that could be why"* (Jill). Due to the shorter rehabilitation period in the 6-week EDS, restoring physical impairment may have been a greater priority in this service compared to the 12-week CSR services. This is supported by the results in Chapter 7 as compared to the other DHBs this service had the highest percentage of interventions for *b7 neuromuscular functions*.

High provision of walking, changing position, and upper limb interventions were supported by the provision of these interventions by three disciplines in the rehabilitation service: physiotherapy, occupational therapy, and therapy assistants. When asked the reasons for high frequency interventions in these areas, Jill said, *"all of us, well both physio, OT and therapy assistant would work on all of those for pretty much all patients, that could be why it falls into really high percentage"*.

Several participants also explained that it was usual practice for physiotherapists to develop an exercise programme and ask therapy assistants to carry them out, *"I'll generally do quite a comprehensive exercise programme and our therapy assistants will usually take the lead on that"* (Linda). Therapy assistants are not formally trained; consequently, it is preferable that the interventions delegated to them are repetitive, have standard instructions, and allow patient progress to be easily observed. Exercise interventions meet these criteria, as the exercise itself can be an *"objective marker"* (Lauren) on whether the exercise should be changed or modified. One therapist said that information on exercise programmes is available online, and *"handouts"* (Tracy) are readily available. All CSR services employ therapy assistants (Table 14, Chapter 7), and consequently, exercise programmes can be developed by physiotherapists and provided to patients via the therapy assistant. Exercise interventions are relatively easy to provide, as they can be

modified to the patient's needs and monitored by observation. Exercise intervention provided by therapy assistants is a cost-effective use of staff time and allows patients to have intensive daily sessions, which are recommended to promote early motor recovery (Stroke Foundation, 2022).

The emphasis given to motor performance by both patients and therapists may have been the reason why therapists provided equipment to address mobility concerns. This may have been the reason why the highest frequency for environmental factor domain interventions were *e115 products of daily living* (2.8%) and *e120 products of mobility* (1.1%) (Figure 11, Chapter 7). This is because *e115 products of daily living* cover raised toilet seats and chair raisers and *e120 products of mobility* cover walking frames and sticks. The link between equipment and patients' mobility was discussed by many therapists. Equipment was used to provide "*postural feedback for walking*" (Carol) and to improve the ability to stand from sitting: "*Raisers for sofas. Armchairs. Beds, bed lever, shower stool... And over toilet frame. It's mostly raising surfaces!*" (Bella) and to promote independence, "*To continue having their independence or ...to do something they are not able to do... some sort of equipment ...can make the task ...easier... they're more likely to go and do it*" (Lucy).

Study 1 findings showed that there were higher frequency interventions for *b7 neuromusculoskeletal function* (17%) compared to *b1 mental functions* (12%) (Figure 7, Chapter 7). This may have occurred because patients placed a higher priority on physical recovery or that physical impairments were more immediately apparent than regaining cognitive function. One participant said, "*it might not be until later in their rehab that ...they recognise that, ooh actually my thinking processes aren't that great*" (Carol). The patient or family's ability to compensate for cognitive impairment may be an additional reason why cognitive interventions are not as frequent as physical impairment interventions, "*So sometimes they can kind of compensate for memory or, or they'll have family members who are doing a lot of things for them that kind of help compensate*" (Carol).

Physical impairment drives the interventions for neuromuscular impairment, mobility, and the provision of adaptive equipment. Participants gave several explanations as to why higher frequency exercise and mobility interventions exist. Physiotherapy and occupational therapy provide these interventions as their scopes of practice address the ICF's neuromusculoskeletal and mobility chapters. Lastly, high physical impairment creates a need for adaptive equipment to compensate for movement loss and increase independence.

Theme 2: Goal-setting process

The use of patient-led goals may have contributed to the type and frequency of interventions provided to patients. Across the three services, therapists asserted they "*try our best to be very client centred and focused and goal oriented for them*" (Carol) and "*always have that conversation at the*

beginning of our service” (Ann). This was a reliable feature of service delivery that participants could “trust” (Ann). “We help people have conversations with the patient about what they actually want, and it doesn’t really matter about whether it’s necessarily going to be achievable” (Sarah). The assessment process that proceeded goal setting prompted therapists to “think about their [patients’] impairment and ...their participation which is often where we get involved in terms of helping them to achieve their goals” (Jill).

Patient goals were seen as an important driver of interventions delivered. In the 12-week services, non-achievement of a goal could provide a reason to extend the rehabilitation period beyond 12 weeks. *“We have extended it past the 12 weeks for some patients. It just depends [on] if they’ve got more goals that they want to achieve or if they’re progressing and they’re still engaged with us” (Emma).*

More interventions for *b7 neuromusculoskeletal functions* and *d4 mobility* may have occurred because all services used patient-led goal-setting tools with similar categories to the ICF. Patient goals were an important driver of patient interventions, as evidenced by participants in the 12-week CSR services who said that the non-completion of goals was a reason for extending the rehabilitation period.

It appears that since the data collection for Study 1 in 2017, CSR teams have made greater use of goal-setting tools. Participants from two different CSR services described using the Schedule of the Evaluation of Individual Quality of Life (SEIQoL) or the Canadian Occupational Performance Measure (COPM) to set goals with patients, *“we’ve recently changed our goal-setting process of really trying to get the patient involved a bit more ... We’ve started using the COPM. We’ve found that SMART goals tended to be very ...therapist led and ...research shows it’s not really that useful in healthcare” (Sarah).* The fact that services have recently introduced formal goal-setting tools indicates that services are refining practices that were present when the Study 1 data was collected. This further supports the theme that staff who contributed to Study 1 in 2017 were working on patient-led goals.

The participants reported that the ICF categories had recently been incorporated into the initial assessment form, *“I know with our most recent initial assessment ...has ...integrated the ICF ... model into that assessment and the questions” (Carol).* Incorporating the ICF into the assessment form made it easier for therapists to see how their interventions contributed to the patient’s overall functioning, *“as a physio we ... have a tendency to look more at the physical function and the impairments and want to focus on that, but having this assessment form helps us to see that bigger picture we are working on [the impairment]” (Carol).* One participant recognised that the initial

assessment used by the service was similar to the ICF categories and *“I think what we do, with our patients, almost covers most of this area [ICF] anyway”* (Jill).

Theme 3: Interventions to support engagement in rehabilitation

This theme explains the reasons why, in Study 1, *b130 energy and drive* interventions had a 3.0% frequency (Figure 5, Chapter 7) and were ranked fourth amongst the most provided body function interventions. Fatigue was a common issue for patients, *“Very commonly...we see problems with fatigue and sleep”* (Lisa). Participants from all services said patients *“don’t understand the role of fatigue and that it is having a huge impact on their daily function”* (Linda). In addition, therapists reported some patients had a poor understanding of the rehabilitation process, which led them to believe they were sick and needed greater rest to recover. *“I’m sick, I’m unwell, I need to rest”* (Penny). When patients did too much activity or too little, this was considered a barrier to the patient’s progress *“because that’s brought up at every case conference if we talk about what were the barriers... someone asks is fatigue a barrier”* (Tracy).

In the 6-week service, patients could receive interventions 5 days per week, resulting in therapists being proactive in preventing high levels of fatigue. *“It is full-on. So, we monitor ...their activity tolerance ...their cognitive function and we always ...allow about 2 hours in between our sessions at least”* (Bella). Therapists managed this situation if a patient presented with fatigue by discussing with the patient *“questions about sleep and water and pacing and having visitors around”* (Bella).

Fatigue education was needed in the community rehabilitation setting as patients were doing more in their home environment, *“fatigue levels when they first get home, especially for the first week or two are so much higher than they ever were in the inpatient setting. The patient’s understanding of that... is really crucial because otherwise, they can feel really down”* (Linda).

Fatigue education consisted of encouraging the patient to gradually increase their activities while also taking short recovery breaks. *“Fatigue management isn’t about resting, it’s about balancing, doing some activity to build your strength, so you don’t get weaker, balanced with some rest so you can do more ...over time”* (Penny). Therapists addressed this issue by *“building routine, pacing, prioritising, and thinking ahead”* (Lisa).

One participant reported they *“spend a lot of time initially and then just a few follow-up conversations”* (Linda) on fatigue management. All therapists monitored patients’ fatigue levels and encouraged patients to use fatigue management strategies, *“we all do that automatically... physio or OT, speech and language therapist, therapy assistant”* (Bella).

This theme explained why there were high-frequency interventions for *b130 energy and drive*. It was reported that all staff provided fatigue management education, and most participants said patients were unaware of how activity levels could be a barrier to rehabilitation. Fatigue was particularly an issue when patients were first discharged home and when patients were receiving the intensive 6-week CSR service. In this service, all therapists closely monitored the patient for fatigue symptoms and provided ongoing fatigue management education interventions.

What limits interventions?

This section outlines the reasons for the limited provision of some interventions for community stroke patients that were observed in Study 1. The four themes that will be discussed are: Theme 4: Not a common patient issue; Theme 5: Health service organisation; Theme 6: Therapist factors; and Theme 7: Māori inequities in health, income, and housing.

Theme 4: Not a common patient issue

Participants thought low frequency or missing interventions (Table 15, 16 and 17, Chapter 7) were because patients did not commonly present with these issues while receiving CSR. Low-frequency interventions for *b415 blood vessels* (0.3%), *b420 blood pressure* (0.2%), and *b440 respiration function* (0.1%) were due to patients needing to be “stable” (Linda) before referral to CSR. Interventions for *b810 protect skin* (1.3%), *b820 repair of the skin* (0.3%), and *b525 defecation* (0.3%) were low frequency because “skin and the defecation are... not common issues for clients” (Carol). Lower-frequency interventions in these areas may have occurred because the CSR did not have nursing staff in the team. As one participant said, these are “more of the nursing things, we don’t have a nurse in the team ...so that may be a reason why” (Lauren).

There were no interventions for *b260 proprioception* (Table 15, Chapter 7) and low-frequency interventions for *b270 temperature* (0.1%). Staff explained this was because it was rare to have patients with significant issues in these areas, “I haven’t had someone who has [had] significant problems with proprioception” (Jill). In the activities and participation domain, interventions for *d172 calculation* (0.2%) (Table 16, Chapter 7) were considered uncommon and “learning currency you know, wouldn’t be that common” (Lisa).

Low-frequency interventions for some categories could have occurred because these issues did not require intensive or continuous interventions. This appears to be the reason for low-frequency interventions for *b280 pain* (0.4%) as “It’s not uncommon that a patient might develop pain during our stay but usually ...it wouldn’t be someone with persistent pain all the way through” (Jill).

Different population needs in each DHB may have contributed to marked differences in interventions between each DHB. An example of this is the interventions linked to *d610 acquiring a place to live* (0.3%, 0.6%, 0.1%) and *e570 social security, services and policies* (0.8%, 8.3%, 0.0%) (Figure 10 and 9, Chapter 7). In one DHB, participants thought there were low numbers of interventions because patients needed to have a home to enter the service and “*to be discharged into our service they have to have a place to go*” (Linda). For most patients, housing issues were not a common problem, “*but it does happen from time to time, but they’re in a safe environment at the time of our input*” (Linda). In another DHB, housing needs were more frequently addressed, and a participant from this DHB said, “*I’ve probably had to do more referrals to social housing for accommodation for them [Māori] in terms of that*” (Selena).

Theme 5: Health service organisation

This theme describes the factors in the health services that limit the provision of interventions and is broken up into three sub-themes: differences in resource use, staff capacity, and other services providing interventions.

Sub-theme 5.1: Differences in resource use

There were differences in the frequency of interventions between the DHBs for *b7 neuromusculoskeletal functions* (ranging from 21%, 10% and 19%) and *d4 mobility* (ranging from 32%, 26%, and 34%) (Figure 9 and 10, Chapter 7). Compared to the two 12-week services, the 6-week service had high frequency interventions for both *b7 neuromusculoskeletal functions* (21%) and *d4 mobility* (32%). This could have been because the 6-week service provided an “*intensive programme so the person would see one or two of us every day, Monday to Friday*” (Bella). In contrast, the 12-week programme provided a less intensive service and treatment frequency depending on the “*person’s impairments, what their goals are...and sometimes they can’t tolerate a lot of input or intensity*” (Carol). Participants reported they saw patients “*two to three times a week... whereas others you might see once a week*” (Carol). One 12-week service had higher frequency interventions than the other 12-week service for *b7 neuromusculoskeletal functions* (19% vs 10%) and *d4 mobility* (34% vs 26%) (Figure 9 and 10, Chapter 7). This may have been because this service offered patient fitness classes as well as the usual CSR service, “*we’ve got hydrotherapy, Pilates, like a fitness group now we have a clinic*” (Tracy).

Participants from all services reported they did not have time to provide interventions for *d620 acquiring goods and services* (0.3%) and *d920 recreation and leisure* (0.5%) (Figure 6, Chapter 7). Due to the time needed to organise a shopping outing, this intervention became a lower priority for therapists, and “*acquiring goods and services is low... I think that’s probably lower due to time, just*

the ability to set that out, the logistics about it... because it would be like at least a 2-hour block of your day to, depending on how you're getting there" (Carol). A therapist from the 6-week CSR thought that due to the short time frame for rehabilitation, patients were not physically able to begin community visits or recreation interventions, and *"recreation, that's a little bit low, as well as community life...however, at the same time we're only in for 6 weeks and often with our more impaired patients we're kind of finally getting them to the point where we can start doing this sort of thing and we have to refer on"* (Linda). In addition, inflexible work hours prevented therapists from taking patients to community events at the weekend, *"I think it's about timing and about flexibility of work hours I suppose as well because a lot of these groups are not during work hours"* (Ann).

It appears that a variation in resource use across the DHBs has impacted the frequency of interventions for *b7 neuromusculoskeletal* and *d4 mobility functions*. The differences were due to the 6-week service being able to provide high-intensity interventions and one 12-week service supplementing interventions with additional exercise groups. In contrast, lack of time and a 6-week rehabilitation period appeared to be the reason for lower frequency interventions for *d620 acquiring goods and services* and *d920 recreation and leisure*.

Sub-theme 5.2: Staff capacity

In Study 1, a few interventions were provided by psychologists (0.1%), social workers (2.2%), and speech language therapists (11.1%) (Table 13, Chapter 7). This section will discuss how reduced staff capacity in these disciplines impacted the provision of interventions.

Participants reported that there are no psychology staff within the DHBs: *"there's no psychology in the hospital, there's no psychology in the community. They just completely miss out on any kind of support"* (Linda). Others reported that the current provision of psychology (in 2021) had not changed from when the Study 1 data was collected, and *"we've only got one full-time psychologist ...and I'm pretty sure it would have been similar back in 2016, for the whole of this DHB"* (Lisa). Low staffing numbers meant psychologists *"might be able to see people for one or two sessions"* and the patient's need for psychology *"has to be quite serious"* (Lisa) before they were accepted into the psychology service. The lack of psychology staff may explain the low percentage of interventions for *b152 emotional functions* (0.7%) and *d240 stress* (1.7%) (Figure 5 and 6, Chapter 7) and no interventions for *b126 temperament and personality* (Table 15, Chapter 7), *d760 family relationships*, and *d770 intimate relationships* (Table 16, Chapter 7). One participant said the lack of psychology services meant that therapy staff were emotionally supporting patients so they could engage in therapy, and *"I'm spending half an hour trying to provide some support around... That's not my role or my skill set."* (Linda). Patients were not able to take advantage of the community rehabilitation service, and

therapists had difficulty helping patients who had severe emotional reactions due to the stroke, *“I really struggle, I have someone who really wants to get better but they’re really low and that’s having an impact on their cognition and their problem-solving skills and their insight and then they’re not safe”* (Linda). Because of not having psychology staff, other staff were asked to take on the psychology role as well as their role *“our poor social worker is, is doing her absolute best to handle these situations which realistically needs a psychologist”* (Linda).

There were different levels of social work support within the CSR teams. This varied from having one full-time or part-time social worker, *“definitely not a full-time role”* (Linda), to not having a social worker in the team. In this situation, the team was able to refer to a social worker who worked in the DHB *“in our locality groups ...there’s social workers ...that we can key into”* (Lisa). The low level of social worker provision within the CSR teams could well explain the low percentage of interventions in Study 1 for the ICF categories traditionally linked to social work, namely, *d610 acquiring a place to live* (0.2%), *d660 assisting others* (0.0%) (Table 11, Chapter 7), *e550 legal services* (0.1%) (Table 12, Chapter 7), *e570 social security* (0.2%), and *e575 general social support* (0.0%) (Table 12, Chapter 7). One participant reported that social work services were under pressure, which impacted how often the social worker could see the patient, *“interventions are very short, they’re a one-off session or a couple of sessions purely meeting the specific need rather than providing a more holistic support”* (Linda). One social worker participant supported this by saying that she needed to prioritise work tasks, *“I’m just aware myself in terms of my workload, I’ve got to prioritise”* (Selena).

Different levels of staff across DHBs were also reported for speech language therapy. One staff member said, *“we’ve got three SLT (speech language therapist) FTE [full-time equivalents]”* (Penny), and another service reported *“there’s only one SLT”* (Ann). Where there was only one speech language therapist, the capacity to see patients fluctuated, *“at the moment ...every single referral that comes through, I’m having to say that we’ll have to decline because I don’t have the time to take them on my caseload”* (Ann). To manage reduced capacity, patients were placed *“on a waitlist for community services”*, inpatient speech language therapists were asked *“to set them up to do their own stuff”*, or patients were offered *“one session a week, when we’re supposed to have three sessions a week”* (Ann). Reduced capacity limited the speech language therapist’s ability to do *“conversation practice with family members to help them communicate better”* (Ann). Referral to slower-stream community rehabilitation services meant patients had *“to sit on a wait list for ...months at times before they get seen”* (Ann). Low levels of speech therapy input resulted in less time for speech language therapists to do treatment *“outside the house and do things more in the community”* and to do *“joint visits with therapy assistants... to make sure that everyone’s working on the same thing together”* (Ann). Interestingly, in the DHB with one speech language therapist, the

frequency of speech therapy interventions was higher or equal to that of the other DHBs. This may have occurred because therapy assistants in this DHB provided a higher proportion of interventions linked to *b3 voice and speech* and *d3 communication* (Figure 12, Chapter 7) than other DHBs. Compared to the other DHBs, this DHB may have employed more therapy assistants as this DHB had the highest frequency of interventions provided by therapy assistants (28.4% compared to 22.8% and 12% in the other DHBs) (Table 14, Chapter 7).

Sub-theme 5.3: Other services provide these interventions

Study 1 found there were lower frequency interventions for *d910 community life* (1.0%), *d475 driving* (0.8%), *d845 work* (0.3%) (Figure 6, Chapter 7) and *e155 housing modifications* (0.1%) (Figure 6 and 6, Chapter 7). These results may have occurred due to other health agencies having a role in these areas.

Concerning interventions for community life (assisting patients to engage in events or clubs in the community), several participants in two different DHBs said that “*we let the Stroke Foundation take the lead*” (Tracy) and another said contacting the Stroke Foundation was “*one of the requirements*” (Bella) before the patient was discharged from the service. One participant recalled how she encouraged patients to attend the social groups run by the Stroke Foundation by saying to the patient, “*as you’re getting better, you have more energy you can go there, they’ve got different groups so you can meet people*” (Bella).

There were few driving interventions as therapists considered driving interventions “*definitely outside of our scope*” (Linda). This is because patients “*right after discharge from hospital, they’re restricted from driving for about four to six weeks [or] even more*” (Bella). To resume driving, patients are “*cleared by their GP within four weeks*” or “*cleared by the geriatrician or neurologist within the three-month review*” (Linda). The therapist’s role in this area was to advise patients of the regulations and to warn them, “*please don’t drive because we’ll have to report you to NZTA [New Zealand Transport Authority]*” (Linda). When a patient had a goal to drive again, therapists referred the patient to the Stroke Foundation for a disabled parking permit and taxi vouchers, as “*the half-price taxis, it’s cheaper to get them through the Stroke Foundation*” (Bella). Another reason for lower frequency driving interventions could be the result of Auckland DHBs not funding driving assessments. One therapist said, “*we know that in Christchurch patients get... a driving assessment funded, whereas in Auckland it’s not*” (Penny). The lack of funded driving assessments was thought to disadvantage people who need to drive to return to their former employment, “*if you want a driving assessment, it’s five or six hundred dollars. There’s a waitlist, so people have just lost their livelihood straight, which doesn’t seem consistent across other DHBs*” (Penny).

The lack of housing modifications in Study 1 could result from CSR services taking steps to reduce the waiting time to access CSR services, *“we try ...not have waitlists and be able to see people quickly”* (Lisa). This is because the process of providing housing alterations takes a long time, as therapists are required to *“do all their paperwork or their forms, organise builders all of that, it takes way too much time, loads of follow up, can’t be achieved in six weeks”* (Linda). Consequently, occupational therapists were instructed to only address basic housing modifications and *“anything that’s more major than [a rail] ... we’re referring on to the allied health OTs”* (Lisa).

Participants said work interventions were low, *“because we’re dealing with retirees”* (Bella) who are not seeking to return to work. Several therapists said work interventions had declined *“as the Stroke Foundation has started to take more of an active role and we do less now than we used to do”* (Lisa). Despite these changes, one participant observed that the need for work interventions may increase as *“our population’s becoming a little bit younger ...but I think ... maybe not acquiring but maintaining their job or returning to their work is probably starting to become more of a higher priority”* (Linda).

Theme 6: Therapist factors

This theme is about the characteristics of the therapist that limit the provision of interventions. The three sub-themes under this theme are the therapist’s lack of knowledge, the therapist’s discomfort, and the wide professional scope.

Sub-theme 6.1: Lack of knowledge

This section presents the theme that therapists may lack knowledge across several spheres of practice, specifically concerning connecting Māori clients with culturally appropriate community services and working with clients presenting with sensory and proprioceptive difficulties, hemianopia, and higher cognitive dysfunction. Links to the intervention data in Study 1 are drawn.

Concerning Māori, staff from one DHB felt that as a team, *“we’ve recognised that we don’t know enough about what’s out there [Māori community support agencies]. I’m aware there may be some marae that offer some good support, but I don’t really know who they are or how to access them”* (Vicky). A marae is situated on communally held land and is a place where Māori come together for meetings, celebrations, classes, and funerals (Whannga, 2013). Locating Māori support organisations was made more difficult as *“there’s a lot of different organisations but there’s no one big hub [disseminating information] ... [if] there were a few more targeted places where we could refer to, that might be a little bit easier to navigate”* (Selena). Other staff wanted to know how to engage Māori in the community after stroke because *“if we can find out what makes the person want to re-engage with their community ...just, learning a bit more about what’s important to them and outside*

of their home could be quite helpful” (Emma). Although staff expressed a wish to know more about Māori community agencies, Study 1 data found that Māori in this DHB were receiving more interventions linked to *d9 community life* than non-Māori (5.0% vs 3.0%) (Figure 13, Chapter 7).

Study 1 revealed few interventions for *b265 touch* (0.1%) and *b270 temperature* (0.1%) and no interventions for *b260 proprioceptive* functions (figure 5, Chapter 7). Participants readily acknowledged that these sensory issues were not routinely assessed. Rather, *“we just might just discover it by chance”* (Bella). The low frequency of sensory and proprioceptive assessments and interventions was attributed to inadequate knowledge as *“we lack... training [in this area]”* (Bella). It appeared that the CSR and inpatient rehabilitation teams had already identified this as an issue for staff development, and *“we’re trying to look at sensory assessments. There is a lot of discussion around it with the... rehab team, the inpatients [service] and us. [We are] trying to do more around that”* (Bella).

Similarly, relatively lower frequency interventions for *b210 seeing* (0.6%) (Figure 5, Chapter 7) were identified in Study 1. One participant thought community occupational therapists needed to know more about the treatment of hemianopia as *“vision falls under OT”* and *“I’d probably say, a good 40 percent of my caseload has a hemianopia of some degree”* (Penny). However, *“none of us really have the confidence to do it... so I would say that’s probably because the training [for] OTs isn’t available”* (Penny). Lack of confidence with treating visual dysfunction was also identified by a physiotherapist, *“Working on vision and things like saccades or smooth pursuits or visual range of motion ... I am less confident on. So, I’m probably less likely to do it as a treatment”* (Linda). An additional rationale for hesitating to treat hemianopias was because *“the medical professionals, they’re saying ‘Don’t worry about vision rehabilitation. [It] won’t do anything, so don’t touch it’ ...whereas there’s probably quite a lot of compensatory activities you can do to improve their function”* (Penny).

Lack of training as a direct contributor to low intervention rates was also identified for *b164 higher cognitive functions* (0.9%) (Figure 5, Chapter 7). One speech language therapy participant emphasised that this was *“an important area of working on cognitive communication”* and linked the low rate of interventions to speech therapy training as, *“we’re not really prepared very well for that kind of work, so I’m not surprised that it’s a bit lower and I think it could be higher if we ... felt better able to tackle it”* (Ann).

To delegate more work to therapy assistants, staff provided training sessions on several topics to therapy assistants, *“we’re... always being encouraged to use therapy assistants more and we have done... quite a bit of training on, across the board on all the whole range of things that we may refer to them for”* (Lisa). Despite training on cognitive interventions, this participant found that delegating

these tasks to therapy assistants was not successful, *“we’re trying to do it [delegate] more but even the people I’ve handed over with cognitive stuff I don’t think they still really get it”* (Lisa).

This perspective was supported in the Study 1 data that show therapy assistants provided 2.0% of the interventions linked to *b1 global mental functions*, whereas, for the *b7 neuromusculoskeletal* and *d4 mobility* chapters, they provided 5.3% and 8.3% of the interventions (Figure 12, Chapter 7).

Thus, participants uniformly volunteered gaps in knowledge as the explanation for the low frequency interventions for a range of common outcomes following stroke. The identified gaps were variously linked to deficits in their undergraduate training or hesitancy in areas where they lacked confidence or were dissuaded from intervening by medical staff who did not appreciate the benefits that could be achieved through therapy. Likewise, lack of knowledge development was identified as a problem that also affected delegation to therapy assistants. In contrast, the perception of needing to improve their knowledge of local Māori community support services did not align with the higher frequency of interventions coded to *d910 community life* for Māori than non-Māori.

Sub-theme 6.2: Therapist discomfort

This section seeks to understand why there were no interventions to address religion and spirituality limited interventions for intimate relationships (two interventions, Table 11, Chapter 7). Concerning religion and spirituality, it appeared participants had different levels of comfort when broaching the topic with patients. One therapist asserted she would discuss this area as *“it’s part of social participation ...and spirituality it fits with OT”* (Bella). In contrast, others confided, *“we might not feel comfortable to go there with clients or that might not be something they...want to share with us”* (Carol). Some therapists would address this area if *“the patients have identified this as a goal ...then absolutely we’ll think about ways that we can support them to do it”* (Linda). Others found that returning to religious activities was not a common goal for patients, *“The majority, [of] my caseload, haven’t been specifically religious or spiritual. I’ve had a couple”* (Penny).

The apparent reticence to discuss religion and spirituality with clients was attributed to not having the skills to talk about this topic: *“I’m not very clued up on how to... or...even to interact on that level with a client”* (Lauren). That made religion both hard to talk about and created the impression that clients would also find the topic difficult, thus explaining why there were few interventions, *“We don’t really raise for discussion about... people’s spiritual lives or sexuality and relationships... because if we find it hard to talk to them about it, they will probably be finding it hard to talk to us”* (Lisa). Spirituality was addressed through interventions that would assist the patient in engaging in religious practices. Examples of such interventions were improving mobility to assist people to get back to church, *“physios have gone out to those places with them to get them back there or working*

on them being able to kneel for prayers” (Anne), or using public transport, “let’s just get the bus and then walk to the church” (Bella). Recognising that therapists find it difficult to discuss religion and spirituality with clients, some services have revised their initial assessment: “Our new form, it’s trying to help people to kind of introduce that topic...sometimes people can be sensitive if you just directly ask” (Lisa). Consequently, these changes may have resulted in more interventions for this area than in 2017 and are supported by the comment, “we definitely ask about religious or spiritual beliefs” (Lauren).

As indicated above, there were also very few interventions to address intimate relationships in Study 1. Most participants recognised that this area of functioning was not covered well by therapists, *“that’s definitely one that I think gets left apart” (Ann). Participants were aware that limitations in expressing sexuality had an impact on relationships: “we’ve been having a lot more younger patients ...and you definitely see it changes the relationship dynamics in families and with partnerships” (Carol). Several participants reported they have access to a sexuality booklet that could be used to support a conversation about sexuality that “talks...about what could be some of the concerns around intimacy after you’ve had a stroke” (Ann). Despite the availability of this resource, most participants said intervention in this area was not provided as “a lot of us don’t broach that subject with clients. I don’t know if it’s either we feel uncomfortable or like we don’t have enough experience or knowledge” (Carol). A cultural taboo about this topic may also be a barrier when discussing this topic, as “it’s not something that Kiwis are willing to talk about with strangers” (Tracy). Although the question of sexuality was on the assessment form, many participants felt it was too early in the patient relationship to raise this issue and “sometimes it’s not appropriate at that initial interview and I think that’s why it gets lost, because you’ve just met that person and it feels very invasive” (Lisa). Several participants recognised that discussing sexuality with patients was “an area we’re probably lacking” (Carol).*

Overall, participants’ discomfort with opening a discussion regarding religion, spirituality, and intimate relationships was a barrier to addressing these aspects of functioning. Prompts in the initial assessment form, introduced after data informing this study was completed, were not enough, as therapists reported that they prioritised building a therapeutic relationship with the patient rather than asking “invasive” questions early in the rehabilitation process. The availability of a written resource did not overcome participants’ discomfort or sufficiently address their perception of not having adequate knowledge or experience on how to intervene.

Sub-theme 6.3: Impact of wide or narrow professional scopes

The ICF categories in Study 1 identified that some disciplines have wider or narrower scopes in the field of stroke rehabilitation. Speech language therapy was linked to 7 ICF chapters, occupational therapy to 19 ICF chapters, and physiotherapy to 16 ICF chapters. Several participants indicated that a discipline's scope of practice can influence the frequency of interventions provided by that discipline. A speech language therapist was surprised at the high-frequency of speech therapy intervention, given the low staffing levels, *"Maybe the coding isn't so diverse for the speech therapy roles that we just get lumped into one thing, so then it makes it look like it's bigger than some other things maybe"* (Ann). Several occupational therapy participants thought this was the reason for lower frequency interventions in some categories, *"There may be so many different areas that we're putting our energies into and, even if we see people more than once a week ...or get a therapy assistant to do some of the repetitive work... we just can't give to all of that"* (Lisa). Another participant said that the wide scope of occupational therapy practice impacted how frequently a patient was seen, *"Occupational therapy is spread a bit more thinly, so our frequency of how many times we document something would drop down purely because of our scope and what we're expected to see"* (Penny). The number of staff in each discipline, combined with differences in professional scope, could also be a reason for the differences in intervention frequency, *"there's three speechies in our team versus four physios and we have four OTs ...all of our patients are pretty much referred to OT, probably about 50 percent are referred to speech language therapy so if you look at their caseloads, they've probably got more ability to increase that frequency and what they can do with people"* (Penny).

The scope of practice for each discipline working in CSR can influence the frequency of interventions in each ICF category. This means that if a discipline has a narrow scope it is possible to provide greater interventions, compared to disciplines with a wider scope where intervention frequency is low but spread over many areas. In addition, therapists' comfort level, skill, and knowledge can impact intervention frequency.

Theme 7: Māori inequities for health, income, and housing

In Study 1, the interventions were collapsed into 19 broad chapters that amalgamated the interventions for body function, activities and participation, and environmental factors. From this list, seven chapters showed clear differences between Māori and non-Māori. Māori received significantly more interventions for *d5 self-care* (22% vs 12%) and *e5 services and systems* (25% vs 114%), and significantly fewer interventions for *b7 neuromusculoskeletal functions* (30% vs 46%) (Table 20, Chapter 7). As most of the Māori data had come from one DHB, the interview questions in Study 2 asked therapists from this DHB to explain the different intervention patterns. Analysis of that data

generated three sub-themes that contributed to understanding the different intervention patterns for Māori and non-Māori: the impact of complex health conditions, poverty and housing issues, and patients living with family.

Sub-theme 7.1: Complex health conditions and social issues

Several participants thought the differences between Māori and non-Māori were caused by complex health and social issues. Māori patients were described as *“often really complicated; a lot of co-morbidities, dialysis”* (Sarah) and *“have their strokes earlier, they tend to be denser”*, and some have *“co-existing mental health issues”* (Vicky).

Māori experienced social issues, *“the biggest ones are economic things and housing”*, *“family members who are involved in prison”* (Sarah), *“extreme poverty, drug and alcohol issues”*, or *“lots of people living in the house”* (Vicky). Due to these issues, patients found their rehabilitation *“hard to prioritise”* and this resulted in *“issues around engagement in the service”* (Vicky).

Others observed that compared to non-Māori, Māori *“understanding of health literacy was quite different, maybe not aware of some of the risk factors or, not sure what to do or there’s not a full comprehensive understanding”* (Emma). It was felt that patients had difficulty understanding health literature as *“it’s not in their language so they’ve been given a piece of paper and it’s got [the words] ‘diabetes’ and ‘stroke’ and what does that mean to them?”* (Emma). Lack of knowledge caused patients with diabetes not to *“manage it for a few years because they think that that’s just how it is”* (Emma), not to access resources because *“they might not know what’s out there”* (Emma), and not to take preventative steps to improve health because *“[they don’t] know what’s caused their stroke or what they could do in the future”* (Vicky). Consequently, participants reported they *“give a lot of education”* to *“reduce further risk”* (Vicky). Others found that when patients understood *“how rehabilitation will affect them in the long-term, their drive might increase”* (Penny). This was supported by others who said, *“I have found that you have to work a bit harder to get people really motivated to participate”* (Sarah).

In Study 1, Māori received higher frequency interventions for *d570 looking after health* than non-Māori (11.1% vs 3.5%) (Figure 13, Chapter 7). This code incorporates many types of interventions that reduce patient risk, such as reducing stroke risk, taking medication, preventing falls, using equipment correctly, and protecting feet. When looking in more detail at the interventions coded to this category, only 30% of the *d570* interventions for Māori were to reduce stroke risk. Consequently, it can be assumed that therapists were providing more of these interventions because Māori patients had more disability-related risks than non-Māori patients.

Sub-theme 7.2: Cultural differences

A difference in cultural values for the health system was regarded as the reason why Māori and Pasifika “*tend to have more DNAs [did not attend]*” (Sarah), as this population did not have the “*Western medicine ideal of you really have to do what the doctor says*” (Sarah). Participants questioned whether past events had impacted engagement, “*is it because of... outcomes from historical abuse and misunderstandings?*” (Penny) or whether “*bad experiences*” had eroded “*trust*” in the health system (Sarah).

Although not significant, Māori had higher frequency interventions than non-Māori for *b1 global mental functions* (39% vs 33%) (Figure 13, Chapter 7). This ICF chapter includes interventions for organisation, cognitive flexibility, judgement, and problem-solving. This result may indicate that Māori had more cognitive impairment than non-Māori. Alternatively, this result could be the result of therapists choosing not to do typical cognitive rehabilitation interventions. Cognitive assessment and pen-and-paper cognitive activities were considered culturally insensitive because “*a lot of those higher-level cognitive tasks aren’t relevant; a lot of my patients haven’t finished school so it’s more reflective of that [traditional cognitive therapy]*” (Penny). As a result, this participant chose to do a cognitive assessment and therapy tasks that were more reflective of the person’s lifestyle, “*I think about the work that they want to return to or the aspects of life that they want to return to, I probably do something a little bit more like the Allen’s because it is the practical needle lacing*” (Penny).

Most participants said Māori did not have the same level of engagement in therapy as non-Māori, and this may have been the reason for lower frequency interventions for Māori. The reduced engagement was thought to have occurred because Māori had more complex health and social issues than non-Māori, which impacted their ability to prioritise rehabilitation. Poor health literacy was also proposed as contributing to reduced engagement with rehabilitation and not accessing resources or taking preventative steps to improve health. Lastly, it was thought that Māori may lack trust in the health service because of the negative impact of colonisation. To address engagement and health literacy, staff spent more time imparting health information, and this was demonstrated in the higher frequency interventions for *d570 looking after health* (11.1% vs 3.5%) (Figure 13, Chapter 7).

Sub-theme 7.3: Poverty and housing issues

All participants acknowledged that Māori experienced poverty. “*Māori have a lot of things like socioeconomic problems especially if they’ve lost their job from the stroke, hard up for funds and housing*” (Sarah). Not being able to work after a stroke meant patients had to go on an invalid’s

benefit that was lower than their previous wages, *“the wages have just gone down so much and they get the basics at Work and Income but it’s still not where they were and managing now is completely different”* (Selena). Loss of income had a huge impact on people’s lives, *“If you’re struggling to do the basic food, struggling to manage all of this, it’s bound to make an impact”* (Selena).

Not having the funds for transport prevented patients from using public transport to access the community facilities such as *“going to the library once a week”* (Penny), and if patients were known to have financial difficulties, therapists stopped suggesting community participation interventions, *“we don’t have as many of those conversations as we could, because... it is just so hard to achieve that engagement if transport isn’t available”* (Penny). Restrictions in available income prevented patients from purchasing adaptive equipment not covered by government funding, *“there’s been multiple occasions where a small piece of equipment [that is] quite cost effective, isn’t available to them”* (Penny).

Not working and being on a benefit made it difficult to find affordable level access rental accommodation. To improve the financial situation, many family members live in the same house, *“there’s a lot of people in the house”* and this creates *“further problems with getting around”* (Sarah). When people are unable to pay their rent, patients seek Housing New Zealand assistance, *“I’ve probably had to do more referrals to social housing for accommodation for them. There’s no housing for people, especially when they live by themselves ... so they go into transitional or accommodation”*. This participant is referring to transitional housing provided by the government for people who urgently need a place to live for a short time before they move to more permanent housing (Te Tūāpapa Kura Kāinga Ministry of Housing and Urban Development, 2024). This is different from public or social housing, which is government-subsidised permanent rental housing for people who cannot afford private rental housing (Ministry of Social Development Te Hiranga Tangata, n.d.). Before being accepted for social housing, applicants must prove they have sought private rental accommodation. The process of looking for homes places extra stress on people who are physically impaired and living on a low income, *“she had to look at a rental home for one person which is non-existent... so she had to use taxis, she only had 50 dollars for food so it was using her food [money] to find accommodation”* (Selena).

To address social issues, Māori received *“a lot of input from CSR into ...trying to help them overall... to get them on the right WINZ [Work and Income New Zealand] benefit or like housing or getting social worker involved, help them with family concerns and I think then sometimes that may take away from active rehab”* (Sarah). The extra time spent on supporting Māori patients was also mentioned by other participants, *“there’s a lot of extra that you do but, I enjoy it”* (Vicky). Although there is a

full-time social worker in the team, other disciplines also linked Māori to community support, *“I’ve just been doing a lot of it this morning, making sure that they’ve got their half-price taxi voucher and know about the St Johns shuttle because often there’s no transport”* (Vicky). These participants’ comments explain why the interventions for *e5 services and systems* were higher for Māori than non-Māori (25% vs 14%) (Figure 13, Chapter 7). The particular interventions that contributed to this result were *e570 social security services* (1.3% vs 0.1%) and *e580 health services* (2.1% vs 1.4%) (Figure 16, Chapter 7).

For many Māori, a stroke results in not returning to work and living on a much lower income provided by a Supported Living Payment. (New Zealand Government, n.d.-b) The impact of poverty resulted in patients being unable to afford transportation to community facilities, purchasing adaptive equipment, and paying rent and mortgages. Financial stress could result in moving in with relatives or seeking rental accommodation through Housing New Zealand. In response to this situation, all members of the CSR team linked patients to housing, income support, health, and transportation services, which then reduced the time allocated to stroke rehabilitation.

Sub-theme 7.4: Living with family

Participants reported that for most Māori patients, *“families are taking care of them, there’s just sort of much stronger family and carer presence through that rehabilitation process”* (Penny). This resulted in patients having *“people who can take them to appointments and people who are attentive to their rehab sessions”* (Emma). Despite these perceived benefits, living with family could be stressful for family members *“you’ve got an extra person living in your household ... it does put a lot of strain on the family dynamics which I have witnessed”* (Penny).

Participants also perceived that over-caring family members can harm the patient’s rehabilitation, *“a lot of family rally around and help them and sometimes it’s almost detrimental to their progress because the family end up doing everything rather than encouraging independence”* (Sarah). Living with family members may have an impact on goal setting, and this may indirectly reduce the interventions to Māori, *“their expectation is ... my family will help anyway and ...they’re receiving less [interventions] because their goal is to have support where maybe non- Māori might need to get back to managing everything because they have less support”* (Sarah). It was thought that reduced interventions to Māori compared to non-Māori could be the result of families doing the interventions as opposed to the CSR team. *“I don’t know [if], the whānau tends to do a lot of the input and so on paper it sort of sometimes seems we’re not maybe doing as much”* (Sarah).

It was also proposed that non-Māori who have severe strokes move to residential care, whereas Māori with severe strokes return to live at home. *“I wonder if it... weeds out the non-Māori...because*

*I know from experience the ones that come to our service, that are [for] only transferring, tend not to be Pākehā families” (Sarah). The proposition that CSR staff are seeing more Māori with severe stroke than non-Māori does have some merit as Māori had higher interventions for *b1 global mental functions* (Māori: 39% vs Non-Māori: 33%) (Figure 13, Chapter 7), *d510 washing* (Māori: 2.4% vs Non-Māori: 1.7%), *d540 dressing* (Māori 3.2% vs Non-Māori: 0.7%) (Figure 15, Chapter 7) and *d450 walking* (Māori: 7.9% vs Māori 5.6%) (Figure 17, Chapter 7). However, if this was the case, there should be more interventions for movement-related interventions. Nevertheless, the opposite occurred as Māori had fewer interventions for *b7308 exercise* (3.2% vs 10.0%), *b730 muscle power* (3.6% vs 5.2%), and *b755 involuntary movement* (1.7% vs 4.7%) (Figure 14, Chapter 7).*

Participants reported that most Māori patients lived with family. This resulted in greater support for patients, but this arrangement could also increase stress on family relationships and decrease the patient’s drive to become fully independent from family members. It was also suggested that CSR staff may expect family members to do the intervention sessions with the patient, but such interventions are not captured in the staff notes. Although Māori have more severe strokes and live with family, it is still unclear why Māori received fewer interventions than non-Māori for *b7 neuromusculoskeletal* and *d4 mobility functions*.

Method to obtain feedback on the results

I spoke to each of the three community stroke services and summarised the results from Studies 1 and 2. Following the presentation, I invited discussion from the staff to share their views and to write their confidential feedback on a feedback form. Staff were also invited to email me their feedback if this was preferred.

For one 6-week and one 12-week CSR, the feedback form asked, “Do the findings in the presentation reflect your experiences working with your patients, and could you briefly explain your answer?”. For the 12-week CSR with the Māori data, the feedback questions were, “Do the findings in the presentation reflect your experiences working with Māori patients and could you briefly explain your answer?” I received two feedback forms from the 6-week service and only verbal feedback from the 12-week service, and 12 feedback forms from the 12-week service with the Māori data.

I also sought a Māori health worker’s opinion on the Māori results in Study 2 and was fortunate to be put in touch with a person who worked for the Middlemore Foundation for many years. The Middlemore Foundation is an organisation based at Middlemore Hospital in South Auckland that obtains charitable funds from the community and spends them on hospital and community health projects. This person understood the Māori experiences of inpatient rehabilitation as part of his job was to check the welfare of Māori patients in the inpatient rehabilitation wards. Although he had no

direct work experience with patients who receive CSR, he had some experience with the staff in the CSR and was aware of their role.

Feedback on the Māori results

Out of the 12 responses from the CSR with the Māori patients, three staff members said the presentation results did not reflect their experiences because the patient's ethnicity did not impact their provision of rehabilitation interventions; instead, they were guided only by the patient's individual clinical needs or the patient's functional goals. One person in this group said they recognised that the healthcare system did not always fit the needs of Māori patients, and often, Māori and Pacific had poor health literacy and complex medical conditions.

Nine staff provided the following reasons for agreeing with the presentation results: Māori and Pacific had a different model of health and, therefore, did not fit the Western model of health provided by the CSR. One therapist said that this was the reason Māori did not like exercise interventions and preferred functional activities. This same person said Māori preferred to do their interventions autonomously without a therapist being present and were unsure of the reasons why this may be the case. Therapists lacked knowledge and skills, and skill level was further negatively impacted by a high staff turnover. Māori patients had complex medical conditions that required extra time from therapists. Therapists thought the lack of interventions for Māori were due to the extra time needed to work with Māori patients. This was due to needing more time to develop a rapport with the patient and address problems due to the combination of complex medical conditions and social situations.

In the opinion of the Māori health worker, the results of Study 2 were not a surprise and reflected the known Māori health inequities in other areas of health. I asked why, in his view, Māori may not be engaging in CSR. He responded by saying that Māori needed to develop trust in the health professional before engaging in therapy, and this process takes time. The need for trust could be related to Māori being suspicious of authority or the importance for Māori to establish a connection based on family and relatives, a person's marae, and the geographical place where a person was born (Walker, 2011). Some Māori may be inhibited by feelings of shame due to their illness, home, circumstances, or not being able to read. Trust can be developed by the therapist showing they are committed to the person's care, spending time developing rapport, showing respect, and using Māori language. Other suggested ways to build rapport and foster engagement are to bring food to share at the first interview, the Tikanga team (usually present in most NZ hospitals) to provide training on Māori protocols to new staff from overseas, employ more Māori staff and offer ongoing support services from the patient's marae.

Feedback on the results from the other services

Two staff from the 6-week CSR service provided feedback forms that said the presentation results reflected their experience. One person said they strongly agreed with the theme that physical intervention drives interventions and that all staff provided fatigue education to maximise patient participation in rehabilitation. They also agreed that lack of time prevents the provision of community visits. The second person agreed with most findings but thought that leisure and community visits had increased in recent times. This person felt strongly that all DHBs needed a CRS and that a 6-week intensive service should be extended for older adults who could not tolerate the intensity of the treatment sessions.

The verbal feedback from the 12-week service was mixed, with one staff member saying they were providing more community visits in their service, while another staff member disagreed with this statement. There was agreement that staff had difficulty discussing sexual intimacy with patients, but in recent times, the service has initiated education sessions to address this. One staff member suggested the consistent use of a tool that helps therapists predict if patients have the potential to improve the upper limb, such as the Predict, Recovery, Potential 2 algorithm (PREP 2) (Stinear et al., 2019), may result in more equitable interventions for both Māori and non-Māori.

Summary

This chapter addressed research question 2: What are the CSR staff explanations for the patterns of interventions seen in Study 1? This was achieved by integrating the results of Study 1 with the qualitative data from 15 staff members employed in the three CSR services in Auckland. The seven themes developed are under two broad headings: what factors facilitate the provision of intervention and what factors limit the provision of interventions?

The themes that facilitate interventions are the common presence of physical impairment, therapists' use of patient-centred goal-setting tools, and the use of interventions to support the patient's engagement in rehabilitation. The common presence of physical impairment and the use of goal-setting tools explain the high number of interventions for ICF chapters *b7 neuromusculoskeletal functions*, *d4 mobility*, and the ICF categories *e115 products of daily living* and *e120 products of mobility*. Therapists supported the patients' engagement in rehabilitation by providing fatigue management education and monitoring the patients' fatigue levels. This resulted in high numbers of interventions for *b130 energy and drive*.

The themes categorised under what limits interventions are not a common patient issue; factors within the health service organisation; therapist factors; and Māori inequities for health, income, and housing.

The interventions that were considered not common in CSR patients were *b260 proprioception*, *b270 temperature*, *b280 pain*, *b415 blood vessels*, *b420 blood pressure*, *b440 respiration function*, *b525 defecation*, *b810 protect skin*, *b820 repair of the skin*, *d172 calculation*, *d610 acquiring a place to live*, and *e570 social security, services and policies*.

The theme “health service organisation” had three sub-themes: differences in resource use, staff capacity, and interventions provided by other services. A high number of interventions for *b7 neuromusculoskeletal functions* and *d4 mobility* were due to the 6-week CSR providing up to 2–3 treatment sessions, 5 days per week, and the 12-week service that offered additional group fitness classes. Not having enough time and a short rehabilitation period in the 6-week CSR service resulted in low frequency interventions for *d620 acquiring goods and services* and *d920 recreation and leisure*. A lack of psychology staff may have resulted in low frequency interventions for *b152 emotional functions*, *d240 stress*, and no interventions for *b126 temperament and personality*, *d760 family relationships* and *d770 intimate relationships*. Low frequency interventions for *d610 acquiring a place to live*, *e550 legal services*, *e570 social security* and no interventions for *d660 assisting others*, and *e575 general social support* (0.0%) may have been the result of low numbers of social work staff. One therapist reported a lack of speech language therapists in one service; however, the provision of speech therapy interventions was equivalent to other services. This may have occurred because many of the speech therapy interventions may have been carried out by a therapy assistant. Referrals to the Stroke Foundation to assist integration into the community resulted in low frequency interventions for *d910 community life*, and referrals to long-term community rehabilitation services for housing modifications resulted in no interventions for *e155 housing modifications*. There were low frequency interventions for *d475 driving* as patients were cleared for driving by their GP and referred to a private driving assessment service.

Under the theme of “therapist factors”, there were three sub-themes: lack of knowledge, therapist discomfort, and impact of narrow and wide professional scopes. Therapists explained that the low frequency interventions for *b164 higher cognitive function*, *b210 seeing*, *b260 proprioception*, *b265 touch*, and *b270 temperature* were due to therapists needing more knowledge and skills. It was also identified that delegating cognitive interventions was not possible as therapy assistants lacked the training to support this action. Therapists from one CSR identified they needed more knowledge on Māori community agencies to provide more community support for Māori patients. Therapist

discomfort and lack of skills were the main reasons for low frequency interventions for *d770 intimate relationships* and no interventions for *d930 religion and spirituality*. However, feedback from staff following the two studies indicated that staff training to address intimate relationships was being provided in one CSR service. It is also evident from the Study 2 interview data that therapists were now providing interventions to assist patients in engaging in religious activities.

The last theme, “Māori inequities for health income and housing”, provided the overall reason for the differences in interventions for Māori and non-Māori. This theme had four sub-themes: complex health and social situations, cultural differences, poverty and housing issues, and living with family. Compared to non-Māori, Māori received significantly more interventions for *d5 self-care* and *e5 services and systems* and significantly fewer interventions for *b7 neuromusculoskeletal functions*. Therapists reported that complex health conditions, social situations, and poor health literacy resulted in Māori having low levels of engagement in rehabilitation. To address this situation, therapists spent more time addressing social problems and providing education, reducing the time available for rehabilitation. Therapists also indicated that lack of engagement may result from the health system not being attuned to Māori cultural values. Māori experienced greater poverty than non-Māori, which resulted in less funds for transport to community facilities and not being able to purchase low-priced adaptive equipment. Interventions may have been disrupted when lack of funds or poor access resulted in Māori moving to cheaper accommodation or social housing. Most Māori patients live with family, which had a beneficial effect on rehabilitation; however, for some, it was detrimental as patients were not encouraged to be independent, there was increased stress on carers and overcrowding in the home. The high numbers of interventions for washing and dressing suggest that Māori have more severe strokes than non-Māori. However, this was not supported as Māori did not have higher interventions for *b7 neuromusculoskeletal functions*, which would be expected if patients were more severely disabled. Feedback from staff in the CSR where the Māori data was collected and from a Māori health worker support the themes outlined above.

Chapter 9: Discussion

The study addressed the following research questions:

1. What are the patterns of community stroke rehabilitation interventions in Auckland.?
2. Do CSR interventions address the scope of patient problems identified by the EICSS?
3. Are there differences in the type and frequency of interventions provided to Māori and non-Māori?
4. What are the CSR staff explanations for the pattern of interventions found in Study 1?

Below is a brief overview of the results for research questions 1–3, followed by an extended discussion of the results for research question 4.

Research question 1: What are the patterns of community stroke rehabilitation interventions in Auckland?

The patient files were sourced from three CSR services, with 39 files from an ESD service providing 6 weeks of therapy and 26 and 48 files (including all Māori patient files) from two different 12-week services. Overall, the highest number of interventions were from the ICF's *d4 mobility* chapter (31%), followed by *b7 neuromuscular functions* (17%) and *b1 mental functions* (12%). The chapters that had the lowest frequency interventions (1% of the total) were *b2 sensory functions and pain*, *b4 cardiovascular, haematological, immunological, and respiratory functions*, *b6 genitourinary and reproductive functions*, *d8 major life areas*, *e3 support and relationships*, and *e5 services, systems, and policies*.

The intervention of *exercise b7308* was the most frequent (6.1%), followed by interventions for *b730 muscle power* (4.6%), *b167 mental language* (4.0%), *b130 energy and drive* (3.0%), and *b755 involuntary movement* (2.7%) and *b320 articulation* (2.5%). There were 19 intervention categories in which interventions were provided 20 times or less. Eight of these categories were linked to basic body systems: *b820 repair of skin*, *b415 blood pressure*, *b525 defecation*, *b545 water*, *b420 blood pressure*, *b134 sleep*, *b515 digestive*, and *b440 respiration*.

The highest number of interventions provided in the activities and participation domain were *d450 walking*, *d410 changing body position* (both at 5.8%), *walking with equipment* (5.4%), *d440 fine hand use* and *d445 hand and arm use* (both at 4.6%), and *d570 looking after one's health* (3.7%). The intervention provided to most people was *d570 looking after oneself* ($n = 68$). There were 24 ICF codes linked to interventions, in which the number of interventions to codes was 20 or less.

The highest provision of interventions for the environmental domain was for *e115 products for daily living* (2.8%), followed by *e120 products for mobility* (1.1%), *e580 health services, systems, and policy* (0.9%), and *e130 products for education* (0.8%). There were 11 categories with fewer than 12 interventions.

Research question 2: Do CSR interventions address the scope of patient problems identified by the EICSS?

The data did not represent 64/166 EICSS categories (23 body function, 20 activities and participation, and 21 environmental factor categories). The missing categories were compared to two studies, one evaluating the Comprehensive ICF Core Set for Stroke (Paanalahti et al., 2014) and the other, the EICSS (Glässer et al., 2012). It was found that the 12 categories (2 body function, 6 activities and participation, and 4 environmental factor categories) were not validated in these studies.

Consequently, these categories were considered not relevant to CSR. To understand the possible reasons for the missing validated interventions that were validated by Glässer et al. (2012) and Paanalahti et al. (2014), the interventions were compared to the recommendations of the NZCGSM 2010. In these guidelines, each recommendation is supported by one of the following five grades of evidence: Consensus, no evidence but is recommended based on clinical experience and expert opinion; D, weak evidence, and practice must be applied with caution; C, evidence gives support; B, evidence can be trusted in most situations, and A, evidence can be trusted to guide practice. This exercise revealed that 15 of the missing categories were recommended in the NZCGSM 2010 (Stroke Foundation of New Zealand and New Zealand Guidelines Group, 2010). Therefore, these categories are considered important to CSR and warrant further investigation into why these interventions were absent in the data. These 15 categories consist of seven body function categories: *b126 temperament and personality functions*, *b156 perceptual functions*, *b176 mental functions of sequencing complex movements*, *b260 proprioceptive functions*, *b640 sexual functions*, *b715 stability of joint functions*, *b735 muscle tone functions*, five activities and participation categories: *d135 rehearsing*, *d155 acquiring skills*, *d160 focusing attention*, *d325 receiving written messages*, *d850 remunerative employment*, and 3 environmental factor categories: *e410 individual attitudes of family*, *e515 architecture and construction services*, and *e590 labour and employment services, systems, and policies*.

This next section draws on the ICF, EICSS, and NZCGSM 2010 and the wider literature to explore the possible reasons why these interventions were missing in the data from this research study. Firstly, some EICSS categories may not be as relevant after discharge in the community rehabilitation phase. This is because the EICSS combines three core sets to include all the functional problems experienced by people with stroke. These core sets are the Comprehensive ICF Core Set for Stroke, the ICF Core

Set for Patients with Neurological Conditions in Acute Hospitals, and the ICF Core Set for Patients with Neurological Conditions in Early Post-acute Rehabilitation Facilities (Cieza et al., 2004; Ewert et al., 2005; Stier-Jarmer et al., 2005). Another reason for the 37 missing interventions could be because they are not recommended by the NZCGSM 2010.

There was no literature to explain why there were no interventions for *b126 temperament and personality*; however, staff explanations about psychology interventions address this issue in research question 4. No explanations were provided by staff for the lack of interventions for *b156 perceptual functions*, *b176 mental functions of sequencing complex movements*, *b260 proprioceptive functions*, *b715 stability of joint functions*, and *b735 muscle tone functions*.

Perception

Perception is defined in the ICF as specific mental functions of recognising and interpreting sensory input from vision, hearing, taste, smell, touch, and the ability to use sight to visually determine the position of objects in the environment or in relation to oneself (World Health Organization, 2001). This definition does not include perceptual neglect or visual hemi neglect, which is coded to *b1114 orientation to space* and defined as “mental functions that produce awareness of one’s own body in relation to immediate space”(World Health Organization, 2017). In this study, 0.8% of interventions were under this category (Figure 5, Chapter 7). A Cochrane review evaluated the effectiveness of perceptual interventions using 18 randomised controlled studies comparing perceptual intervention with a control population. Of this number, three trials provided interventions for touch, seven for somatosensory (pressure), seven for visual perception disorders, and one for patients with both touch and somatosensory disorders. No studies evaluated perceptual interventions for hearing, taste, and smell after stroke. This review found insufficient evidence to support or refute the provision of interventions for perceptual impairments. As it is still unclear whether perceptual interventions are effective, the review recommended that perceptual interventions should still be provided until stronger evidence is developed (Hazelton et al., 2022). This viewpoint is shared by the Stroke Foundation of New Zealand and New Zealand Guidelines Group (2010), as it provided a consensus-based recommendation that patients with stroke with possible perceptual impairment should be assessed, given advice on the impact of the impairment on daily life, and given adaptive strategies. From this information, it is difficult to determine whether perceptual impairment interventions were not provided due to patients not being assessed (and therefore this issue was not identified), because of low numbers of patients with this impairment, or because therapists were not providing this intervention due to the lack of evidence to support interventions for perceptual impairments.

Apraxia

The category *b176 mental functions of sequencing complex movements* has been identified in the ICF as impairments of ideation, ideomotor, dressing, oculomotor, and speech apraxia (World Health Organization, 2001). People with apraxia are “unable to retrieve a set of movements to accomplish a task, and this inability cannot be explained by weakness, sensory loss and or lack of comprehension” (Rounis & Binkofski, 2023, p. 31). Limb apraxia affects the ability to carry out motor movements to complete ADL tasks and to learn new movement patterns after a stroke (Rounis & Binkofski, 2023). Limb apraxia is assessed by evaluating if patients can imitate meaningless and meaningful gestures, use tools, and carry out multistep actions to use an object. Estimates of prevalence rates for limb apraxia within 6 weeks of stroke range from 25.3% (Zwinkels et al., 2004) to 46% (Bickerton et al., 2012). Based on some evidence, the NZCGSM 2010 (Stroke Foundation of New Zealand and New Zealand Guidelines Group, 2010) recommends that patients with apraxia receive strategy training. It is possible that interventions were not provided because therapists were not identifying apraxia impairments and, consequently, not providing a cognitive screen for this issue. This is supported by research that evaluated the ability of 53 occupational therapists to recognise a range of cognitive issues from 10 patient vignettes (Geraghty et al., 2020). It was found that 94% of participants recognised memory as an issue, 60% recognised attention deficits and 68% recognised apraxia. The lack of recognition of attention and apraxia in the vignettes impacted on whether therapists would use a cognitive screen, as only 79% would screen for the attention issue and 74% would screen for apraxia. This lack of recognition of apraxia and limited use of a cognitive screen could be the underlying reason why no interventions were provided in this area.

Proprioception

Proprioception is defined as sensing body position, motion, and force of body parts (Fisher et al., 2023). Awareness of body position allows individuals to learn new movements, produce movements with the correct force, and adjust movements in line with the task requirements. Not having this ability after a stroke is associated with poor upper and lower limb recovery and reduced independence in daily living (Fisher et al., 2023). In a group of 70 stroke patients, at 15 days post-stroke, 34% had proprioceptive impairment in the ankle, and 63% had proprioceptive impairment of the shoulder (Connell et al., 2008). The NZCGSM (Stroke Foundation of New Zealand and New Zealand Guidelines Group, 2010) gave consensus support for the recommendation to provide a sensory assessment for people with stroke and gave some support based on evidence for sensory-specific training and strategies to transfer sensory learning to other contexts. Consequently, it is interesting that no interventions were recorded for proprioception in the present data. This may have occurred because therapists had not conducted a sensory assessment; consequently, sensation

impairments may not have been identified. That is, NZ therapists could be like their Australian counterparts, as a recent Australian study found that therapists were not using evidence when it reviewed therapists' use of sensory assessment and sensory-specific interventions from audits of medical records and therapists' descriptions of usual care (Cahill et al., 2022). This study found only 6% of 3,358 assessments specifically tested sensory impairment and of the 86 patients diagnosed with sensory impairment, 84% received a sensory intervention. Although this is encouraging, only 18% used a recognised evidence-based intervention to address sensory impairments, and the majority used sensory rehabilitation in the context of everyday activities (69%), sensory re-education (68%) and compensatory strategies (64%).

Further, Hoh et al. (2023) found that health professionals prefer to use non-standardised over standardised tests for sensation ($p < .0001$, effect size 71.4%). The high use of non-standardised tests can result in health professionals not assessing all the modes of sensation that are impaired after a stroke. This is particularly relevant for proprioception, as it was found that the non-standardised test for tactile sensation was the most used (median 55% IQR 10,95), whereas no one in the 431 participants used the mirror position matching assessment (0%, IQR 0,23), a non-standardised test for proprioception. Hoh et al. (2023) found that the barriers to using somatosensory assessments were lack of time to conduct the assessment, lack of training on how to do the assessment, and poor access to somatosensory assessments.

Muscle tone

The lack of interventions for *b735 muscle tone* is concerning, as a systematic review of 23 observational studies found the overall incidence of spasticity in stroke patients 1–6 months post-stroke was 25.3% (95% CI 0.213–0.293) and the incidence of severe spasticity was 9.4% (95% CI 0.056–0.133) (Zeng et al., 2021). When only focusing on patients with paresis (1–6 months), the overall incidence rose to 39.5% (95% CI 0.351–0.439). In this group, it was found that the incidence of spasticity increased over time and at 6 months, the incidence was 45.3% (95% CI 0.407–0.500). The lack of intervention for spasticity could be due to the NZCGSM (Stroke Foundation of New Zealand and New Zealand Guidelines Group, 2010) recommendation that patients with mild to moderate spasticity should have no specific interventions other than task-specific practice, and patients with severe spasticity should be treated with botulinum toxin A and rehabilitation therapy. It is possible that there were no patients with severe spasticity amongst the patients involved in this study who had been discharged home or there was poor access to botulinum toxin A therapy.

Missing activities and participation interventions

Five categories were missing in the data but were present in the NZCGSM: *d135 rehearsing*, *d155 acquiring skills*, *d160 focusing attention*, *d325 receiving written messages*, and *d850 remunerative employment*. The lack of interventions for *d160 focusing attention* may have occurred as this category has a similar meaning to *b140 sustaining attention*. The definition of *d160 focusing attention* is “Intentionally focusing on specific stimuli such as filtering out distracting noises” (p 126), and the definition of *b140 sustaining attention* is “mental functions that produce concentration for the period of time required” (p 53), (World Health Organization, 2001). Consequently, all interventions for attention may have been coded under *b140 sustaining attention* (0.4%). There were no explanations in the literature for the absence of interventions linked to learning (*d135 rehearsing* and *d155 acquiring skills*) and *d325 receiving written messages*.

Missing environmental factor interventions

There are several possible explanations for why there were no interventions from *e410 individual attitudes of family*. Staff may not have considered the act of talking to family members about how they were coping as an intervention, or interventions that had the target of changing family attitudes could have been coded as education. Alternatively, there may not have been organised carer support programmes to which staff could refer patients. This possibility is supported by a finding from Qureshi et al. (2022) that caregivers of people with stroke in NZ felt the hospital had not prepared them for the task of caregiving and had not provided information or training on how to address the patient’s ADL needs.

Research question 3: Are there differences in the type and frequency of interventions provided to Māori and non-Māori?

To determine whether there were differences in the provision of interventions for Māori and non-Māori, this analysis used all the available 34 Māori patient files from one DHB from May 2016 to May 2017, and 40 randomly chosen non-Māori files from two DHBs. All services had a similar service provision time of 12 weeks.

There were two ICF chapters in which Māori received significantly ($p < 0.5$) more interventions than non-Māori: *d5 self-care* (22% vs 12%), ($p = .00$), and *e2 services and systems* (25% vs 14%) ($p = .04$). Within these larger chapters, the categories that contributed to higher frequency interventions for Māori were *d240 dressing* (3.2% vs 0.7%), *d510 washing* (2.4% vs 1.7%), *d570 looking after one’s health* (11.1% vs 3.5%), *e570 social security* (1.3% vs 0.1%) and *e580 health services and systems* (2.1% vs 1.4%).

Chapter *b7 neuromusculoskeletal function* was the only chapter in which Māori received significantly fewer interventions than non-Māori (30% vs 46%) ($p = .00$). Within this chapter, non-Māori received more interventions than Māori for most categories, with the largest differences in the categories of *b730 muscle power* (5.2% vs 3.6%), *b7308 exercise* (10.0% vs 3.2%), *b755 involuntary movement* (4.7% vs 1.7%), *d410 changing position* (11.2% vs 10.1%), *d440 fine hand use* (5.1% vs 3.8%), and *d455 stairs* (3.6% vs 2.8%). There were notable exceptions to this trend, with Māori receiving more interventions than non-Māori for *b710 mobility of joints* (4.5% vs 1.9%) and *d450 walking* (7.9% vs 5.6%).

Research question 4: What are CSR staff explanations for the pattern of interventions found in Study 1?

Question 4 was answered by integrating the data from Study 1 and Study 2 which resulted in the following themes. Interventions were facilitated by: 1) the common presence of a physical impairment in CSR patients, 2) patient goals, and 3) interventions to support engagement in rehabilitation. Interventions were limited by: 4) issues being uncommon in patients receiving CSR, 5) the impact of the health organisation, 6) therapist factors and 7) Māori patients presenting with poor health, low income, and housing issues.

Theme 1: Physical impairment drives interventions

Staff thought the high frequency interventions linked to *b7 neuromuscular functions* (17%) and *d4 mobility* (31%) were due to several reasons. The main reason given was that most people referred to CSR have some physical impairment, and for most clients, the priority goal was to improve their ability to walk and use their affected hand. Other reasons identified were: a) based on the belief that it takes 6 weeks to improve muscle strength, therapists in the 6-week service wanted to achieve this goal in the shortest possible time; b) the presence of the three disciplines (physiotherapy, occupational therapy, and therapy assistants) who were able to provide this intervention; and c) the ease with which exercise interventions could be provided by and delegated to therapy assistants. The emphasis on mobility was also evident in environmental interventions, as the highest environmental interventions were for *e115 products of daily living* (2.8%) and *e120 products of mobility* (1.1%). High frequency interventions for physical mobility were also influenced by how DHBs organised their resources. One DHB offered an intensive Early discharge community service where patients could be seen up to 6 days per week, and another DHB offered additional community group exercise classes that increased patients' physical exercise interventions.

The NZCGSM 2010 (Stroke Foundation of New Zealand and New Zealand Guidelines Group, 2010), has no recommendations on the time needed to improve muscle strength after stroke. However,

based on trusted evidence, the NZCGSM 2010 recommends progressive resistance exercise to improve strength. Progressive resistance exercise (PRE) is defined as progressive high resistance to a held or moving muscle for a small number of repetitions (Dorsch et al., 2018). This recommendation for PRE was upgraded to a strong recommendation in the Australia and New Zealand Living Guidelines for Stroke (Stroke Foundation, 2022). However, it was found that PRE had insignificant effects on improving activity (Dorsch et al., 2018). de Sousa et al. (2018) states that PRE is infrequently used with people with stroke as it is time-consuming and difficult to implement with patients who have very weak muscles. Instead, the preferred method is to improve strength by using repetitive practice (RP) for tasks such as walking, reaching, and hand manipulation in functional tasks. In this method, tasks are modified to enable task completion and patients do a high number of repetitions with no resistance (de Sousa et al., 2018). A meta-analysis of 46 studies evaluating the impact of repetitive practice on strength after stroke showed that RP was more effective at improving strength than sham or no intervention (SMD 0.25, 95% CI 0.16–0.34) (de Sousa et al., 2018). In this meta-analysis, 25 studies provided therapy 5 days per week and 15 studies provided therapy 3 days per week. The remaining studies had differing frequency schedules. In comparing the timing of therapy pre and post-the first 6 months, it found greater improvements in strength occurred in the first 6 months (SMD, 95% CI 0.13–0.52 vs SMD 0.31, 95% CI 0.13–0.49). In addition, it found that patients receiving a total dosage of more than 24 hours of RP had greater strength improvement than those receiving less than this amount (SMD 0.31, 95% CI 0.10–0.53 vs SMD 0.24, 95% CI 0.14–0.34). These findings support the current study participants' view that early and intense strength training using RP is beneficial for patients with stroke.

Theme 2: Patient goals

In Study 2, CSR teams were using goal-setting tools as a basis for patient interventions. The high use of goal-setting tools is supported by Thompson et al. (2020), who found that all CSR services in NZ used goal-specific rehabilitation plans. The participants' rationale that patient goals are driving interventions for walking and the upper limb is supported by the findings from Rice et al. (2017). This study of 287 Canadian outpatients receiving stroke rehabilitation found that the most common priority goals were hand function (21%), mobility (18%), and cognition (11%). When reviewing the top three goals of all the patients in the study, it was found that 67% were impairment-based, 28.7% were activity-based, and 6.6% were participation-based. The strong emphasis on the importance of regaining physical function after stroke is also supported by findings from a review of 23 quantitative studies on unmet needs after stroke. By combining the results of these studies, it was found that 49.80% of participants said that regaining physical function after a stroke was an unmet need (Lin et al., 2021). Although the 12-week and 6-week services follow the stroke guidelines for high-intensity

interventions, the length of rehabilitation time may not be sufficient to maximise physical recovery. This is based on the evidence that people with moderate stroke improve from onset to 6 months, and those with severe stroke improve up to 18 months post-stroke (Lee et al., 2022).

Theme 3: Interventions to support engagement in rehabilitation

High frequency interventions were also provided for *b130 energy and drive* (3.0%) because fatigue was common as patients transitioned from the hospital to the home environment. Therapists identified that patients typically had little awareness of how fatigue could be a barrier to patients progressing with rehabilitation. To manage this situation, all staff provided fatigue management education and monitored how patients were coping with the demands of the home environment and therapy visits. Providing high-frequency interventions to manage fatigue is supported by the finding that fatigue is prevalent in 46.79% of people after a stroke (Zhan et al., 2022). In addition, fatigue management education is supported by the NZCGSM (Stroke Foundation of New Zealand and New Zealand Guidelines Group, 2010), which recommends that families and patients should receive education on fatigue management.

Theme 4: Not being a common patient issue led to missing or low frequency interventions

Participant's reasons for lower frequency body function interventions for *b415 blood vessels* (0.3%), *b420 blood pressure* (0.2%), *b440 respiration function* (0.1%), *b810 protect skin* (1.3%), *b820 repair of the skin* (0.3%), *b525 defecation*, *b260 proprioception*, *b270 temperature* (all 0.1%) and *d172 calculation* (0.2%) were that these issues were not commonly present in the CSR population. Medical interventions were not required as patients were medically stable on admission to CSR, and nurses who would usually provide these interventions were not employed in the CSR teams. Low frequency interventions for *b280 pain* (0.4%) were because interventions in this area were provided for short periods of time.

Some interventions could have been related to patients' socioeconomic and demographic characteristics within each DHB. For example, the interventions for *d610 acquiring a place to live* were higher in one 12-week service in a region known to have high levels of socioeconomic disadvantage (CMDHB: 0.6%, ADHB: 0.3%, WDHB: 0.1%) (Counties Manukau Health, 2016). A stroke typically occurs at a younger age for Māori patients (Feigin et al., 2015), and this may explain why interventions for *d845 acquiring and keeping a job* were higher in number in CMDHB compared to WDHB (0.6% vs 0.3%).

Theme 5: The impact of organisational factors on interventions

Service provision

The three services varied in how rehabilitation was typically provided per patient. The 6-week service provided the highest frequency interventions for *neuromusculoskeletal functions* (21%) and the second highest frequency interventions for *mobility* (32%). If patients required longer rehabilitation following the 6 weeks, patients were referred to a slow-stream community rehabilitation service. At the time of data collection, there was approximately a 2-month delay in receiving this additional service. The 12-week service with the second highest frequency interventions for *neuromuscular functions* (19%) and the highest frequency for *mobility* interventions (34%) may have been due to this DHB providing group community exercise classes and individual therapy sessions at home. This DHB follows the NZCGSM (Stroke Foundation of New Zealand and New Zealand Guidelines Group, 2010) since task-specific circuit training can increase practice time and, as a result, improve walking distance and gait speed (Wevers, 2009).

Participants explained that the lack of interventions for *e515 architecture and construction services* was because all housing modifications were referred to a slow-stream community rehabilitation service. This practice was followed for all the DHB community stroke services so that patients waiting for housing modifications were not preventing new patients from being accepted by the CSR team. The explanation for no interventions for *e590 labour and employment services, systems, and policies* could be again linked to the explanation that referrals to employment services may not have been needed as most of the patients were over 65 years old or had decided to retire after the stroke.

Lack of time

Compared to the high-intensity interventions for physical recovery, there were low frequency interventions for *d620 acquiring goods and services* (0.3%) (planning or carrying out a shopping trip) and for *d920 recreation and leisure Intervention* (0.5%). Interventions were coded to *d920 recreation and leisure* when patients were doing a hobby or problem-solving how to return to a leisure activity. However, more interventions were provided to connect people to social groups in the community (*d910 community life* 1.0%).

The provision of interventions for shopping, leisure, and community life is supported by the finding that at 6 and 12 months post-stroke, people experience a significant loss of pre-stroke leisure, work, and domestic activities (Adamit et al., 2015; Castagnoli et al., 2023; Reeves et al., 2022; Tse et al., 2019), and loss of pre-stroke activities is associated with depression at 3 and 12 months post-stroke (Tse et al., 2019). The NZCGSM 2010 states there is trusted evidence to support therapy for extended ADL (shopping), outdoor journeys, and targeted occupational therapy programmes that can improve

leisure engagement. Participants said the reason for not providing more shopping interventions was the extra time these visits required to organise and carry out. Consequently, it can be presumed that community visits to the shops, using public transport, and attending social groups are not done frequently because of the higher time requirements and staff managing a busy workload.

Community life interventions are distinct from interventions for leisure and recreation as they assist people in attending social activities outside the home or in the home when social activities are not part of the family role or are linked to living in an institution (Lee et al., 2019). As mentioned earlier, low frequency interventions for *d910 community life* (1.0%) could have been due to the extra time and organisational requirements to carry out this intervention.

Although there are no recommendations in the stroke guidelines for community participation interventions, a recent systematic review found that four out of nine randomised control studies focusing on this area showed significant improvements in participation or health-related quality of life (Lee et al., 2019). When comparing the common attributes of the studies that improved participation or quality of life, it concluded that all the studies used individualised interventions, strategies, goals, or opportunities to build self-efficacy by allowing participants to identify problems and develop tailored solutions (Lee et al., 2019). When reviewing the 18 studies selected for the systematic review, Lee et al. (2019) found that determining the effectiveness of studies was limited by small sample sizes and heterogeneity in duration of treatment, participant demographics, and outcome measures. In contrast, a more recent NZ study has shown promising results using a self-management technique called “Take Charge”, where participants improved their physical quality of life and their engagement in activities (Fu et al., 2020). Using a randomised control design, 400 people who were 16 weeks post-stroke were divided into three groups: a control group receiving no intervention, an intervention group who had one 1-hour session, and an intervention group receiving two 1-hour sessions 6 weeks apart. The intervention was a one-to-one session with a facilitator who asked participants what was important to them, what they wanted to achieve over the next 12 months, and the possible ways they could achieve these outcomes. This process was facilitated with a workbook with prompt questions that the participant could keep. It was found at 12 months that the participants who received two sessions, scored 2.9 times higher on the Short Form 12 Physical Component Score (SF-12PCS) (95% CI 0.95–4.9, $p = .004$), and 2.7 units higher on the FAI (95% CI 0.8–4.6, $p = .006$). This intervention was thought to be effective as it stimulated the participant’s motivation and sense of personal control.

Although more expensive, a French CSR (Daviet et al., 2023) approach appears to be more effective at improving community participation than the “Take Charge” approach. The service provides

community rehabilitation for patients with chronic conditions with the specific aim of improving social participation. The service is provided alongside an ESD service and a post-discharge CRS. The “late CSR service for chronic patients” (Daviet et al., 2023, p. 2) is staffed by a part-time doctor, a neuropsychologist, an occupational therapist, a physical activity teacher, and a nurse coordinator. The team’s role was to identify the patient’s goals, provide weekly visits, contract health professionals to address ongoing needs, and provide carer education sessions. The median duration for patients attending the programme was between 75 and 144 days. By comparing patients’ mean scores at the beginning and end of the programme, it was found that patients significantly improved on the FAI from 12.9–17.85 ($p < .0001$). In addition, there was reduced carer burden as the mean scores on the mini Zarit moved from 2.79–2.06 ($p < .001$), and patients had improved quality of life on the EuroQol, as mean scores improved from 57.51–66.36 ($p < .00001$). A retrospective analysis of the interventions that were provided found that 55% of patients received an intervention for *chapter d9 community social and civil life*, 30% received an intervention for *chapter d7 interactions and relationships*, and 63% received an intervention for *chapter e3 support and relationships*. This pattern of interventions is clearly different from what was provided to patients seen by the Auckland CSR services over the period when data were gathered for Study 1. There was no indication from participants that services had subsequently expanded in this direction.

Staffing levels

Low staffing levels for psychologists, social workers and speech therapists impacted the ability to provide interventions. Depression after stroke is common, and a recent systematic review found the overall prevalence rate was 27% (95% CI 25%–30%) (Liu et al., 2023). It has been found that 71% (95% CI 65%–76%) of all new cases of depression after stroke occur in the first 3 months after stroke. Of this group, 53% (95% CI 47%–59%) are likely to have depression for 1 year after onset. In response to this evidence, the NZCGSM 2010 states there is trusted evidence for the following recommendations: a psychological assessment for patients with altered mood and the use of psychological strategies to prevent and address depression in people with stroke. Consequently, it is a concern that participants from all CSR services indicated limited availability of psychological services. The lack of psychological staff is supported by the finding that only 13/28 NZ hospital inpatient wards and 12/28 community rehabilitation services have access to psychological services (Thompson et al., 2020). In NZ hospitals and community rehabilitation services, other disciplines, such as social workers and health improvement practitioners, can address mental health issues after a stroke (Bright et al., 2023). Despite the ability to refer patients to these disciplines, a nationwide survey of NZ DHBs found that hospital and community stroke services staff wanted increased social work and psychology staff to improve access to specialist psychosocial skills (Bright et al., 2023).

Low numbers of psychology staff may have resulted in no interventions for Chapter 7 Interpersonal interactions and relationships and low frequency interventions for areas traditionally associated with psychology: *b152 emotional functions* (0.7%), and *d240 stress* (1.7%), and no interventions for *b126 temperament and personality*, *d760f relationships*, and *d770 intimate relationships*. Due to a high number of referrals for psychology services, patients only received psychology if their health concerns were perceived to be serious and the interventions provided were for a short period. The lack of psychology staff meant other staff who were not trained in this field provided supportive interventions. As a result, therapists had less time to carry out their role, and patients who needed psychological help were too distressed to take full advantage of the rehabilitation service.

Another reason low frequency interventions may have occurred was that community staff did not provide routine mood screens to all patients. This is supported by the finding that out of nine NZ community rehabilitation services, two did not routinely screen for mood changes, one used a transdisciplinary screening tool and a validated mood screen, four screened using a discipline-specific or a transdisciplinary assessment, and two used a validated mood screening tool (Bright et al., 2023). Poor use of mood screening may have occurred as the NZCGSM (Stroke Foundation of New Zealand and New Zealand Guidelines Group, 2010) only gave consensus support for the recommendation that all patients with stroke be screened for depression with a validated tool. As stated by Medeiros et al. (2020), more research is needed to determine the impact of routine mood screening.

The social work role is to improve patients' social support so they can live well in the community. Broadly, the social worker's role is to provide emotional support to the person with stroke and their families, connect the patient and family to support groups and relevant agencies, and provide advice on how to access food, housing, transport, services in the home such as housework, respite care, residential care and financial benefits (Lehnerer et al., 2019; McDermott, 2023). The NZCGSM 2010 states there is a body of evidence that provides some support for the following recommendations that are within the social worker's role: during and after the rehabilitation period, carers should receive information on stroke support groups and support services in the community, and efforts should be made to reduce socioeconomic disadvantage. In this study, the areas that social work usually covers that had low-frequency interventions or missing interventions were: *d160 acquiring a place to live* (0.2%), *d660 assisting others* (0.0%) (Table 11, Chapter 7), *e550 legal services* (0.1%), *e570 social security* (0.2%) and *e575 general social support* (0.0%) (Table 12, Chapter 7). This result could be due to low staffing levels, as participants reported that only high-priority patients were seen and only the most pressing needs were addressed. Less social work input may mean patients develop social needs some time after the stroke event. Lehnerer et al. (2019) found this to be the case after interviewing 57 German stroke patients, 2–3 years post-stroke, who were living at home. After

interviewing each participant on unmet social needs, stroke impact, quality of life and carer burden, it was found that 40% had social needs that would have benefitted from social work input (Lehnerer et al., 2019). It was also found that 30% of the group had not received previous social work during hospital or community rehabilitation, and only 11% of the group had long-term social work support. Lehnerer et al. (2019) propose that this result occurred because social needs usually emerge after the person has adapted to living in the home. Consequently, the low number of social work interventions in these data may mean that unaddressed issues may have become more problematic for patients' months after discharge.

The prevalence rates for communication impairment are high, with Baker et al. (2022) reporting that 1 year after stroke, 70% of people will have dysarthria, 36% will have aphasia, and 78% will have cognitive communication disability. The NZCGSM 2010 gave a C grade recommendation (evidence provides some support for practice) that all patients be assessed for communication deficits using a screening tool and receive any of the following: training in word meaning and word sounds, constraint-induced language therapy, supported conversation techniques, and use of conversation groups. A consensus-based recommendation was given for teaching others how to communicate with a person with aphasia and for using alternative communication methods. Assessment for dysarthria, dyspraxia, and cognitive communication deficits was given a consensus recommendation, but only dysarthria interventions of strategy training and alternative communication devices were supported by a consensus recommendation. A strong recommendation was given for patients to have a swallow screen with a validated tool before being given food, liquid, and medications, and for swallowing interventions. A recent review of research studies found that swallowing training provided by speech language therapists improved swallowing in 85.26% of participants (Andrade et al., 2017). The data in this study found that speech language therapists and therapy assistants were providing interventions recommended by the NZCGSM 2010 as interventions were provided in *b1b global mental (cognitive communication)*, *b3 voice and respiration (dysarthria)*, *b5 digestive (swallowing)*, *d1 learning*, and *d3 communication*. Compared to social work and psychology, speech language therapy maintained intervention frequency by transferring some of this work to therapy assistants. Although this is the case, it is concerning that speech language therapy staff reported having to decline incoming referrals or refer to slower-stream community stroke services, as the prevalence rates for speech impairments are high 1-year after stroke.

This section has highlighted that although the NZCGSM 2010 provides recommendations based on some evidence or trusted evidence for interventions provided by psychology, social work and speech therapy, this study has found low frequency or missing interventions in the interventions that are usually provided by these disciplines.

Outsourcing interventions

It appears that some interventions were not in the data because other health agencies had taken on this role. This section relates to low frequency interventions for *d845 acquiring and keeping a job* (0.3%), *d850 remunerative employment* (no interventions), *d910 community life* (1.0%), and *e155 products for private buildings* (0.1%).

Concerning *d845 acquiring and keeping a job* (0.3%) and no interventions for *d850 remunerative employment*, the reasons provided by participants for the lack of interventions in this area were that most of the patients were retired, and consequently, there was little need for work interventions. Despite that claim, 17.6% of the patients in this study were under 65 years old, the age when all New Zealanders become eligible for a pension, and all these patients were Māori. The low frequency of work interventions in this study will also have been influenced by one of the services being a 6-week ESD service. This would mean interventions would not be provided as patients are in the early stages of recovery, and the 6-week time frame of the service would limit further interventions in this area.

An additional influence reported by participants in this study was that the Stroke Foundation had started to assist people in returning to work, and consequently, the need for work interventions had reduced. The Stroke Foundation does offer return-to-work services and currently provides a service in three NZ cities (Auckland, Tauranga, and Christchurch) (Stroke Foundation of New Zealand, nd). Return-to-work services are also provided by other non-government organisations such as Geneva Healthcare and Workbridge. Although this is the case, it is not known if these services are available to everyone and whether they are effective.

An additional reason the services may not have provided work interventions is the lack of evidence for return-to-work interventions. The NZCGSM (Stroke Foundation of New Zealand and New Zealand Guidelines Group, 2010) gave a consensus recommendation (supported by clinical experience and expert opinion) that all stroke patients wishing to return to work should be offered return-to-work interventions or be referred to a supported employment service. The latest Australian and New Zealand guidelines (Stroke Foundation) provide a weak recommendation for this intervention, stating there is a lack of evidence on the outcomes of return-to-work programmes.

In contrast to the participants' explanations for low frequency work interventions, recent NZ-based research indicates that both return-to-work agencies and health services are not able to meet current need. Research from stroke patients identified that many did not receive assistance from the health service or other services to return to work (Harwood et al., 2022). Participants said that the employer mainly assisted in returning to work, and many patients said they would have liked expert advice on returning to work (Harwood et al., 2022). In addition, a nationwide survey of health

professionals said there were inadequate services to assist people with stroke who wished to return to work and driving (Thompson et al., 2023). Due to Māori experiencing stroke at a younger age, the lack of services is likely to have a greater impact on Māori. This may explain the finding that compared to NZ European, Pacific, and Asian people with stroke, unemployment for Māori after stroke was significantly higher at 6 and 12 months post-stroke (Denison et al., 2023).

Concerning low frequency interventions for *d910 community life* (1.0%), participants said they addressed community re-engagement by referring patients to a Stroke Foundation advisor. The role of the Stroke Foundation advisor is to visit patients in the hospital and at home and provide support and information on local community groups that may interest the person and link people to the Stroke Foundation social groups (Stroke Foundation NZ, n.d.). Unfortunately, it is not possible to determine from this study how often referrals were made to the Stroke Foundation, as referrals were not classified as an intervention and were not captured in the data. Low frequency interventions in this area could also have occurred because the NZCGSM (Stroke Foundation of New Zealand and New Zealand Guidelines Group, 2010) has provided no recommendations for community participation other than a consensus recommendation for providing information on stroke clubs.

Theme 6: Therapist factors

In several areas, therapists indicated that interventions were not provided because they needed more training. The areas they identified were assessment and intervention for sensory impairment (occupational therapists), visual impairment (occupational therapists and physiotherapists), and higher cognition impairment (speech language therapists). In Study 1, the following interventions had low percentages: *b164 higher level cognitive function* 0.9%, *b210 seeing* 0.6%, *b265 touch* 0.1%, *b270 temperature* 0.1%, and no interventions for *b260 proprioception*. When providing cognitive rehabilitation, one participant explained that it was difficult to delegate cognitive interventions to therapy staff despite the provision of in-service training for them. Participants from one DHB identified that they needed more knowledge of Māori support services and that no centralised place existed to access this knowledge. Therapists across all services acknowledged that therapist discomfort was the reason why therapists did not provide interventions to address sexual intimacy, despite the presence of a patient information booklet on this topic and this topic being on the initial assessment form. This could explain why there were no interventions for *b640 sexual functions* and only two interventions for *d770 intimate relationships*. The following sections will explore whether these findings have been reported in the literature.

Responding to uncertain evidence

This section will discuss the reasons for the lack of *b265 touch* (0.3%) and *b270 temperature* (0.3%) interventions. Participants said the lack of these interventions could be because sensation was not routinely assessed.

Based on best practice and expert opinion, the NZCGSM recommends assessing stroke patients for sensory impairment. As there is some evidence for sensory intervention, some support is given for the recommendation to provide sensory-specific training and strategies to transfer sensory training to other contexts (Stroke Foundation of New Zealand and New Zealand Guidelines Group, 2010). In the most recent Australian and New Zealand Living Guidelines for Stroke Management, there is a weak recommendation for sensory-specific training to address sensory loss in the upper limb. This is because one RCT study showed significant results for sensory training versus conventional treatment, but due to methodological issues, the certainty of the evidence was rated only moderate (Carey et al., 2011). From these two stroke guidelines recommendations, it appears that the lack of evidence for sensory interventions may have influenced therapists not to provide this intervention. In addition, this is an area where researchers are exploring a range of intervention techniques, such as compression therapy, mirror therapy, sensory stimulation methods, and sensory retraining methods, so therapists may consider using intervention strategies other than sensory retraining.

Two recent reviews have evaluated the effect of sensory retraining. Turville et al. (2019) reviewed 10 studies that were either randomised control trials, controlled clinical trials, or single-case experimental designs. When there was no comparison group for 7 of the studies, the results of the study were compared to control groups used in similar studies. The analysis showed sensory retraining improved sensation (pooled average effect size of 0.85) with non-significant improvement in arm use. Contrasting results were found by Yilmazer et al. (2019), using 9 RCTs and a meta-analysis of 8 studies. This review found that sensory retraining had non-significant improvements for light touch (SMD = 1.52, 95% CI 0.45–3.48) and proprioception (SMD 0.20, 95% CI 0.83–1.23), but significantly improved upper limb motor function (SMD = 0.73, 95% CI 0.14–1.32). This was mainly from the results of one study that used sensory retraining and mirror therapy. In contrast, sensory stimulation intervention using pressure and temperature significantly improved light touch (SMD = 1.13, 95% CI 0.20–2.05) but did not affect motor function. From these two conflicting reviews, more research using large, randomised control studies needs to be conducted to provide more conclusive guidance to therapists, which may in turn prompt higher numbers of interventions for sensory deficits.

Lacking confidence

Study 1 found a lack of interventions for *b210 seeing* (0.6%). An occupational therapist and a physiotherapist in Study 2 said low frequency interventions in this area may have occurred as therapists did not feel confident to assess and treat visual field loss and a range of visual impairments such as diplopia (double vision), ocular convergence (both eyes looking at the same point), and loss of saccadic movement (both eyes looking from one point to another). Lack of training and poor recognition that treatment was effective were reported as barriers to providing this intervention.

Therapists' lack of confidence existed alongside an NZCGSM 2010 consensus recommendation based on clinical experience and expert opinion that patients should be screened for visual impairment, and patients with impairment should have a comprehensive visual assessment from a relevant health professional. Based on one randomised trial each, some support was given to treat homonymous hemianopia by providing 15-diopter Fresnel prism glasses or by using a computer-based visual training program. It is interesting to note that these recommendations are not present in the latest Australian and New Zealand Living Guidelines for Stroke Management (Stroke Foundation, 2022). Instead, there is a consensus recommendation that all stroke patients be given a visual acuity, visual field, and eye movement assessment, but there are no recommendations for visual interventions.

The lack of clear recommendations for visual interventions may have been influenced by the findings from a more recent Cochrane review (Pollock et al., 2019). Ten randomised control studies published before 2018 found restorative interventions for visual field deficits had no effect on improving the visual field, but they did have a significant effect on quality of life (Pollock et al., 2019). Due to insufficient evidence, it was not possible to draw firm conclusions about the effectiveness of this type of intervention. Scanning interventions (compensation) improved quality of life (M difference 9.36, 95% CI 3.10–15.62) but did not affect extended activities of daily living, reading, and scanning ability. There was some evidence that prism glasses (substitution), which increase the visual field of the sound eye, improved scanning ability (M difference 9.80, 95% CI 1.91–17.69), but there was no effect on activities of daily living, reading, falls, or quality of life (Pollock et al., 2019). The authors stated that evaluating the evidence across the three intervention categories (restorative, compensatory, and substitution) was difficult due to the lack of studies comparing the interventions to a control group. Very few studies evaluated whether the intervention influenced daily living, and a meta-analysis was difficult as interventions varied across the three intervention categories. In addition, due to a high risk of bias, small numbers of participants, differences in participant characteristics, and the varied range of interventions, the quality of the evidence for the review was considered low to very low.

Pollock et al. (2019) indicated little evidence to support interventions for visual field deficits; however, a systematic review by Howard and Rowe (2018) supports compensatory interventions. This review included 30 studies, of which some were randomised control trials, controlled trials, systematic reviews, and case-controlled trials published before 2016. Each study was evaluated against a recognised quality checklist appropriate for the research method. This found that 27/30 studies were of good quality evidence. These authors found 11 studies that reported that compensation training, where the person is trained to scan their eyes to the blind side, had the outcome of subjective improvement in ADL, mobility, reading, driving, and detection of obstacles. Two recent studies using digital technology accessed via a computer program or internet app successfully improved scanning ability and aspects of daily living (Sahraie et al., 2020; Szalados et al., 2021). Sahraie et al. (2020) evaluated the NeuroEyeCoach program, where participants search out targets on a computer screen. Of the 294 self-selected participants, 87% improved their reaction time, 80% decreased their error rate, and 66% reported a perceived improvement in self-reported disability. Similar results were found using a free app called Eye-Search Therapy with 426 self-selected participants (Szalados et al., 2021). Compared to the pre-intervention scores, participants significantly improved their visual search time for the visually affected side ($F, 8.3, 643.1, = 3.1, p = .001$). These changes significantly impacted the participants' self-reported ability to "find things" ($F, 8.3, 643.1, = 3.3, p = .001$). It appears there are promising interventions for visual field loss, but therapists may not become aware of these recent developments by just accessing the latest stroke guidelines. Without that guidance, actions to increase their competence and confidence in intervening for visual field loss are unlikely to improve.

Capacity to use therapy assistants

From the Study 1 results, it is evident that therapy assistants carried out 22.4% of the total interventions, and these were supervised by an occupational therapist, physiotherapist, or speech language therapist. Consequently, therapy assistants provided a large range of interventions coded to *b1 global mental functions, b2 sensory and pain, b7 neuromusculoskeletal, d1 learning, d2 tasks, d3 communication, d4 mobility, d5 self-care, d6 domestic, and e1 products and technology*. The chapters where the therapy assistants provided the most interventions were for *b7 neuromusculoskeletal* and *d4 mobility*. The high number of interventions in these areas compared to the other chapters may have been because there are standardised routines for progressing exercise and walking abilities, and a patient's progress can easily be determined by observation. One participant thought the lack of interventions for chapter *b1 global mental functions* could be due to not being able to delegate these interventions to therapy assistants. The reason was that therapy assistants had no formal training to feel confident carrying out these interventions.

Compared to the United States (Johnson et al., 2019), in NZ, no specific qualification is required before people can take up the therapy assistant role. However, once employed, the employee is expected to engage in formal training from a level 1 to level 4 qualification within 6 years of starting employment (New Zealand Government, 2022). Informal training is provided on the job by the health service where the therapy assistant is employed, and formal training is provided by Te Pūkenga – New Zealand Institute of Skills and Technology. It offers a national apprenticeship in health and well-being level 4 qualification, specialising in diversional therapy or rehabilitation support, brain injury strand (Careerforce Te Pūkenga, 2023). In this system, a person wishing to do this qualification must be an experienced staff member employed by a health service. A coach supports trainees, and training occurs on the job and via distance learning. The diversional therapy qualification enables the person to work as a diversional therapist or occupational therapy aide. The rehabilitation support brain injury strand is suitable for anyone employed as rehabilitation support staff in hospital, residential, or community-based settings. Under this organisation, there are six workforce development councils (WDC). The role of the WDC is to work with specific industries to identify the skills that the industry needs and then incorporate these skills into training programmes (Tertiary Education Commission, 2023). Health services can use these new structures to influence the training provided to staff who choose to do these qualifications. The collective viewpoint of health professionals working in community rehabilitation services on this issue could be led by the Allied Health Aotearoa New Zealand (AHANZ) (Allied Health Aotearoa New Zealand, n.d.). This is a national voice for allied health professions in NZ and aims to provide a forum to discuss issues and provide advice to government ministers.

It appears that Australia and NZ are similar in that employment as a therapy assistant does not require a specific entry qualification, and training is provided on the job by completing a recognised qualification while working in the field. Two studies carried out in Victoria, Australia, have looked at the factors that influence the use of therapy assistants or allied health assistants (Huglin et al., 2021; King et al., 2022). Therapy assistants reported that when their role was not clear to health professionals, they were not used to their full capacity (King et al., 2022). It was also highlighted that the amount of training provided in the workplace depended on whether staff had time to engage in this activity and whether the leadership of the team considered this important (King et al., 2022). It was found that the health professionals delegating therapy tasks to the therapy assistants depended on the therapy assistant's training, the relationship quality, the therapist's supervisory skills, and their confidence in delegating tasks to therapy assistants (Huglin et al., 2021). Participants in Study 2 indicated that lack of training impacted whether they could delegate cognitive training to therapy assistants. Based on the findings by Huglin et al. (2021) and King et al. (2022), this may have occurred

for a variety of reasons: a) lack of role clarity on what interventions should be delegated; b) the lack of time to engage in training; c) poor support by management for training for therapy assistants; d) poor working relationships between therapist and therapy assistant; and e) health professionals lacking the skills to supervise or delegate these tasks to therapy assistants.

Therapists' knowledge of Māori support agencies

Participants said they did not know enough about Māori health support agencies, and accessing this information appeared to be difficult. The lack of Māori health services within current stroke services has also been identified by patients with stroke in focus groups within each of the 28 DHBs (Harwood et al., 2022) and from individual interviews with Māori caregivers (Fernandez, 2020). Similar findings have been found from 50 written submissions and 29 meetings with disabled people that contributed to the *Provisional Health of Disabled People Strategy 2023* (Ministry of Health, 2023). Māori and Pacific wanted health services to acknowledge and incorporate their health beliefs so they were culturally safe services. From these sources the following recommendations have been made: a) for health services to partner with Māori and Pacific health providers to improve their capacity and accessibility (priority 2) (Ministry of Health, 2023); b) the employment of more Māori staff who would provide traditional Māori health interventions (Māori rongoā, karakia, and mirimiri) (Harwood et al., 2022); and c) the use of a Māori liaison person who would act as a guide between the patient and family and the health service through the different stages of the rehabilitation process (Fernandez, 2020).

From reviewing this topic, staff may be having difficulty referring patients to Māori support services because, currently, these services are not widely available.

Avoiding embarrassment and offence

Study 1 found limited interventions for sexual intimacy, and participants recognised that this was not covered well. Participants thought this issue should be addressed due to the increasing numbers of young people with stroke who may wish to continue a sexual relationship after a stroke. In addition, staff were aware that not addressing this issue harmed the patient–partner relationship.

The barriers to discussing these topics that the participants identified were not having enough experience or knowledge, a desire not to embarrass or offend the patient, being part of a culture that does not discuss sexuality openly, and the belief that the topic of sexuality should be discussed only after the therapist had developed a trusting relationship with the patient.

There were no interventions for religion and spirituality, although participants said this issue was addressed in current practice. Participants said they supported religious practices by providing

interventions that enabled the patient to participate in this activity. For example, interventions would be provided to enable the person to assume a prayer position or take public transport to a church.

From the participants' responses, the factors that enabled interventions to be provided on these two topics were the patient identifying it as a goal to achieve while receiving CSR, the health professional feeling that the topics were within their scope of practice, having a booklet on sexuality that patients could read, having the topics of sexuality and religion on the initial assessment form, and the presence of a trusting relationship between the therapist and the patient.

This next section will discuss the stroke guidelines on sexuality interventions, whether there is going to be an increasing need for this intervention based on higher numbers of younger people with stroke, how a stroke impacts the patient–partner relationship, the barriers to providing sexual intimacy interventions, and recommendations to address these barriers.

The Stroke Foundation of New Zealand and New Zealand Guidelines Group (2010) provide consensus-based recommendations that patients and their partners should have the opportunity to discuss psychosocial and physical aspects of sexuality issues with a health professional with some expertise in sexuality counselling. Patients should also have access to written information on sexuality issues post-stroke. In the Australian and New Zealand Living Guidelines for Stroke Management (Stroke Foundation, 2022), recommendations are the same and are given a weak recommendation.

Although participants thought there were increasing numbers of younger people with stroke, the research by Feigin et al. (2015) and Ranta (2018) indicates this is not the case. Overall, the age of first stroke remained fairly stable, from 71.2 years in 1981 to 71.6 years in 2012 (Feigin et al., 2015).

Ranta (2018) predicted that due to NZ's population ageing, there will be higher numbers of people with stroke over 65 years, while the proportion of people under 64 will be considerably smaller. By 2028, it is projected that there will be 9,609 people with stroke over 65 years and 2,206 people under 64 years. However, it is projected that there will be higher numbers of Māori and Pacific people with stroke who are under 64 years old as this group currently experiences first-ever stroke 15 years earlier than European New Zealanders (Feigin et al., 2015; Ranta, 2018).

The participant viewpoint that there needs to be a greater focus on sexuality interventions due to the increasing numbers of younger people with stroke suggests that staff have a viewpoint that only younger people with stroke have an interest in maintaining sexual intimacy. This is a misconception, with a study in Britain reporting that of those aged 60–69 years, 84.5% of men and 59.9% of women

reported they were sexually active. This decreased with increasing age, with 59.3% of men and 34.3% of women in the 70–79 age group reporting they were sexually active (Lee et al., 2016).

The viewpoint that not addressing sexuality causes distress in relationships is supported by findings of a systematic review by McGrath et al. (2019b), which found there was a culture of silence regarding sexual intimacy. It was not discussed between the stroke patient and their partner, as people thought it might cause distress to their partner or they may feel rejected. When the topic of sexual intimacy was not brought up by health professionals, the patient and partner thought their concerns were not validated. The social norm also reinforced silence on the topic that sexual intimacy is private and should not be openly discussed. In addition, sexual intimacy was affected by the changed relationship dynamic between the patient and their partner. The patient reported a negative view of their own body and a loss of identity and self-esteem due to not being able to fulfil previous gender roles. The partners also reported a change in identity as they took on a caring role rather than an intimate partner role. When the relationship changed to a parent–child role, it caused ill feelings as the patient thought the partner was overly caring or hypervigilant. Partners also had feelings of grief and frustration on how the patient’s stroke had an impact on their life and future.

The lack of communication on this issue meant people were unprepared for the impact that the stroke had on their sexuality, were uncertain about their concerns, and did not know where they could get help. It also meant that conversations about sexual intimacy were harder to initiate or engage in with their partner. Therefore, patients and partners reported feeling a loss of mutual understanding and feeling lonely (McGrath et al., 2019b).

The findings from Low et al. (2022) support the view that sexuality is not addressed well by health professionals working in stroke rehabilitation. Although 91% thought health professionals had a role in supporting patients with sexuality, approximately one-third (29%) of the 720 multidisciplinary staff did not or did not recall (5%) having addressed any aspect of sexuality with a patient. A possible barrier to patients bringing up the subject of sexuality with health professionals was the belief that it was the responsibility of the patient to raise this question with the health professional. It was also found that most health professionals prefer to bring this topic up indirectly (the issue is not explicit) rather than directly, which means important issues may be missed or ignored (Low et al., 2022).

Other research supports the finding in this study that health professionals lack knowledge of sexuality interventions. Auger et al. (2023) reported that sexuality education was not present in undergraduate health professional qualifications. Currently, it is unknown whether sexuality and disability are covered in NZ health professional curricula. Another barrier mentioned by Auger et al. (2023) was that sexuality was absent in interdisciplinary assessment forms. There was uncertainty in

some health professions whether sexuality was within their professional role. Health professionals feared that they were not trained in some aspects of sexuality interventions such as couples therapy. Lastly, health professionals did not know of services or experts to whom the patient could be referred.

To address the barriers identified above, participants in the Auger et al. (2023) study provided the following recommendations. Sexuality training needs to be provided to everyone on the rehabilitation team, and in-depth training needs to be offered to those particularly interested in this area. Participants thought that each discipline's role in sexuality interventions needed to be clarified to enable good communication and a holistic approach to sexuality interventions; for example, psychologists would discuss relationship issues, speech language therapists might develop communication methods for people with aphasia, and occupational therapists and physiotherapists would discuss positions and technical aids. Sexuality should be added to all assessment forms, and to help ensure it was brought up, the team should designate someone to discuss this with the patient. To help reduce embarrassment for the patient and to understand the nature of the issue, it was recommended that a self-administered screening tool be developed. Health professionals wanted access to an expert who could give guidance when needed and someone they could refer to if they felt the person needed more help than they could give. Finally, it was thought there needed to be accessible information for patients on sexuality after stroke and a list of services or agencies that were available to patients on discharge. All these recommendations could be applied in the context of NZ.

Theme 7: Māori presenting with poorer health, low income, and housing issues

Study 1 found that in the body function domain, Māori received significantly fewer interventions for *b7 neuromuscular functions* (10.0% vs 20.0%), *b755 involuntary movement* (1.7% vs 4.7%), *b7308 exercise* (3.2% vs 10.0%) and *b730 muscle power* (3.6% vs 5.2%). In the activities and participation domain, Māori received significantly more interventions for *d5 self-care*, with high frequency interventions for *d570 looking after health* (11.1% vs 3.5%), *d540 dressing* (3.2% vs 0.7%) and *d510 washing* (2.4% vs 1.7%). In line with lower frequency interventions for neuromuscular functions, Māori received fewer interventions for *d4 mobility* (28% vs 32%). Although the differences in interventions between individual categories were not great, Māori received lower frequency interventions in 7 out of 12 *d4 mobility* categories, with the most notable difference for *d440 fine hand movement* (3.8% vs 5.1%). In the environmental factor domain, Māori received significantly more interventions in *e5 services systems and policies*. The higher frequency interventions for Māori were *e580 health services and systems* (2.1% vs 1.4%) and *e570 social security* (1.3% vs 0.1%).

The community rehabilitation staff in the DHB where these data were generated gave various reasons for the differences in the intervention patterns between Māori and non-Māori. In summary, it was thought that Māori have more complex medical and social problems, and these issues prevent Māori prioritising rehabilitation over other concerns. Increased stroke severity would explain why Māori received high frequency interventions for *d570 looking after health* (11.1% vs 3.5%), as health professionals were providing information to reduce the risks associated with increased disability such as increased falls. Māori were reported to be less aware of the risk factors of stroke, and less knowledgeable about community resources and the impact of rehabilitation. Consequently, in addition to stroke rehabilitation, Māori received interventions to address the social barriers impacting rehabilitation, such as poverty, housing, transport, and health education to improve the management of the condition. Spending more time on these interventions may have reduced the time to carry out the neuromuscular and hand function interventions. The need for patient education could be linked to higher frequency interventions for *d570 looking after health*, and the need for increased social services could be linked to higher frequency interventions for *e580 health services and systems* and *e570 social security*. Other reasons given for reduced engagement were different cultural values on the importance of following medical advice, lack of trust in the health service due to past experiences, and a reduced need for rehabilitation due to family members assisting with daily living activities. These rationales may have contributed to the result, but there were no direct links between these reasons and the specific intervention frequencies in Study 1. The next section will examine if the current literature supports the above findings.

More severe strokes

Participants' explanations that Māori had more complex strokes and co-morbid conditions are supported by Thompson et al. (2022). Thompson et al. found that Māori had significantly reduced odds of achieving functional independence on the Modified Rankin Scale at 3 months (aOR = 0.66, 0.43–0.999) and 12 months (aOR = 0.59, 0.36–0.96) than non-Māori. In addition, this research found that compared to European New Zealanders, Māori had a non-significant trend at 3, 6 and 12 months to have a recurrent stroke, which further increases disability and decreases the likelihood of a good outcome. Change of residence after stroke to live in residential care or with family is a measure of stroke severity, as it presumes that the person is not able to live alone due to decreased functional ability. Denison et al. (2023) found the change in residence after stroke was significantly higher for Māori at 3 (1.6, 95% CI 1.3–2.1) and 6 months (1.3, 95% CI 1.1–1.7) compared to European New Zealanders. The poorer outcome after stroke may partly be the result of Māori having more risk factors for stroke than European New Zealanders. Māori have higher rates of hypertension (35.8% vs 19.9%), diabetes (45.9% vs 41.5%), dyslipidaemia (40.4% vs 35.3%), atrial fibrillation (37.2% vs 8.8%)

and rheumatic heart disease (11.4% vs 6.3%), than European New Zealanders (Thompson et al., 2022).

Poverty

Staff expressed the view that Māori patients experienced greater poverty and loss of employment than non-Māori, which is an observation supported by Auckland Tourism Events and Economic Development (2020). In this report, Auckland household prosperity is scored from lowest to highest on a sliding 0–10 scale, using the following indicators: annual household income, home ownership rate, the percentage of 15–65-year-olds on benefits, rental affordability, and unemployment rate. The local boards in the south of Auckland and served by the DHB that provided the Māori data had the lowest household prosperity out of all the Auckland boards, and there had been no improvement since the last 2018 report. It found that the local boards with the lowest household prosperity were Mangere-Otahuhu (2/10), Manurewa (2.1/10), Otara-Papatoetoe (2.5/10), and Papakura (3.2/10). In addition, in 2020, out of all the boards, these areas had the lowest median incomes: Otara-Papatoetoe \$76,900, Mangere-Otahuhu \$77,900, and Manurewa \$83,000. Concerning the nationwide incomes of Māori people with stroke, it was found that 50% of Māori and Pacific stroke patients live in the most socioeconomically deprived quintile compared with less than 25% of New Zealand Europeans and Asians (Denison et al., 2023). It is also evident that Māori had significantly greater odds of unemployment than European New Zealanders at 6 months (OR 1.5, 95% CI 1.1–2.1) and 12 months (OR 1.5, 95% CI 1.1.–2.1) after stroke. This result is likely because Māori experience stroke while they are still employed, as the median age for stroke for Māori was 65 years, and the median age for European New Zealanders was 79 years (Denison et al., 2023).

The social worker participant said Māori who are 65 years and under are unable to return to work due to stroke and experience a sudden drop in income despite the income-supporting benefits that are available from the Ministry of Social Development (MSD). Consequently, a sudden drop in income after a stroke can trigger a person to move to cheaper rental accommodation or move in with family members, creating an unstable situation for delivery of CSR or requiring input to meet housing needs rather than rehabilitation needs. In NZ, there are two systems of financial support if you are unable to work due to ill health. Accident Compensation Corporation (ACC) assists people whose ill health is caused by an accident. An accident is defined as a specific incident, event or series of events that causes an injury and is diagnosed by a registered health professional (New Zealand Government, n.d.-a). The MSD covers all other conditions, however, there are stark differences in the benefit amount from each system. Under the MSD system, a person is not able to get a Supported Living Benefit if their partner is working, and if they are eligible, the amount they receive is considerably less than an ACC benefit or income from the NZ pension. Under ACC, if a person is

unable to work due to a work injury, they receive 80% of the person's former weekly earnings, and the total amount of this benefit is not impacted by the wages earned by the person's partner. A stroke patient under MSD who has a working partner would receive \$177.00 per week, whereas a person receiving ACC would receive \$455.11 per week (Kia Piki Ake Welfare Expert Advisory Group, 2019), and a person receiving a pension would receive \$356.00 per week (Work and Income, 2023). Consequently, the sudden drop in income after a stroke can trigger the person to move to cheaper rental accommodation or move in with family members.

Housing

The social worker participant said much of her role was related to finding suitable housing for Māori and Pacific patients. Many stroke patients cannot find accessible rental accommodation within their budget. There are several options for people in this situation: moving in with family, renting a cheaper home, obtaining transitional housing (which is temporary housing for 12 weeks or longer) and public housing that is provided by Housing New Zealand or NGOs called community housing providers (Work and Income, 2023). Currently, all these options are difficult to access. In Auckland, the median weekly rental cost is \$670.00 and has increased 11.7% from the 2022 median rental price (Bell, 2023). Interestingly, in August 2023, the total number of people waiting for public housing in NZ was 25,082, and of this group, 49% were Māori (Ministry of Housing and Urban Development, 2023b). The average wait time for public housing is 344 days, but the average waiting time for people who require a modified house is 435 days (Shivas, 2023). For many, the alternative is to use transitional housing until public or rental accommodation becomes available. Transitional housing is run by a housing provider contracted to the government, and people pay up to 25% of their income in rent. A person in this situation has short-term accommodation for 12 weeks and wrap-around social services to assist them in moving into rental accommodation. Although transitional housing may be a short-term solution, it creates stress as people with and without disabilities are asked to find affordable and accessible rental housing on the open market within the 12-week time frame. There are reports that people are staying up to 20 weeks or more due to the lack of rental housing that is affordable (Cooke, 2021; Latif, 2022). The number of people waiting for public housing in Auckland in August 2023 was 10,690 (Ministry of Housing and Urban Development, 2023b). With the number of transitional housing in Auckland being 2,767 in August 2023 (Ministry of Housing and Urban Development, 2023b), there is not enough temporary housing for people waiting for public housing. Consequently, it can be assumed that in this waiting period, people are living under difficult economic circumstances or are homeless if they are "living without shelter, in emergency and temporary accommodation and living as a temporary resident in severely overcrowded private dwellings" (Ministry of Housing and Urban Development, 2023a, p. 2). Consequently, if Māori are

experiencing stress when finding suitable housing after a stroke, it is reasonable to assume that Māori patients will have difficulty focusing on rehabilitation.

Lack of knowledge about the risk factors for stroke

Several participants said that Māori were less aware of the risk factors for stroke than European New Zealanders. One staff member said that lack of knowledge resulted in patients not managing conditions like diabetes, which then increased the person's risk of stroke. Consequently, staff provided education to reduce further risk of stroke. Staff education on stroke risk factors may explain why Māori had higher frequency interventions for *d570 looking after health* (11.1% vs 3.5%) compared to non-Māori. Of the interventions for *d570 looking after health*, 30% of the interventions aimed to reduce health risks and 70% were linked to reducing safety risks. This finding indicates that the Māori group may have had greater stroke severity, and interventions were provided to reduce safety risks. Research supports the view that Māori have less health literacy about stroke than non-Māori (Bay et al., 2015; Krishnamurthi et al., 2020). It was found that 42.7% of people were not aware that a stroke involved the blood and the brain. Of this group, Māori, Pacific, and Asian people had significantly less knowledge about stroke than European New Zealanders (Bay et al., 2015). In addition, Māori and Pacific are less likely to identify the signs and symptoms of a stroke (OR 0.57, 95% CI 0.36–0.97 and OR 0.47, 95% CI 0.29–0.77) (Krishnamurthi et al., 2020). However, this research does not support the view that Māori are less aware of stroke risk factors than non-Māori. A nationwide survey of 400 participants, of which Māori comprised 28% of the sample, found that only 34.5% of participants were able to identify one of the following risk factors for stroke: high blood pressure, high cholesterol, low levels of physical activity, poor or unhealthy diet and 30% could identify two risk factors or more (Krishnamurthi et al., 2020). There were no significant differences in the identification of risk factors between Māori and European New Zealanders. In contrast, Pacific people were 58% less likely to identify risk factors than European New Zealanders (OR = 0.42, 95% CI 0.26–0.66). These results present a confusing picture as although Māori have the same awareness of the risk factors for stroke as European New Zealanders, they experience more stroke risk factors (Thompson et al., 2022). This indicates that other factors may be at play to prevent Māori making lifestyle choices that would improve their health outcomes.

Research by Minhas et al. (2023) found a significant association between increasing levels of low income with a high risk of diabetes, hypertension, cardiovascular disease, cardiac heart failure, stroke, and death from cardiovascular causes. Using logistic regression, the results were adjusted so that the impact of age, race, ethnicity, cardiovascular risk factors, educational attainment, marital status, citizenship status, and access to health insurance did not affect the results. Minhas and colleagues were of the view that the prevalence of cardiovascular disease is multifactorial and

related to food insecurity, lifestyle factors, lack of suitable housing and transportation, health literacy, and not being able to afford medications and access to preventative health care. The stress of living in poverty may also lead people to seek relief by using drugs and alcohol, which further increases their cardiovascular risk (Minhas et al., 2023). This result has implications for NZ as Māori are 2.1 times more likely to have a stroke than non-Māori (Ministry of Health, 2015), and Māori in South Auckland, where these data was sourced, experience the lowest income and the lowest housing prosperity score compared to other parts of Auckland (Auckland Tourism Events and Economic Development, 2020). To address the impact of poverty on cardiovascular disease, Minhas et al. (2023) recommended that governments, health systems, and clinicians develop strategies to reduce poverty and improve access to healthcare, health education, housing, and good quality food. This suggests that NZ needs to improve and monitor access to healthcare, health education, housing, food, and income levels to achieve an improvement in Māori health outcomes.

Research supporting different patterns of interventions for Māori patients with stroke

There is limited research examining the equity of CSR service provision in NZ. However, two recent research studies have also found differences in stroke rehabilitation between Māori and non-Māori (Bright et al., 2023; Thompson et al., 2022). An NZ-wide observational study evaluated the impact of ethnicity on stroke care access and stroke outcomes for patients admitted to hospitals in 2018 (Thompson et al., 2022). Data were collected on functional outcomes and process measures such as access to reperfusion therapy, stroke units, interventions to investigate the cause of stroke, swallow screening, early mobilisation, medication, lifestyle counselling, access to a cultural advisor, and therapist contact time during inpatient and community rehabilitation. This research found most stroke interventions were accessed equally across all ethnicities, but non-European New Zealanders (Māori, Pacific and Asian) were significantly less likely to receive treatment in an acute stroke Unit (aOR = 0.68, 0.51–0.91) and receive a swallow screen in the first 24 hours (aOR = 0.57, 0.33–0.99). There were also non-significant trends showing non-European New Zealanders were less likely to be mobilised within 48 hours after the stroke and less likely to have access to 1 hour of physical therapy per day in the rehabilitation ward. This finding has parallels to this study, where it was found that Māori receive significantly fewer interventions for physical exercise and mobility.

Thompson et al. (2022) found non-Europeans (Māori, Pacific, Asian and others) were more likely to receive advice on managing reoccurring symptoms than non-European New Zealanders (aOR 1.79, (95% CI, 1.41-2.27), which does suggest that efforts are being made to achieve health equity for Māori. In addition, Māori received a greater number of community rehabilitation visits compared to European New Zealanders with a median of 5 (1–13) visits compared to 3 visits (1–8) (Thompson et al., 2022). Interestingly, the present study did not support this finding, as the median number of

community rehabilitation sessions for Māori was 16.5 compared to 22.5 sessions for non-Māori. Consequently, this study does not support the view that community health services are providing enhanced interventions to improve equity.

Living with family

Two participants reported that Māori family members positively affected rehabilitation as family members could take the patient to appointments and assist the patient with rehabilitation activities. However, participants reported that some family members did too much for the patient and that living with family could reduce the person's motivation to become independent. One participant thought that the number of interventions may be less because health professionals were educating family members to do therapy tasks with the patient and these interventions were not captured in the clinical notes. However, the data collected in Study 1 did not support this explanation.

Research findings from in-depth interviews with five Māori whānau (family) of patients with stroke support the finding that looking after a family member with a stroke is stressful (Fernandez, 2020). This was due to a person with a stroke moving into the home of relatives. In some cases, the caregivers provide care, hold down employment, and look after their own families while living in cramped conditions. In other cases when a person needed 24-hour care, a family member had to give up work and as a result was worse off financially. Family members acknowledged that support was available, but it was declined as it was not led by Māori staff or run on Māori cultural principles. In a similar study exploring Māori stroke patients and whānau experiences of speech therapy, it was found that patients and families wanted staff to use te reo Māori and have more knowledge of Māori worldviews and health concepts (Eustace et al., 2023). In practice, this would mean health professionals would have greater knowledge about Māori gods and Māori spirituality and well-being, Māori food, performing arts, and song. With this knowledge, health professionals would be better able to practice in ways that strengthen Māori identity and customs. It was also felt there needed to be more Māori staff in all health disciplines to better support Māori and to increase cultural safety (Eustace et al., 2023). With inpatient care, Māori patients and whānau have said they are not getting the chance to build connections or whakawhanaungatanga with health professionals. For Māori, this is a vital first step to building trust in the relationship. In addition, Māori want greater communication and shared decision-making with health professionals (Komene et al., 2023). In this study, one participant voiced that Māori patients would feel more comfortable if there were Māori staff members. It is possible that the lack of interventions for Māori in this study could be due to the lack of cultural safety felt by the Māori patients and the whānau, resulting in patients and families not fully engaging in the rehabilitation process. More research is needed in this area to fully understand if any of the factors described in research by Eustace et al. (2023), Fernandez (2020), and

Komene et al. (2023) are impacting the provision of community stroke interventions. No research evidence could be found supporting one participant's claim that living with family reduced the person's motivation to become more independent.

Summary

This chapter summarised the high and low frequency, and missing interventions to answer research question 1: "What are the type and frequency of interventions provided to patients receiving CSR in Auckland?". For research question 2: "Do the CSR interventions address the scope of interventions identified by the EICSS?", it was reported that CSR services provided 64/166 of the EICSS categories. To determine if the missing categories were relevant to the CSR, they were compared to two ICF validation studies (Glässer et al., 2011; Paanalahti et al., 2014) and the recommendations in the NZCGSM 2010. This process found 15 missing interventions that should have been in the data. Following this, the reasons for the missing interventions were explored by reviewing the literature on the evidence for these interventions and other studies that have evaluated the use of these interventions in practice. This was followed by a summary of the results for research question 3: "Are there differences in the type and frequency of interventions provided to Māori and non-Māori?". The main part of this chapter was exploring the literature that supported the seven themes that explain the answer to research question 4: "What are the staff explanations for the patterns of interventions in Study 1?". Three themes facilitated interventions: 1) physical impairment drives interventions, 2) patient goals, and 3) interventions to support engagement in rehabilitation. Four factors limited interventions: 4) not a common patient issue, 5) the impact of the organisations, 6) therapist factors, and 7) Māori presenting with poorer health, low income, and housing issues.

In the next chapter, the significance of the main findings is explained, and recommendations are made for health funders and policymakers, CSR managers and staff, and health educators. The limitations of the research are presented, and recommendations to develop this knowledge area further are suggested.

Chapter 10: Conclusion

Understanding the type and frequency of interventions provided to patients receiving community stroke services is important. Having this information would create a benchmark that allows community stroke services to be compared across the country, with other countries, and over time. Knowledge about what the service provides can determine if services meet patient needs, whether services follow guidelines for stroke rehabilitation, and whether service delivery is equitable between Māori and non-Māori. Knowledge of intervention provision would allow managers and health funders to confidently plan how to improve services and address identified staff training needs.

Having a baseline generated through rigorous research is particularly important because the number of people with stroke is projected to increase due to NZ's rising population and a disproportionate number of people over 65 years. Based on the 2015 stroke figures and the expected population figures, the incidence of stroke in NZ is expected to rise to 11,828 in 2028, 14,282 in 2038, and 15,532 in 2048 (Ranta, 2018). Stroke in NZ has a disproportionate effect on Māori. The incidence of stroke in the Māori population is twice that of New Zealand Europeans, and a stroke occurs on average 15 years earlier than for New Zealand Europeans (Feigin et al., 2015). Furthermore, Māori have significantly reduced odds of a favourable outcome 3 and 12 months after stroke (Thompson et al., 2022).

Understanding the overall performance of community stroke rehabilitation in NZ is also important because CSR services can significantly improve physical function (Chi et al., 2020) as well as social participation (Daviet et al., 2023). Consequently, it is likely with the increased numbers of people experiencing stroke that there will be a need for more efficient and effective CSR services.

Unfortunately, recent research has found that CSR services provide a different level of service depending on where the community stroke service is located (Thompson et al., 2020). There are differences in the waiting time to access the service as the duration of service delivery varies from 6 weeks to 1 year, and urban community stroke services provide more treatment sessions than non-urban centres (Thompson et al., 2020). There are also differences in how services are organised across NZ. It was found that not all services used a standardised rehabilitation assessment or had guidelines for cultural support (Thompson et al., 2020). In addition, it was found Māori support services were present but significantly underused (Thompson et al., 2022). Further, there is generally a lack of psychosocial care after stroke with inconsistent use of mood screening and insufficient employment of psychological and social work staff (Bright et al., 2023; Thompson et al., 2020). Gaining the perspectives of patients and health professionals identified that patients and families wanted more information on services, more support on discharge, and more access to speech

therapy, return to work, and driving rehabilitation services (Harwood et al., 2022; Thompson et al., 2023).

At the time of initiating this research, there were no international studies on the type and frequency of interventions provided to patients receiving CSR and only one small NZ study that identified the interventions provided by one community stroke service (Evans et al., 2017). More importantly, no research explored the reasons why therapists in community stroke services provided specific interventions. Based on this rationale, this research addressed the following research questions:

1. What are the patterns of community stroke rehabilitation interventions in Auckland?
2. Do CSR interventions address the scope of patient problems identified by the EICSS?
3. Are there differences in the type and frequency of interventions provided to Māori and non-Māori?
4. What are the CSR staff explanations for the pattern of interventions?

Overview of the methodology and method

The pragmatic philosophy of John Dewey informed the use of a mixed methods research paradigm. This is because Dewey was concerned about understanding our everyday experiences. Dewey (1984/1929) proposed that knowledge can be gained by understanding our actions and their consequences. This links to my research questions, as I wanted to understand the reasons why interventions were selected. Dewey (1984/1929) believed that multiple perspectives are needed to interpret reality, and one should not be limited by traditional practices. Instead, humans should choose the most appropriate tools to solve a problem. This edict was apparent in this research as I used a quantitative approach to understand what was provided to patients and a qualitative approach to understand why.

As no prior research has investigated the provision of interventions by community stroke services, I decided to use a mixed methods design called sequential quantitative to qualitative explanatory design, in which the first study gathers data on a phenomenon and the second study attempts to explain the rationale for the first study (Plano Clark & Ivankova, 2016). In this case, the first study was a retrospective observational study that identified and selected interventions from 113 medical files from patients who had received community stroke intervention from March 2016 to March 2017. This study identified whether the interventions addressed the functional needs of patients by comparing the intervention target to the EICSS (Starrost et al., 2008). Study 1 identified the frequency of interventions and missing interventions. In addition, it identified interventions provided

by each health service and each health discipline and compared interventions provided to Māori and non-Māori.

To establish the reliability of the data gathered in Study 1, an inter-rater reliability study was conducted using 10 patient files that were randomly selected from the main data set. This revealed there was poor inter-rater reliability as only 44.01% of interventions and codes were the same between both linkers. Further analysis revealed the differences in coding were due to linkers extracting interventions from different parts of the patient notes, the linker interpreting the target of the intervention differently, professional bias causing linkers to favour their own profession's interventions over others, differences in recording the aim of the session versus the aims of the different interventions provided in that session, and difficulty coding interventions when similar ICF codes could be used to describe the intervention target. Following this exercise, the two linkers came to a consensus agreement on the mismatched interventions and codes, and new rules were added to the coding guidelines. Using the updated coding guidelines, the original data set was reviewed and modified. This study was significant as it provided guidance on how to check linker coding using a percentage method rather than the Kappa statistic. It also explained methods to improve inter-rater reliability when two linkers independently code patient records to the ICF. Recommendations arising from these efforts to improve inter-rater reliability in future ICF studies of this nature included researchers asking health professionals to use a consistent patient note that identifies the target of the intervention using ICF language *before* the study commences. In addition, inter-rater reliability will be improved if researchers follow the recommendation to conduct inter-rater reliability checks and analysis at the beginning of the study until an acceptable inter-rater reliability is achieved.

Summary of findings

This study found that CSR services in Auckland do not provide 15 ICF categories that were expected to be in the data as they are recommendations in the NZCGSM 2010. Of the missing body function categories, it is of concern that there were no interventions for *b156 perceptual functions*, *b176 mental functions of sequencing complex movements*, *b260 proprioceptive functions*, *b715 stability of joint functions*, and *b735 muscle tone functions*. There were no staff explanations for the missing interventions, but the literature suggests several possible reasons: a lack of research evidence regarding the effectiveness of interventions, therapists not identifying these issues due to not using standardised assessment tools, therapists not recording the target of the intervention in the patient notes, and a lack of services to address muscle tone impairments. All these impairments are common after stroke, and it may mean that patients are experiencing increased disability due to the limited provision of these interventions.

Of the missing activity and participation interventions, the lack of interventions for *d325 receiving written messages* (reading) is a concern as reading contributes to following written instructions for leisure and domestic activities and enables communication via email and text message.

Consequently, not receiving interventions in this area may prevent or impede patients from engaging in these activities. Lastly, the missing environmental factor intervention of *e410 individual attitudes of family* is of concern because it is known that carers need support to manage the changes in their spouses after stroke. The lack of interventions and services for carers of stroke patients has been previously recognised in NZ research. Carers who do not receive support are more likely to experience increased stress and depression, and this can have a negative effect on the marital relationship (Qureshi et al., 2022).

Integrated findings

Integrating the results from Study 1 and Study 2 found seven themes addressing factors that facilitate or limit the delivery of interventions. The next section considers those results and the implications for CSR staff and health funders under the following headings: what increases interventions, the causes and implications for low frequency and absent interventions, factors that increase inequity for Māori patients, and the variability of CSR services.

What increases interventions

The finding that the highest frequency interventions were for improving physical function is significant because it indicates CSR services, and particularly ESD rehabilitation services, are driven by the patients' goal to improve physical function, and evidence states that intensive physical rehabilitation is effective at reducing physical impairment. The provision of this intervention is supported by the fact that two health professions (one occupational therapist and one physiotherapist) have the provision of exercise as part of their professional scope, that therapy assistants can carry out this intervention, and that particular DHBs have the financial resources to provide additional services such as group fitness classes. Recent research has found that out of 28 NZ hospitals, only three provide ESD services, and 14 provide CSR services in NZ (Thompson et al., 2020). This means that patients receiving an early stroke discharge or a CSR service are likely to receive more interventions for physical impairment and possibly make faster physical recovery than stroke patients who are not able to receive these services.

It is evident that CSR is guided by supportive evidence in the NZCGSM 2010 for the provision of interventions. This resulted in high frequency interventions for fatigue management and for physical impairment interventions. Following the NZCGSM 2010 could also explain the lack of strong evidence and recommendations in the guidelines for *b156 perceptual function* and *b260 proprioception* and

few interventions for *b210 seeing*, *b265 touch*, *b270 temperature*, and *d920 community life* (social participation).

Causes and implications for low frequency and absent interventions

Some low-frequency interventions, such as *b415 blood vessels*, *b420 blood pressure*, *b440 respiration*, *b810 protects skin*, *b820 repair of skin*, and *b525 defecation* may indicate that these categories in the EICSS do not represent the interventions required in the CSR phase of rehabilitation. This finding has implications for the possible future development of an ICF core set that specifically represents CSR interventions. The codes *d135 rehearsing* and *d155 acquiring skills* appear to be redundant in the CSR context as most rehabilitation interventions include some form of practice and acquiring a skill.

Although recommended by the NZCGSM 2010, there were few interventions for *d620 acquiring goods and services* and *d920 recreation and leisure*. Therapists reported this was because these interventions required more time or organisation. In the 6-week service, it was reported that these interventions were not conducted as patients were not yet ready to progress to community mobility. Although patients were referred to the Stroke Foundation for community integration, the Stroke Foundation does not provide patients graded support to attend outings, practice using public transport, and advice on how current leisure activities can be modified. This means that health professionals are providing physical impairment interventions but not taking the next step of coaching people to use these physical abilities to re-engage in past ways of living or to assist people in redesigning how they live to make the most of their physical capacities. Not providing these interventions can result in reduced social participation and quality of life, and an increase in depression.

Despite some evidence in the NZCGSM 2010 for interventions to address apraxia (*b176 mental functions sequencing complex movements*), there were no related interventions in the data. This indicates there is a training issue that needs to be addressed by undergraduate educators of occupational therapy, physiotherapy, and speech therapy students, and by CSR managers.

The lack of driving interventions was due to stroke patients needing legal clearance for driving from a GP or consultant. In contrast to other DHBs, the Auckland region does not have a free driver assessment service and patients need to pay for a driving assessment and ongoing driving rehabilitation. Due to other agencies providing driver assessment and training, there is no method currently to determine the need for driving interventions. Consequently, the extent of need is not quantified and therefore at risk of being overlooked by health funders.

There were no interventions for housing modifications across all the CSR services as it is a common policy that housing modifications larger than installing a rail, are referred to another community rehabilitation that specialises in this work. This is because the high levels of paperwork and waiting time for housing alterations can decrease the service's capacity to take on new patients. This policy is designed to increase the throughput of patients and prevent patients from waiting to receive a CSR service. However, it is unknown how long patients must wait for the housing modification service and to what extent this service delay impacts the patients' lives.

CSR is providing low levels of interventions to address return to work, even though many Māori have a stroke before they have reached retirement age. The cost of not returning to work has serious financial implications for themselves and their families. In addition, many patients over the age of 65 wish to remain employed. There are other organisations that assist patients to return to work, but currently, it is not known whether these organisations are meeting the need or if they are effective at enabling patients to stay in paid work.

This study found the lack of sexuality intervention could be due to the lack of strong evidence for this intervention in the NZCGSM 2010, therapists' lack of knowledge and discomfort when discussing this topic or the need for a trusting relationship between patient and therapist before this topic can be discussed openly. Other reasons found in the literature were that there is a culture of silence on sexual intimacy, a lack of undergraduate training, an expectation by health professionals that the patient should initiate this conversation, and that sexuality was absent on assessment forms (Auger et al., 2023; Low et al., 2022; McGrath et al., 2019a). This intervention area needs to be addressed in ways that acknowledge that staff have different levels of knowledge and comfort with this topic.

The lack of psychology staff resulted in low frequency interventions for *b152 emotional functions* (0.7%), *d240 stress* (1.7%) and no interventions for *b126 temperament and personality*, *d760 family relationships* and *d770 intimate relationships*. This resulted in only patients with severe psychological issues receiving psychological treatment. The remaining group with psychological issues were supported by the CSR staff which reduced therapy time for rehabilitation. Staff reported that not having the appropriate psychological care reduced the patient's motivation to engage in rehabilitation. Stroke is a condition that frequently results in grief and depression, and if these are not treated, it can result in people not participating fully in their rehabilitation. Consequently, if patients are in this situation, they may not reach their full potential and are at risk of worse outcomes such as being dependent on family members or going to residential care. It is interesting to note that staff did not attempt to provide psychological interventions themselves. This indicates that

staff are staying within their professional scope, as required by the Health Practitioners Competence Assurance Act (New Zealand Government, 2003).

The varying levels of social work across the services may have contributed to low frequency interventions for *d610 acquiring a place to live* (0.2%), and no interventions for *d660 assisting others*, *e550 legal services*, *e570 social security* and *e575 general social support*. It was interesting to note that the DHB with the highest socioeconomic needs was the only DHB that had a full-time social worker employed in the service. Despite providing more social work cover in this DHB other members of the CSR team provided social interventions, which reduced the time available for rehabilitation. This indicates that the number of social work staff is insufficient to meet the needs of patients in this DHB.

This thesis builds upon the assumptions of disability as described in the ICF, and the expectation that community stroke rehabilitation has the mandate and purpose to address activity limitations. However, Study One results (chapter 7 figure indicate the highest percentage of interventions were directed at improving physical impairment (17%) and mobility (31%), with a lower percentage of interventions directed at self-care (7%), domestic life (3%) major life areas (1%) and community life (3%). This indicates that current practice continues to have a biomedical focus and community stroke rehabilitation is not fulfilling its potential to fully integrate patients with stroke back into the community.

Equity for Māori

It was found that Māori received significantly fewer interventions than non-Māori for *b7 neuromusculoskeletal functions* and significantly more interventions for *d5 self-care* and *e5 health services and systems*. This result is interesting, as research findings indicate that Māori have worse stroke outcomes than non-Māori, so it is reasonable to assume that Māori would have higher frequency interventions for *neuromusculoskeletal functions*. The reasons provided by the staff were that Māori were not fully engaged in their rehabilitation because of multiple medical and social issues. Staff time was directed at addressing social issues, as indicated by the higher frequency interventions for *e5 health services and systems*. Consequently, this focus reduced the rehabilitation time available to the patients. It is apparent that low wages, low levels of financial assistance, and the high cost of rental housing in Auckland contribute to the social issues experienced by Māori who have strokes. However, it appears the housing and the benefit system in NZ does not consider how these factors impact Māori who are recovering from a stroke. In addition, there are other factors,

such as unconscious bias and whether patients are receiving services that are culturally safe, that may have resulted in Māori not wishing to engage in the rehabilitation process.

Variability of service

This research found marked differences in interventions across the three CSR services. This was particularly evident for *b1 global mental functions*, *b7 neuromusculoskeletal*, *d4 mobility*, *d5 self-care*, and *e1 products and technology* (Figure 13, Chapter 7). This indicates there will be variability of services across NZ CSR services. These differences could mean that patients are not receiving evidenced-based interventions, and as a result, have poorer outcomes after stroke. Currently, there is no mechanism in DHB services for measuring the type and frequency of interventions in a timely and cost-effective way. Without this type of information, it is impossible to evaluate the quality of CSR services and measure change over time.

Recommendations

Based on the results of the study I would like to make the following recommendations to health funders and policymakers, CSR managers and staff, health professional educators, and researchers:

A) Health funders

- CSR services, and in particular, ESD services, should provide intensive interventions to improve physical function. This level of service provision is recommended by the NZCGSM 2010 and supported by the evidence that demonstrates community stroke services can significantly improve physical function in the first 6 months after stroke (Chi et al., 2020).
- The study found that CSR services were guided by patient goals. For the two services that provided a service for 12 weeks, the duration of rehabilitation could be extended if patients had not met all their goals. However, patients receiving the 6-week intensive service with remaining goals had to wait for some months for further rehabilitation from another community rehabilitation service. This is a concern as it has been found that patients with moderate impairment make the most improvement from stroke onset to 6 months and those with severe impairment from stroke onset to 3 months, and then from 6 to 18 months (Lee et al., 2022). This delay of service may prevent the patient with moderate and severe impairment from continuing to progress in their rehabilitation goals over this critical period. To remove delays in rehabilitation, it is recommended that health funders ensure that there is prompt follow-up from a CSR service after discharge from an ESD service.

- As noted in this research, Māori have difficulty focusing on rehabilitation due to the issues of complex, severe medical conditions, poverty, and housing insecurity. As a result, CSR staff spend time addressing social issues rather than providing rehabilitation. It is apparent that dedicated staff are required to address such issues and that the provision of such services should be commensurate with the ethnic mix in the region the CSR serves. The provision of adequate support in relation to social issues would free rehabilitation specialists to deliver rehabilitation. This finding, however, also signals broader social issues of the significant discrepancy between MSD benefits and provisions under ACC. If the respective support provisions were equivalent, a person working before their stroke would receive 80% of their previous wages, irrespective of whether their partner was working. In this respect, the study findings have generated evidence to support the equalisation of the health and accident compensation systems.
- The reason for the lack of or limited interventions addressing psychological care, social services and social support for patients and carers was the lack or limited psychological and social work staff. To improve interventions in these areas, it is recommended that more funding be available so that psychologists and social workers are adequately provided in all CSR services. From the study, it was found that patients needed support to address social issues before they were able to focus on rehabilitation. Consequently, it is recommended that there be sufficient social work staff in areas where there is high economic deprivation.
- Despite trusted evidence to support leisure interventions from NZCGSM 2010 and the finding that a loss of pre-stroke activities is associated with depression (Tse et al., 2019), this research has found that therapists lacked the time to provide interventions for community life, shopping, leisure, and recreation. Recent NZ research has found that the “Take Charge” self-management technique can improve physical quality of life and engagement in activities (Fu et al., 2020); therefore, it is recommended that this cost-effective intervention be introduced to CSR services throughout NZ.
- This research found few interventions for driving and returning to work. Therapists suggested this was because outside agencies were providing these interventions. Although this is the case, research indicates that patients find these interventions difficult to obtain (Harwood et al., 2022). Currently, there is no one system to monitor the current need for driving assessments and return-to-work programmes; therefore, it is recommended one national service, such as the Stroke Foundation, be resourced by the government to monitor the need for services and provide return to work and driving rehabilitation.

- To monitor and evaluate the provision of CSR services, so that services are equitable and evidence-based across the country, it is recommended that the health service develop a national IT system whereby digital notes can quickly determine the type and frequency of interventions and contribute to the ongoing quality of CSR services. In this research, the inter-rater reliability study found that it was difficult to reliably link interventions to the EICSS due to variable methods of writing patient notes and therapists not clearly indicating the aims or target of interventions. The ability to evaluate the provision of interventions using patient notes depends on a consistent and clear format. This will allow either therapy staff, researchers, or computer systems to quickly identify the interventions that are linked to an ICF function. To generate reliable information from patient notes, it is recommended that all therapy staff use a consistent method in patient notes that clearly shows the aim of the intervention.

B) Managers

1. The study identified high, and low frequency, and missing interventions by comparing interventions to the EICSS and comparing the interventions provided to Māori and non-Māori. Despite the following interventions being recommended by the NZCGSM 2010 or by research findings, they were either missing or provided at lower frequency rates.
 - a) Interventions in the body function were *b126 temperament and personality, b152 emotional functions, b156 perceptual functions, b176 mental functions of sequencing complex movements, b164 higher cognitive functions, b260 proprioceptive functions, b265 touch, b270 temperature, b210 seeing, b715 stability of joint functions and b735 muscle tone functions.*
 - b) Interventions in the activities and participation domain were *d240 stress, d325 receiving written messages, d610 acquiring a place to live, d620 acquiring goods and services, d660 assisting others, d760 family relationships, d770 intimate relationships, d920 recreation and leisure and d910 community life.*
 - c) Interventions in the environmental factor domain included *e410 individual attitudes of family, e570 social security, and e575 general social support.*
 - d) In addition, this study found that Māori were receiving significantly fewer interventions linked to *b7 neuromusculoskeletal function and d4 mobility.*

To evaluate if these interventions are being provided and provided equitably, it is recommended that CSR services audit patient records for the presence of these interventions.

2. In relation to sexuality, it is recommended that a self-administered screening tool be developed so that patients can identify this issue early without embarrassment. To ensure that the topic of sexuality is discussed, it is recommended that sexuality be placed on the initial assessment and discharge form. To allow staff members to develop confidence and competence when addressing this issue, it is recommended that one staff member on the team is designated to follow up on any patient who identifies sexuality as an issue. Alternately, it might be recognised that specialist competencies are required to broach and intervene with this deeply personal issue beyond the competencies demonstrated by therapists on the CSR team. That admission implies the need to recruit additional sexuality expertise to CSR teams.

C) Managers and educators of health professionals

1. Therapists reported they lacked knowledge of interventions in the following areas: sensation, vision, higher cognitive function, apraxia, and sexuality. Consequently, it is recommended that educators of health professionals and managers of community stroke services provide education on these topics.

Limitations and further research

It is possible that the interventions recorded in the patient notes are not fully representative of what was provided by therapists. This is because notes are usually written concisely and designed to assist the therapist in planning for the next intervention session. Therapists may only report what was successful or what is considered important by the CSR service. Despite these limitations, collecting interventions retrospectively from patient notes means therapists are not influenced by being in a research project, and the research reflects the real-life constraints of CSR.

This research has explored the reasons for high, and low frequency, and missing interventions provided by a CSR service. However, it was not possible to explore the rationale for every intervention provided. To fully understand the rationale for interventions and why some interventions are favoured over others, further research could analyse intervention provision using a case study methodology to explore interventions provided to individuals with stroke from the perspective of the therapist and the patient. This type of research would uncover the clinical reasoning, knowledge gaps of the therapist, and the goals and resources of the patient, as all these factors influence intervention choice.

For most of the time, I was the only person collecting and encoding interventions. This was a limitation as it was not possible to compare coding with another researcher to check that data

extraction and coding were conducted consistently. However, reliability was assessed using the inter-rater reliability study, and after the errors were found, the coding was modified according to an agreed protocol. Future studies in this area would benefit by therapists using a consistent patient note method that clearly identifies the target of the intervention. Prior to starting the research it would be beneficial for the researcher and the community stroke team to extract and code interventions together. This would ensure that the researcher understands the aim of the interventions from each discipline's perspective.

The interventions in Study 1 were written by therapists between 2016 and 2017. However, Study 2 asked the reasons for interventions from therapists in 2021. This four-year time gap may be a limitation as therapy practice may have changed during this time. In future, the validity of the research on this topic would be improved if the time gap was reduced to 1 or 2 years between the studies.

In the future, it could be possible to use the methodology used in this research to explore the type and frequency of interventions that are most effective when treating people with stroke. This could be conducted by recording patient goals, impairment, and disability levels pre and post-stroke and comparing this with the interventions that were provided.

This research explored the reasons for the provision of interventions from the perspectives of the CSR health professionals. In relation to Māori, staff thought that the differences in interventions for Māori were due to a lack of engagement in the rehabilitation process that was caused by complex medical conditions and social situations. To explore this in more depth, it is recommended that research be carried out on the experiences of Māori receiving CSR. This type of research may indicate other factors impacting the provision of interventions and suggest solutions to improve the provision of CSR to Māori.

In order to limit waiting times for CSR, patients who required housing modifications were referred to another long-term rehabilitation service that only addressed this issue. Currently, it is unclear how the delay in the provision of housing modifications impacts the patient and their carer. Consequently, it is recommended that the provision of housing modifications to patients receiving CSR be further researched.

Conclusion

This research is unique as it has identified, in detail, therapy interventions and how often they are provided in three CSR services. The intention was to understand from the therapists' perspectives the rationale behind why interventions were provided and to use this information as a basis for

targeted improvement in the quality of CSR for patients. Improving the delivery of community of stroke services is a worthwhile endeavour, as the impact of a stroke can have devastating lifelong impacts. The results of this research are relevant to health funders, managers of CSR services, educators of health professionals, and CSR staff and patients, as they provide clear guidance on what further work can be done to improve these services.

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Appendices

Appendix A: Māori-specific ethical approval



**He Kamaka Waiora
Waitematā and Auckland DHB**
Level 2, 15 Shea Terrace,
Auckland 0740,
New Zealand
Private Bag: 93-503

13/11/2017

Melissa Evans
North Shore Hospital
Shakespeare Rd
Takapuna
Auckland 0622

Re: Stroke interventions provided by community rehabilitation teams in Auckland

Thank you for providing the following documents the:

- RRC application
- Study protocol
- PIS/CF
- HDEC application

This is a regional study that will explore Stroke interventions provided by community rehabilitation teams in Auckland. There will be up to 234 participants recruited from within the Auckland and Waitematā District Health Board (DHB) region. It is estimated that the number of Māori participating in the study may be approximately 117. This exact number may vary but the researcher aims to ensure that Māori will make approximately 50% of the study.

Māori responsiveness:

This is a low risk observational study that aims to identify whether people in Auckland are receiving community stroke rehabilitation (CSR) interventions that address the full scope of patient needs. The study includes a focus on Māori health inequity and aims to determine if there are differences in the type and amount of interventions provided to Māori and non-Māori. It is intended that the results of the study will be shared with service managers within each DHB with a view to contributing to improved service provision.

Initial stages of research will include identifying the numbers of Māori patient files within each DHB for the period March 2016 to March 2017. This will determine the number of Māori patient files that are randomly selected from each DHB. Overall the researcher intends to include a representative number of Māori patient files to ensure that Māori have equal explanatory power within the study.

The researcher has noted the importance of engaging in meaningful and appropriate analysis of evidence including information extracted from clinical files. This is a particularly relevant and valuable aspect of research involving Māori in terms of the attributions that are made about Māori health status.

On behalf of the Waitematā and Auckland District Health Boards Māori Research Committee the study has been approved.

Heoi ano

[Kim Southey](#)

Kaupapa Māori Analyst

Waitematā and Auckland DHB

Level 2, 15 Shea Terrace, Auckland 0740,

New Zealand

Private Bag: 93-503

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email kim.southey@waitematadhb.govt.nz

Appendix B: Ethical approval and amendment

8 December 2020

Clare Hocking
Faculty of Health and Environmental Sciences

Dear Clare

Re Ethics Application: **20/378 Community stroke rehabilitation: Staff viewpoints on patterns of service provision**

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 8 December 2023.

Standard Conditions of Approval

1. The research is to be undertaken in accordance with the [Auckland University of Technology Code of Conduct for Research](#) and as approved by AUTEC in this application.
2. A progress report is due annually on the anniversary of the approval date, using the EA2 form.
3. A final report is due at the expiration of the approval period, or, upon completion of project, using the EA3 form.
4. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form.
5. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
6. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.
7. It is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard and that all the dates on the documents are updated.

AUTEC grants ethical approval only. You are responsible for obtaining management approval for access for your research from any institution or organisation at which your research is being conducted and you need to meet all ethical, legal, public health, and locality obligations or requirements for the jurisdictions in which the research is being undertaken.

Please quote the application number and title on all future correspondence related to this project.

For any enquiries please contact ethics@aut.ac.nz. The forms mentioned above are available online through <http://www.aut.ac.nz/research/researchethics>

(This is a computer-generated letter for which no signature is required)

The AUTEC Secretariat
Auckland University of Technology Ethics Committee

Cc: mevans@aut.ac.nz; Richard Siegert; nick.garrett@aut.ac.nz

13 January 2021

Clare Hocking
Faculty of Health and Environmental Sciences

Dear Clare

Re: Ethics Application: **20/378 Community stroke rehabilitation: Staff viewpoints on patterns of service provision**

Thank you for your request for approval of amendments to your ethics application.

The amendment to the research methodology (graphs linked to interview questions) and changes to the indicative questions has been approved

I remind you of the **Standard Conditions of Approval**.

1. The research is to be undertaken in accordance with the [Auckland University of Technology Code of Conduct for Research](#) and as approved by AUTEK in this application.
2. A progress report is due annually on the anniversary of the approval date, using the EA2 form.
3. A final report is due at the expiration of the approval period, or, upon completion of project, using the EA3 form.
4. Any amendments to the project must be approved by AUTEK prior to being implemented. Amendments can be requested using the EA2 form.
5. Any serious or unexpected adverse events must be reported to AUTEK Secretariat as a matter of priority.
6. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEK Secretariat as a matter of priority.
7. It is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard.

AUTEK grants ethical approval only. You are responsible for obtaining management approval for access for your research from any institution or organisation at which your research is being conducted. When the research is undertaken outside New Zealand, you need to meet all ethical, legal, and locality obligations or requirements for those jurisdictions.

Please quote the application number and title on all future correspondence related to this project.

For any enquiries please contact ethics@aut.ac.nz. The forms mentioned above are available online through <http://www.aut.ac.nz/research/researchethics>

(This is a computer-generated letter for which no signature is required)

The AUTEK Secretariat
Auckland University of Technology Ethics Committee

Cc: mevans@aut.ac.nz; Richard Siegert; nick.garrett@aut.ac.nz



Health and Disability Ethics Committees

Ministry of Health
133 Molesworth Street
PO Box 5013
Wellington
6011

0800 4 ETHICS
hdec@moh.govt.nz

11 December 2017

Mrs Melissa Evans
4 Bryers Place
Glenfield
Auckland 0629

Dear Mrs Evans

Re:	Ethics ref:	17/CEN/244
	Study title:	Stroke interventions provided by community rehabilitation teams in Auckland

I am pleased to advise that this application has been *approved* by the Central Health and Disability Ethics Committee. This decision was made through the HDEC-Expedited Review pathway.

Conditions of HDEC approval

HDEC approval for this study is subject to the following conditions being met prior to the commencement of the study in New Zealand. It is your responsibility, and that of the study's sponsor, to ensure that these conditions are met. No further review by the Central Health and Disability Ethics Committee is required.

Standard conditions:

1. Before the study commences at *any* locality in New Zealand, all relevant regulatory approvals must be obtained.
2. Before the study commences at a *given* locality in New Zealand, it must be authorised by that locality in Online Forms. Locality authorisation confirms that the locality is suitable for the safe and effective conduct of the study, and that local research governance issues have been addressed.

Non-standard conditions :

- Please email to the secretariat, the confidentiality document that people involved will sign. Please use the email address hdec@moh.govt.nz and indicate that the document has been requested by the Committee. Please include your HDEC reference number.

Non-standard conditions must be completed before commencing your study. Non-standard conditions do not need to be reviewed by HDEC before commencing your study.

For information on non-standard conditions please see section 128 and 129 of the Standard Operating Procedures at <http://ethics.health.govt.nz/home>.

After HDEC review

Please refer to the *Standard Operating Procedures for Health and Disability Ethics Committees* (available on www.ethics.health.govt.nz) for HDEC requirements relating to amendments and other post-approval processes.

Your **next progress report** is due by **10 December 2018**.

Participant access to ACC

The Central Health and Disability Ethics Committee is satisfied that your study is not a clinical trial that is to be conducted principally for the benefit of the manufacturer or distributor of the medicine or item being trialled. Participants injured as a result of treatment received as part of your study may therefore be eligible for publicly-funded compensation through the Accident Compensation Corporation (ACC).

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Helen Walker', enclosed in a thin black rectangular border.

Mrs Helen Walker
Chairperson
Central Health and Disability Ethics Committee

Encl: appendix A: documents submitted
appendix B: statement of compliance and list of members



Health and Disability Ethics Committees

Ministry of Health
133 Molesworth Street
PO Box 5013
Wellington
6011

0800 4 ETHICS
hdec@moh.govt.nz

18 February 2019

Mrs Melissa Evans
4 Bryers Place
Glenfield
Auckland 0629

Dear mrs Evans

Re:	Ethics ref:	17/CEN/244/AM02
	Study title:	Stroke interventions provided by community rehabilitation teams in Auckland

I am pleased to advise that this amendment has been approved by the Central Health and Disability Ethics Committee. This decision was made through the HDEC Expedited Review pathway.

The main issues considered by the HDEC in giving approval were as follows.

1. Please also update the Participant Information Sheet.

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,

Mrs Helen Walker
Chairperson
Central Health and Disability Ethics Committee

Encl: appendix A: documents submitted
appendix B: statement of compliance and list of members

Appendix C: Standard terms and linked codes

Temperament and personality functions	b126	Temperament and personality functions-b126
sleep	b134	sleep-b134
mental fatigue, energy and drive functions	b130	mental fatigue, energy and drive functions-b130
attention related to neglect L side/or sustaining attention	b140	attention related to neglect L side/or sustaining attention-b140
memory fuction	b144	memory fuction-b144
dairy/or calendar	b144	dairy/or calendar-b144
Psychomotor functions	b147	Psychomotor functions-b147
emotional functions	b152	emotional functions-b152
visual preception (spatial or distance or objects)	b156	visual preception (spatial or distance or objects) -b156
pace of thinking (slow it down)	b160	pace of thinking (slow it down)-b160
knowledge of condition	b164	knowledge of condition-b164
improve ability to sequence a task	b164	improve ability to sequence a task-b164
improve organisation	b164	improve organisation -b164
discussed goals	b164	discussed goals-b164
improve reception or expression of spoken or verbal language	b167	improve reception or expression of spoken or verbal language-b167
word finding tasks	b167	word finding tasks-b167
learning the sequence of movement steps	b176	learning the sequence of movement steps-b176
touch	b265	touch-b265
proprioception	b260	proprioception-b260
sensory functions related to stimuli	b270	sensory functions related to stimuli-b270
pain	b280	pain-b280
articulation of speech ie clarity of sounds	b320	articulation of speech ie clarity of sounds-b320
fluency and clarity of speech	b330	fluency and clarity of speech-b330
reduce swelling	b415	reduce swelling -b415
taking persons blood pressure/any action to reduce BP	b420	taking persons blood pressure/any action to reduce BP-b420
respiration functions	b440	respiration functions-b440
exercise tolerance and reduce fatigue	b455	exercise tolerance and reduce fatigue-b455
swallowing liquids or solids by using a technique	b510	swallowing liquids or solids by using a technique-b510

monitor blood sugar levels	b525	monitor blood sugar levels-b525
maintain body weight (food choice or frequency of food	b530	maintain body weight (food choice or frequency of food-b530
urination functions	b620	urination functions -b620
increase or maintain ROM in arm or leg	b710	increase or maintain ROM in arm or leg-b710
strength, in any muscle group	b730	strength, in any muscle group-b730
practicing weight shifts in sitting	b730	practicing weight shifts in sitting-b730
exercise (strength, endurance, control)	b730	exercise (strength, endurance, control)-b730
endurance	b740	endurance-b740
balance reactions	b755	balance reactions-b755
control of voluntary movet	b760	control of voluntary movet-b760
control of voluntary movement	b760	control of voluntary movement-b760
gait pattern by giving a prompt to the person	b770	gait pattern by giving a prompt to the person -b770
shown how to place foot	b770	shown how to place foot-b770
protect the skin	b810	protect the skin-b810
coaching/prompting family/client leaning new skill	d155	coaching/prompting family/client leaning new skill-d155
writing	d170	writing-d170
counting money or doing sums	d172	counting money or doing sums-d172
Undertaking a task	d210	Undertaking a task-d210
Carrying out daily routine	d230	Carrying out daily routine-d230
providing support to decrease stress	d240	providing support to decrease stress-d240
reception of spoken messages	d310	reception of spoken messages-d310
the production of speech	d330	the production of speech-d330
community group (e555 association) to improve conversation (d350)	d350	community group (e555 association) to improve conversation (d350)-d350
conversation with others	d350	conversation with others-d350
using techniques (stategies) or devices for communication	d360	using techniques (stategies) or devices for communication-d360
assist family members to use communication strategies	d360	assist family members to use communication strategies-d360
sit to stand	d410	sit to stand-d410
standing	d410	standing-d410
moving floor to chair	d410	moving floor to chair-d410
maintaining a sitting or standing position	d415	maintaining a sitting or standing position-d415
changing body position	d410	changing body position-d410

ability to lift and move a house hold object (eg a glass to tap	d430	ability to lift and move a house hold object (eg a glass to tap-d430
picking up, holding or releasing an object	d440	picking up, holding or releasing an object-d440
arm and use in a functional activity	d445	arm and use in a functional activity-d445
walking, can be independently or without stick	d450	walking, can be independently or without stick-d450
crawling/stairs	d455	crawling/stairs-d455
walking using equip	d465	walking using equip-d465
to return to driving	d475	to return to driving-d475
washing/cleaning oneself	d510	washing/cleaning oneself-d510
Caring for skin,hair or teeth	d520	Caring for skin,hair or teeth-d520
toileting(positioning clothing cleaning)	d530	toileting(positioning clothing cleaning)-d530
dressng	d540	dressng-d540
eating	d550	eating -d550
providing a health advice/advice on personal safety/actions to maintain health	d570	providing a health advice/advice on personal safety/actions to maintain health-d570
information on food options	d570	information on food options-d570
shopping	d620	shopping -d620
meal making/cooking	d630	meal making/cooking-d630
house work	d640	house work -d640
lawns and gardening	d650	lawns and gardening-d650
assisting or caring for family members	d660	assisting or caring for family members-d660
Basic interpersonal interactions	d710	Basic interpersonal interactions-d710
Complex interpersonal interactions	d720	Complex interpersonal interactions-d720
Family relationships	d760	Family relationships-d760
information on sexuality after stroke	d770	information on sexuality after stroke-d770
advice on how to return to work	d845	advice on how to return to work-d845
advice to gain economic self sufficiency	d870	advice to gain economic self sufficiency-d870
Community life	d910	Community life-d910
doing a hobby	d920	doing a hobby -d920
Religion and spirituality	d930	Religion and spirituality-d930
food or liquid/medication consumption	e110	food or liquid/medication consumption-e110

use of product to assist with self care (eg splint, shower commode), and ADL	e115	use of product to assist with self care (eg splint, shower commode), and ADL-e115
using a stick/Wheelchair/cushion/hoist/transfer sheets for mobility	e120	using a stick/Wheelchair/cushion/hoist/transfer sheets for mobility-e120
providing transport options such as taxis	e120	providing transport options such as taxis-e120
aid to improve communication	e125	aid to improve communication-e125
providing an exercise sheet/or speech worksheet	e130	providing an exercise sheet/or speech worksheet-e130
products for work	e135	products for work-e135
products leisure and sport/gardening	e140	products leisure and sport/gardening-e140
improving accessibility of home (ramps/stair lift/ showers/housing mod/repair)e155	e155	improving accessibility of home (ramps/stair lift/ showers/housing mod/repair)e155-e155
physical geography	e210	physical geography-e210
sound	e250	sound-e250
family support to help patient reach goals (add intended goal)	e310	family support to help patient reach goals (add intended goal)-e310
increasing support to family by providing physical assistance	e340	increasing support to family by providing physical assistance-e340
referral for person care or home help	e340	referral for person care or home help -e340
emotional /support from HP	e355	emotional /support from HP-e355
referral or liase on to a health professional	e355	referral or liase on to a health professional-e355
communicating with builders	e360	communicating with builders -e360
individual family attitudes to the person	e415	individual family attitudes to the person-e415
social norms and religious practices	e465	social norms and religious practices-e465
work with builder /architect to build or design housing mod	e515	work with builder /architect to build or design housing mod-e515
requesting approval from a housing organisation for housing mod or repair	e525	requesting approval from a housing organisation for housing mod or repair-e525
transport systems to enable accessibility	e540	transport systems to enable accessibility-e540
become aware of legal laws eg POA	e550	become aware of legal laws eg POA-e550
information about engaging in a community group	e555	information about engaging in a community group-e555

advice to improve financial situation by welfare funding	e570	advice to improve financial situation by welfare funding -e570
knowledge about/referral to organisation that will arrange care/funding for personal care	e575	knowledge about/referral to organisation that will arrange care/funding for personal care -e575
gaining funding for a health service	e580	gaining funding for a health service-e580
referral to stroke foundation or respite care	e580	referral to stroke foundation or respite care-e580
referral Accessable to get approval or funding for equip/housing mods/collect equip	e580	referral Accessable to get approval or funding for equip/housing mods/collect equip-e580
informaton on health services	e580	informaton on health services-e580
reading	d166	reading-d166
shaving	d520	shaving-d520
community group	e555	community group -e555
orientation	b114	orientation-b114
reception of spoken or written language	b167	reception of spoken or written language-b167
improve planning	b164	improve planning-b164
maths home work	b172	calculation functions-b172
paying for things	d620	paying for things-620
writing	d170	improving vestibular sense (decrease dissyness)-b235
vision	b210	vision-b210
tablet and phone	e125	tablet and phone-e125
money	e165	use of money-e165
bowel continence	b525	bowel continence-b525
bladder continence	b620	bladder continence-b620
A column: standardised language that is used to interpret the meaning of text taken from the notes		
B column: is the ICF code		
C column is the ICF code with the standardised language. This was used to help populate excel automatically with the ICF code		

Appendix D: Coding guideline

<i>intervention examples</i>	<i>ICF coding</i>
Advised to practice memorising 3 items that need for shopping	b114 memory.
orientation boards	b114 mental functions of time, e115 products for personal use
Visual retraining (neglect	b114 Metal functions that produce awareness of objects and not b140 attention functions
Asked client about suicide and if that is something she would do?	b152 emotional functions
discussed counselling sessions that are offered	b152 emotional functions and d240 handling stress
Perceptual tasks clock (construction)	b156 visual perception tasks that involve construction code to
completed picture puzzle for visual perception	b156 visual perception, do not code hobby
Talked through question and how it could be answered”	b167 improve reception and expression of language. as the aim is written comprehension
Home work-continue to target familiar words	b167 improve reception or expression of verbal language as this is the aim ,
reception and expression of language, and understanding written lang	b167 mental functions of language
Provided education on scanning ex to assist with living with hemianopia	b210 vision, when person has a hemianopia, Not education to d138 acquiring information
Horizontal head turns when walking	b235 Improving vestibular sense
sensory education on how to be safe with hot water	b270 sensory functions related to water and d570 providing a health advice toon personal safety
advised to take regular pain medication	d570 looking after one health, e110 medication
voice functions and breathng	b310 voice functions and b440 respiratory functions
working on producing sound due to apraxia	b320 articulation of speech
Positioning to reduce swelling	b415 blood vessel functions of arteries, capillaries and veins
Requested to follow bowel routine	b525 Bowel continence
standing posture	d415 maintain a body position
Requested to follow bladder voiding routine	b620 Bladder continence
when strength primary goal	b730 strength
bed exercises	b730 strength, b740 endurance, b760 control of voluntary movt
Exercise worksheets or Home exercise programme (HEP)	b730,strength, b740 endurance, b760 control of voluntary movt
Stretching	b710 mobility of joint functions

Balance	b755 Balance reactions
standing without frame and reaching	b755 balance reactions and d445 hand and arm use
Posture or scapula setting	b760 Control of voluntary movement
step ups to improve weight transference	b770 gait pattern not b755 balance reaction, as working at the impairment level if working on stair climbing would be d455
Retraining how to use the iPad	d131 learning through actions with objects' e125 the iPad (the object)
Education about knowledge of condition	d138 Acquiring information, definition: obtaining facts about persons, things and events,
education to incorporate L upper limb into function tasks	d138 hand and arm use d445. Do not code education
reading for the purpose of getting information	d166 reading
writing	d170 writing
Discussed ways that can provide 24 hour supervision	d175 solving problems not b164 higher level cognitive functions
Daily activities	d230 Carrying out a daily routine
Mindfulness	d240 handling stress
Gestures	d335 producing non-verbal messages
conversations with others	d350 conversation
Using phone, iPad or computer	d360 using a communication device
Turning	d410 Changing basic body position
practiced getting down to knees for gardening	d410 changing basic body position only
sit to stand ex	d410 sit to stand
Demonstrated finger putty	d440 Picking up and releasing an object
when picking up an object eg taking teabags from a jar	d440 picking up holding or releasing an object
when person gripping object, and using the whole arm	d445 hand and arm use
reviewed bowling action of arm not hand	d445 hand and arm use
walking without equipment	d450 walking
walking with equipment	d465 moving around using equipment
Advice on regulations around driving and stroke	d475 driving
Discussed the impact of memory on driving and that she will have to find alternatives	d475 driving as the aim is about driving
Shaving/brushing teeth & hair	d520 Caring for body parts
Making a hot or cold drink	d360 preparing meals
Verbal prompt to switch power off at the wall after using oven	d570 looking after one health, e115product and technology for personal use in daily living

Advised patient needs supervision in shower	d510 showering, and code supervision from family e310, or personal care assistant e340
encouraged to sit upright in bed to eat food	b510 ingestion function
Patient advised to reinforce routine processes and checks when doing kitchen activities	d630 Meal making. Do not code memory as the aim of the intervention is to make a meal
prompted to wash knives safely	d640 housework (not including d570 providing a health advice as this is not the target of the intervention)
Drove patient to soup kitchen to meet old friends and volunteer	d910 community life and code the social get together ie not the act of driving patient to venue
Jigsaw working on visual spatial and executive functioning ability	b156 perceptual functions and e130 products for education
Singing (if previous hobby)	d920 Hobby, if not a previous hobby use b340 alternative vocalization
Bible reading	d930 Religion and spirituality
Accessible band 1 service request for bathboard	e 580 funding for equip, and e115 product for self care (not coding the function of washing self as the target of the intervention is purchasing equipment)
Encouraged to use his alarm on his phone as a reminder for task/medication	e125 product for communication and d570 maintaining ones health (do not code memory functions b144, or e110 medication)
Advice given re footwear	e115 Product or technology for ADL and d450 walking (including the function)
education on environmental set up in the kitchen to increase safety and independence at meal making	e115 product to assist with self care and d630 preparing meals. Do not code education or environmental set up
Information on medical alert bracelet	e115 product for self-care and d570 looking after one's health (no code for information)
instruction to use mirror for postural control	e120 products for mobility and d760 control of movement
Frame set up at correct height	e120 when adjusting mobility equipment code the product for mobility and d450 walking
Advised to privately purchase ankle weights	e120 products for mobility and b730 muscle power
Purchasing a computer	e125 equipment products and a d code that indicates the function of the computer for the person (communication, work or recreation)
written information on managing saliva	e130 product that helps learning and b510 salivation
Written information	d570 managing ones health
diet information	d570 managing ones health
Advised family that bathroom alterations would not be an option (not funded)	d510 washing oneself

Education given to son on how to use wheelchair with patient	d465 moving around using equipment and 120 product for mobility . Do not code education as d138, .
Recommended to family that patient remain in bed if they are unable to transfer the patient	d410 changing a body position (addressing function that therapists working on)
Talked to family about increasing the clients participation in normal tasks	e310 family support and d210 undertaking a task
Suggested a family meeting	not coding as this as not a function but a rehabilitation process
Explained to family why working on left sided neglect	b114 orientation to self
Discussed with carer ways of managing stress	e310 when giving support to family and d240 handling stress. This research looks at interventions provided to the family and the client so code this way
Encouraged family not to do so much for the patient	e410 individual and family attitudes
Permission from Housing NZ	d450 walking (using this code and not d460 moving around in different locations) and e155 design and construction to gain access to building (e and d code)
mobility card	e540 transport systems to enable accessibility
Information about power of attorney	e550 legal policy and d950 political life and citizenship
Information given about the stroke foundation	e555 community group and d910 community life
Sent information about private home help:	e575 social support services and d640 housework
Impact of life questionnaire and prioritisation tool	e580 Gain funding for a health service and the purpose of the funding: eg walking, self care etc, use d code
Provide information on communication groups	d350 conversation
Not coding referrals, phone calls, meetings, goal setting returning equip, and family meetings	
Where possible aim to code intervention to one code, ie the target aim of the intervention	
advised needs supervision in the shower transfer	d510 washing and cleaning and d570 managing ones health
postural alignment	d410 maintaining a body position
maintain neck range	b710 joint mobility

Appendix E: Interview guide

Hi

Thank you for allowing me to interview you today. This study follows on from an earlier study, where I collected patient interventions from community stroke teams in the 3 Auckland DHBs. The data was collected from patients who received community stroke rehabilitation during the period: March 2016-March 2017. After extracting the interventions, they were linked to the ICF terms in the extended ICF core set for stroke (a specific set of ICF categories that represent common functional problems after stroke). The results of this study enabled me to identify the type and frequency of interventions provided by each DHB.

This second study aims to find out reasons for the high, moderate and low-frequency interventions and interventions are missing from the data,

To address this aim I have chosen to talk to community stroke team staff because staff have knowledge of their service and the factors influencing the decision process when designing an intervention plan

Before we begin, I would like to ask you a few questions about your work history and the type of service that you work in. Would that be, Ok?

What is your role?

When did you graduate?

How well has your training prepared you for working in stroke rehabilitation?

How long have worked in stroke rehabilitation

How long have you worked in this service?

Can you tell more about the service you work for eg. What proportion of patients are referred for rehabilitation after a stroke?

How often would you provide rehabilitation to a person over a week?

Do you use the ICF in your practice and if so, how does it influence your practice?

I am going to show you graphs of the team's interventions that were linked to the ICF components of body function, activities and participation and environmental factors. Just are reminder with the ICF terms, body function interventions are provided for body impairments, activities and participation interventions are provided to enable a person to do a task and the environmental factor interventions indicate what environmental factors were used to deliver the intervention ie the means

Here are interventions linked to the body function (or activities participation or environmental factor) categories in the ICF.

This graph represents all the body function, activities and participation, and environmental factor interventions provided by the community stroke rehabilitation team in your DHB (number) for (number) patients.

The ICF terms are sometimes unclear and on the following page, you will see some examples of interventions that were matched to the ICF codes.

Could you spend some moments looking at the data, and ask if yourself, does this data represent current practice from your perspective?

For those interventions that don't represent the current practice in your service, identify them and explain how why these interventions should be higher and lower on the graph

Can you explain why there are high and low frequencies for certain interventions?

Health professional interventions

Here are the interventions for (health profession) for (number of patients) . This graph shows the frequencies of interventions that were provided by your discipline for these patients in March 2016-March 2017. If you are not sure what the terms mean, please have a look at this page which provides examples of interventions that were given this ICF term

Could you spend some moments looking at the data, and ask yourself, does this data represent current practice from your perspective?

For those interventions that don't represent the current practice in your service, identify them and explain how why these interventions should be higher and lower on the graph

Can you explain why there are high and low frequencies for certain interventions?

We are now going to look at interventions that were missing or provided at low frequencies in all three DHBs services providing community stroke intervention, from March 2016-March 2017.

Spend some time looking at this list

Does this list represent current practice in your service?

If not, can you identify the interventions that are present or have higher frequencies than is currently shown in the data? How does your service manage these areas of intervention?

If you agree with the data can you explain why these interventions are missing or have low frequencies?

For CMDHB staff only

This graph compares the percentage of intervention for Māori and non-Māori. To make it easier to see I have only selected interventions where there is a clear difference in the frequencies of interventions.

Could you spend some moments looking at the data, and ask if yourself, does this data represent current practice from your perspective?

For those interventions that don't represent the current practice in your service, identify them and explain how why these interventions should be higher and lower on the graph

Can you explain why there are high and low frequencies for certain interventions?

We are coming to the end of the interview and I only have two more questions

In an ideal world (where expertise resources and time are not limiting the service), that you would like your service to provide more of?

Would you provide you less interventions in any area?

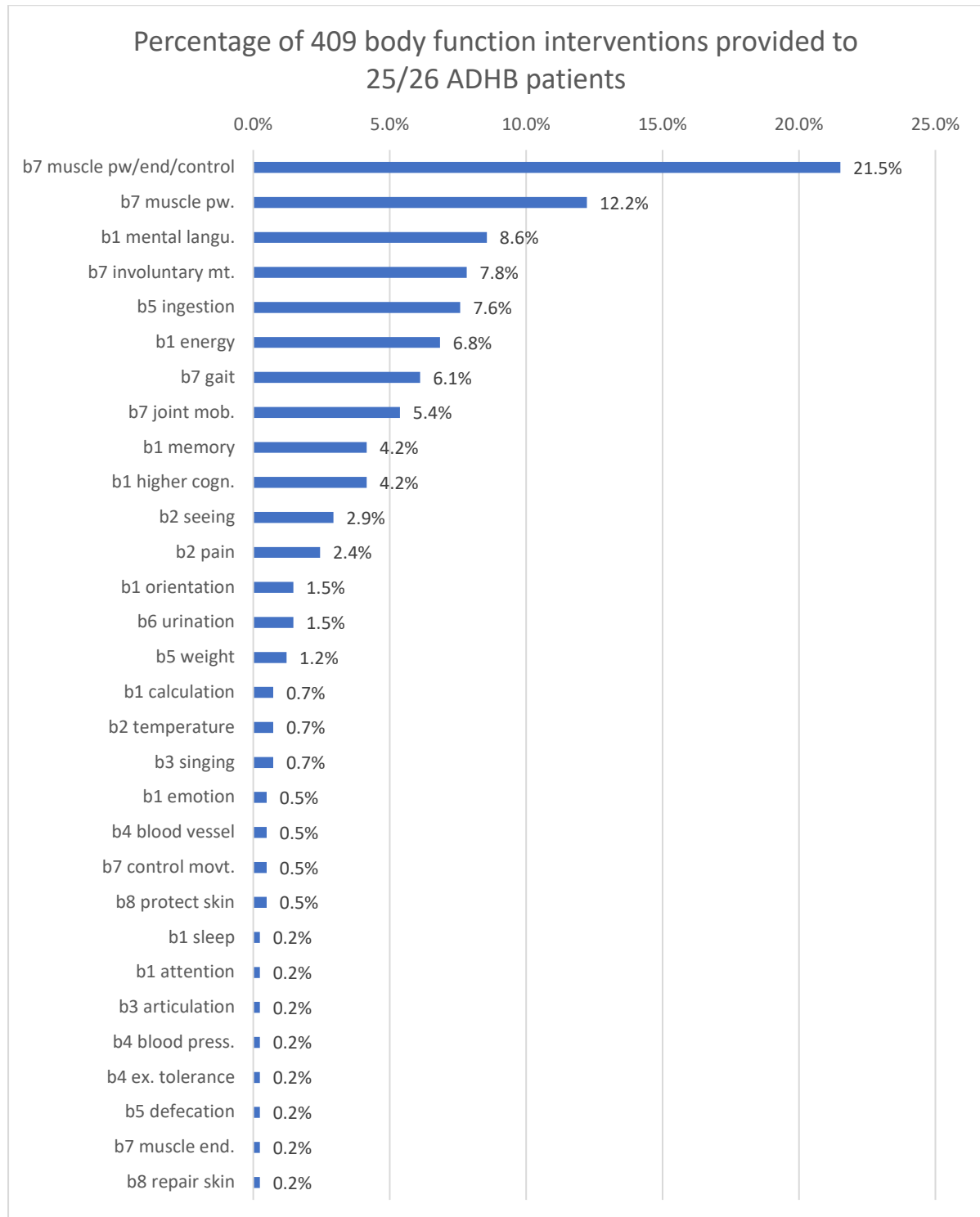
Are there any interventions that are provided in practice but not usually documented in the clinical notes?

If so, can you provide a reason why this occurs?

Thankyou!

Appendix F: Graphs presented to the participants from the three DHBs

Interventions linked to Body Function categories for your DHB

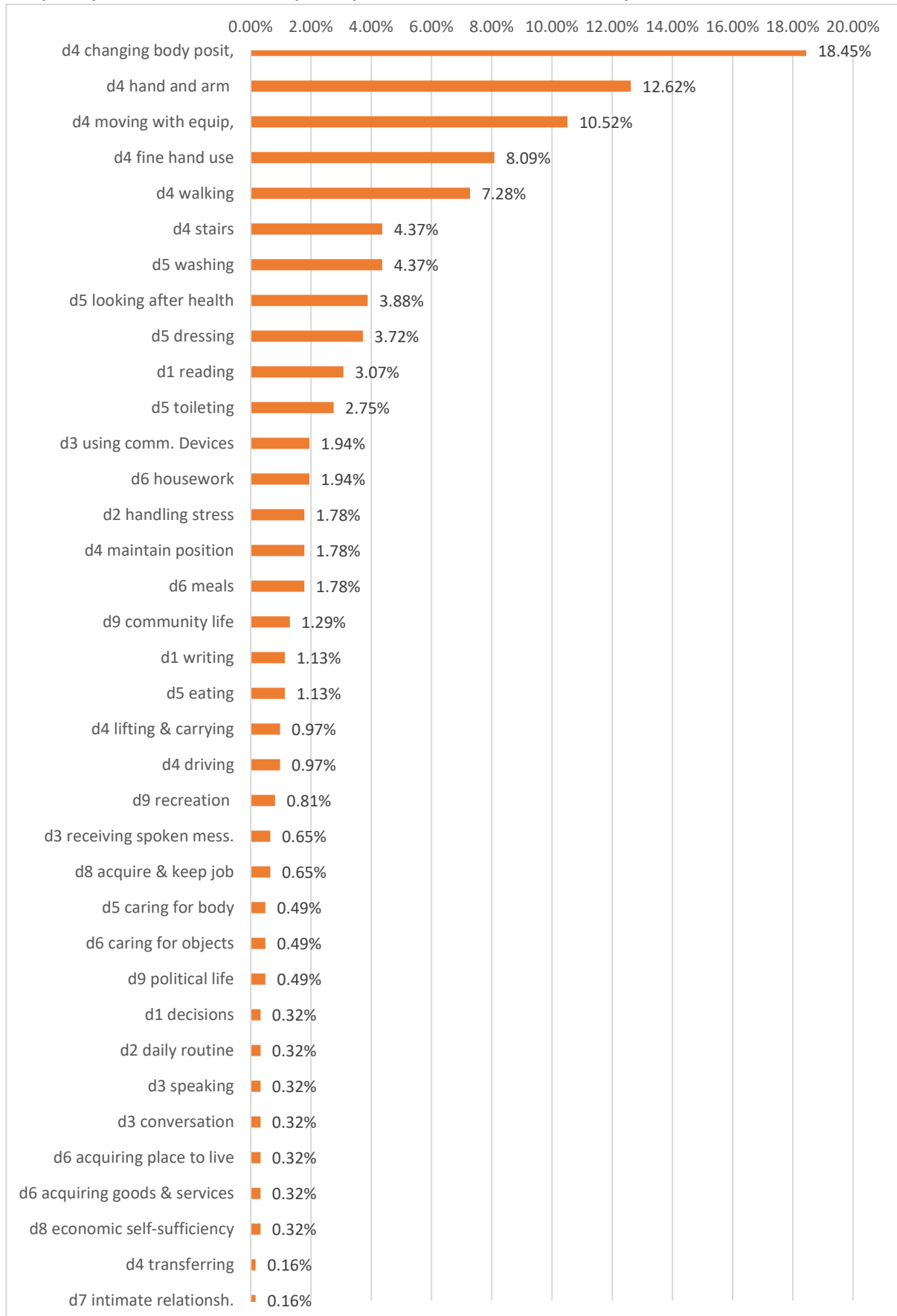


ICF body function terms
Examples of interventions coded to this category

b7 muscle power, endurance, and control	Exercise programme, provided handouts on exercise programme, advised need to increase intensity of exercise, trialled foot pedal on exercise programme
b7 muscle power	Heel toe exercises, heel to standing, seated ex., knee bend ex. Practicing lunge position, step-ups on stairs, added hip adductors 2x10 to ex. programme
b1 mental language	Strategies for word finding, cued naming therapy, feedback for word finding errors, given verbal or written prompts
b7 involuntary movt.	Balance ex.
b5 Ingestion	recommended to sit upright in bed to eat food, patient encouraged to take small mouthfuls of fluid and food at a time, recommended thickened fluids, swallowing exs.
b1 energy	Discussed fatigue and potential strategies, advised fatigue management strategies
b7 gait	Prompting to lift left foot, gait re-education, gait practice with walker
b7 joint mobility	Passive movements left arm, trunk and neck rotations, shoulder shrugs and shoulder retractions
b1 memory	Stuck blue tape on power point to remind her, encouraged to use diary to write names and numbers, provided memory strategies
b1 higher cognition	Picture puzzle to help with planning and sequencing, working on organisation with prompting, working on drawing conclusions and rationale for ideas, categorising worksheet
b2 seeing	Provided information on scanning and tracking, gaze stabilization exs, snakes and ladders game to improve scanning, trialled eye patch when reading,
b2 pain	Educated on breathing ex to relieve pain, median nerve stretches, recommended to rest if pain persists
b1 orientation	Clock drawing working on too and past concepts, updated calendar, introduced daily schedule, homework for L sided neglect
b6 urination	Ordered more continence pads, advised to reduce caffeine intake, given bladder diary
b5 weight	Education on nutrition, advised to have small frequent meals, discussed weight management concerns
b1 calculation	Went over maths homework, advised to slow down and use times tables, simple maths, adding up notes and coins
b2 temperature	Discussed and took pt through thermal tactile stimulation exs
b3 singing	Rehearsed singing song, sang a nursery rhyme
b1 emotion	Asked about his mood, discussed info on emotional lability and anger management, consent to talk his GP about his mood.
b4 blood vessel	Advised how to reduce swelling, left hand elevation to reduce swelling, advised massage of arm
b7 control of movement	Improve control by tapping alternate foot, tandem and unilateral stances for 15 secs. Work on the mat to gain control of trunk
b8 protect skin	Client reminded to wear footwear, reminded patient to ex to relieve pressure, dressed the wound, ordered air mattress
b1 sleep	Hand out on sleep hygiene, suggested the "Headspace" app,
b1 attention	needed verbal and visual prompts for attending, attention activities card sort
b3 articulation	Oro-motor ex, speech ex, sustained vowel phonation,
b4 blood pressure	Advised patients GP of BP, advised on local Pharmacies that will check BP, took BP

b4 exercise tolerance	Education on exercise tolerance, information on how to pace activities through day, advised to increase activity tolerance by..,
b5 defecation	Interventions given for double incontinence, advised can adjust bowel meds
b7 endurance	RA plan devised for endurance and conditioning
b8 repair of skin	Wound cleaned,

Frequency of 618 Activities and participation interventions to 25/26 patients from this DHB

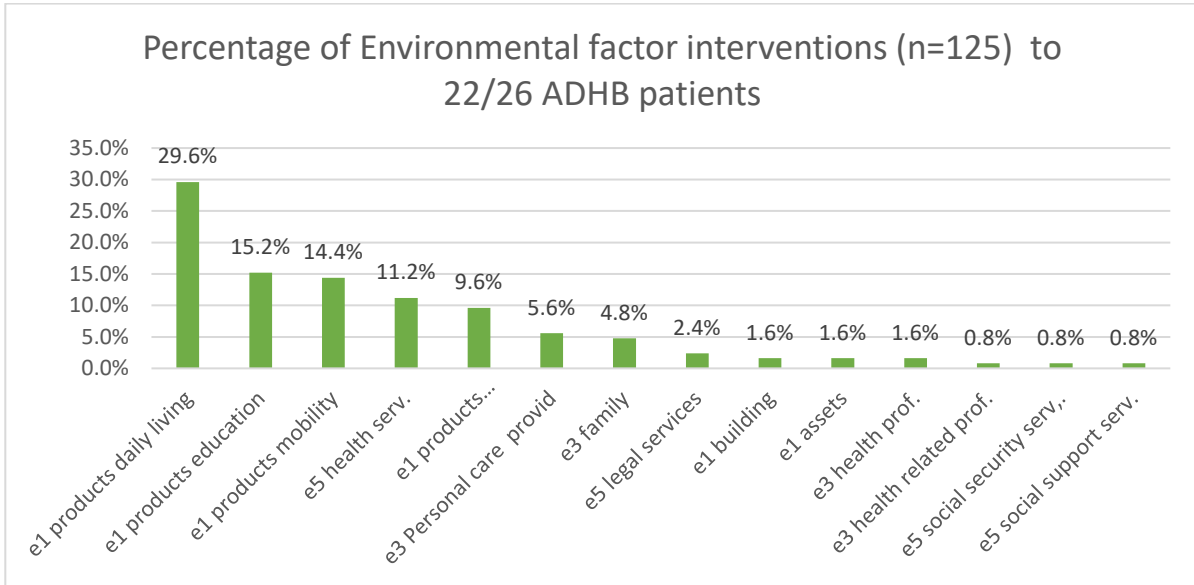


ICF activities and participation term Examples of Interventions coded to this category

d4 changing body position	Sit to stands, discussed with wife how to assist client off chair
d4 hand and arm	Incorporate L arm into functional tasks, upper limb exs. Water pouring
d4 moving with equipment	Mobility with LWF, mobilising with aid
d4 fine hand use	Picking up things around the home, opening and closing jars
d4 walking	Outdoor mobility practice, walking inside without an aid
d4 stairs	Practiced stairs with right hand grip on rail, practiced stairs
d5 washing	Discussed options for accessing shower, trialled swivel bather, provided for strategies for self-care
d5 looking after one's health	Discussed need to press medical alarm if client falls, advised use alarm on watch to remind to take meds. Medical alarm information, discussed safe footwear, discussed safety features on WC,
d5 dressing	Demonstrated dressing technique
d1 reading	Functional reading with prompt, written comprehension
d5 toileting	Explained funding process to buy toilet equip, discussed to do two-hour toileting for urine, demonstrated raised toilet seat
d3 communication devices	Used computer mouse with L hand,
d6 housework	Washing dishes, wrote down steps for dishwashing, gave information on home help, hanging out washing
d2 handling stress	Discussed ways can manage stress, discussed possible support at home, discussed with wife about carer stress
d4 maintain a position	Standing posture, information on where to buy back rest, posture control when reaching and sitting
d6 meals	Practiced breakfast making, made a hot drink
d9 community life	Gave details of community class, informed about groups to improve communication, drove client to RSA,
d1 writing	Practiced handwriting
d5 eating	Trialled built up cutlery, practiced picking up cutlery
d4 lifting and carrying	Carrying drink to dining table, using frame to carry glass water, taking cans from pantry, practice carrying laundry basket
d4 driving	Discussed returning to driving, discussed may need driving assessment
d9 recreation	Advice about returning to dancing, played ukulele, recommended to play bowls for a short period, practiced bowling swing
d3 receiving spoken messages	Spoken comprehension, following directions, simple instructions using objects
d8 acquire & keep job	Advised on support to return to work, graduated return to work plan
d5 caring for body	Discussed shaving technique, oral care practice, combing hair
d6 caring for objects	Gardening using right UL, raked leaves both hands, use R hand to separate plants, watered plants
d9 political life/citizenship	Discussed legal issue, discussed about EPOA
d1 decisions	Advanced care planning book provided
d2 daily routine	Encourage to engage in daily activities with carer, discussed day programme, planned schedule for day,
d3 speaking	Reading out loud, advised to make voice as clear as possible, write down words as a cue to wordfinding, describing pictures
d3 conversation	Conversation practice, conversation skills

d6 acquiring place to live	Inquired about bed at private hospital, discussed residential care, discussed future care options
d6 acquiring goods & services	Visit to garden centre, discussed how she will get her shopping
d8 economic self-sufficiency	Discussed financial strain, given information on the disability allowance, took client to WINZ appointment
d4 transferring	Advised client to continue using transfer bench to access bath,
d7 intimate relationships	wife discussed intimacy with me, discussed sexuality

Interventions linked to Environmental factors for this DHB



ICF Environmental factor terms
Examples of Interventions coded to this category

E115 products daily living	Built up cutlery, orientation board provided, measured up for rails in toilet, trialled foot pedals.
E130 products education	Provided handouts on exercise, categorising worksheet, provided with a fatigue diary
E120 products mobility	Use mirror for postural feedback when walking, ordered walking frame, trialled chair raisers
E580 health services and systems	Discussed options for further rehabilitation, given list of companies that provide home support
E125 products communication	Using computer mouse with L hand, using picture cards
E340 personal care providers	Discussed with care giver how she can help client with computer use, discussed support available
E310 family	education to son on how to walk client with frame, daughter to arrange medications in blister pack
E550 legal services	Given information on advance care planning, discussed importance of having an EPOA
E155 products for building	measurements taken of doorways for ramps, review ramp made by relative
E165 Assets	recognising NZ currency, learning currency
E355 health professionals	Phone call to renal team for training of caregiver, phone call to GP,
E570 social security	We took v to WINZ appointment
E575 general social support	Informed about care hours

Table 1. Missing and low frequency interventions, found in the combined DHB data

Interventions coded to the following categories:

1. b156 perceptual functions. Defined as “specific mental functions of recognising and interpreting stimuli and includes auditory, visual, tactile and visuospatial perception (depth). Visuospatial perception is defined as “distinguishing by sight the relative position of objects or their position in relation to the self” (World Health Organisation, 2001 p56).
This description does not describe the interventions for neglect. Interventions for neglect are coded to b114, orientation to space, “mental functions that produce awareness of one’s body in relation to the immediate physical space”. When interventions are provided for hemianopia, this is coded to b210 seeing “seeing functions related to the entire area that can be seen with fixation of gaze”
2. b260 proprioceptive functions, defined as “sensory functions of sensing the relative position of body parts”.
3. b715 stability of joint functions, defined as “functions of the maintenance of structural integrity of the joints”.
4. b735 muscle tone functions, defined as “functions related to the tension present in the resting muscles and the resistance offered when trying to move the muscles passively”
5. d160 focusing attention, define as “intentionally focusing on specific stimuli, such as by filtering out distracting noises”
6. d930 religion and spirituality defined as “engaging in religious or spiritual activities, organizations and practices for self-fulfilment, finding meaning, religious or spiritual value and establishing connection with a divine power’

7. e515 architecture and construction services, defined as “services, systems and policies for the design and construction of buildings, public and private”
8. e525 housing services, systems, and policies defined as “services, systems and policies for the provision of shelters, dwellings or lodging for people

Categories that occurred once in the data:

d335 producing nonverbal messages, define as “using gestures, symbols and drawings to convey messages”

e555 associations and organisational services, defined as “services, systems and policies relating to groups of people who have joined together in the pursuit of common, non-commercial interests, often with an associated membership structure”

A category that occurred twice in the data

d770 intimate relationships, defined as “creating and maintaining close or romantic relationships between individuals, such as husband and wife, lovers or sexual partners”.