Conceptualisations of *Movement* (and *Movement Loss)* in New Zealand Adults Living with Spinal Muscular Atrophy: A Critical Analysis

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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.

Signed:

Ethics Approval

Ethics approval was granted for this project by the AUT Ethics Committee on 14th September 2023 (Reference Number 23/228). The application was approved for three years until 14 September 2026. At this stage, further consultation with the AUT Mātauranga Māori Committee was undertaken to support Māori engagement in the research. With the advice received, additional amendments to the research design were made. Following review by the AUT Ethics Committee of these amendments, ethics approval was granted on 17 October 2023.

Abstract

Spinal Muscular Atrophy (SMA) is a neurogenetic condition that causes progressive muscle weakness. From 2016, new pharmaceuticals to treat the condition have reformed prognostic outlooks for children and adults living with SMA, however, this shift has also resulted in new challenges. In 2022 and 2023, Pharmac (New Zealand's drug funding agency) approved funding for children under 18 to access Spinraza (Nusinersen) and Risdiplam (Evrysidi) respectively. However, New Zealand adults with SMA currently remain without access. While the lack of equity in treatment access is concerning, these pharmaceuticals are *not* curative. Empirical evidence has shown treatments to provide only modest benefits in adults, and it has been questioned whether treatments result in increased subjective well-being or quality of life. While adults with SMA live with significant physical limitations largely attributed to genetics, functional decline is often multifactorial, with modifiable factors such as disuse atrophy, contractures and comorbidities also contributing to movement loss. Adults with SMA also experience reduced psychosocial well-being, social stigma and challenges in integrating into and participating in mainstream society. Such findings highlight the necessity to look beyond bodily limitations to support well-being in SMA.

The purpose of this study was to explore how NZ adults living with SMA conceptualise *Movement* and *Movement Loss* and to consider how these constructions are impacted by interactions in healthcare and broader society. By increasing awareness of social constructions of *Movement*, the intent was to generate discussion about the impact of language and discourse on disease experience and well-being.

This research involved ten, 90-minute semi-structured interviews with NZ adults living with SMA. Data generation and analysis were completed using Braun and Clarke's six-step method for reflexive thematic analysis and applied social constructivist epistemology informed by critical disability and critical rehabilitation scholarship.

The analysis resulted in a framework detailing the ways in which adults with SMA conceptualised *Movement* and *Movement Loss*, and identified three broad themes: '*Movement* Matters', '*Movement* is being and doing', and '*Movement* is Transformation'. Participants conceptualised *Movement* in ways that reflected the influence of biomedical discourse in health contexts. Social-political discourses expressed more broadly in society, including ableism and neoliberalism were also found to be influential. Interestingly, participants and close others often acted in ways to resist dominant discourses about *Movement* and *Movement Loss*. In doing so, participants were able to intentionally reclaim *Movement,* and move towards understandings of *Movement* that supported wellbeing.

In the discussion, I consider how the study findings relate to current qualitative literature from the adult SMA community and draw on critical scholarship to highlight the importance of addressing language, discourse in health, and broader society to support the well-being of those living with SMA. Finally, I consider avenues for change and share a personal reflection on the impact of this research as an insider to this community.

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To my participants and the wider SMA community. Writing this thesis has felt like coming home after many years of searching. I am honored to share whakapapa with such incredible, generous people who challenge the idea that a diagnosis should define you. I hope this work speaks to you as it did to me, and that you too might feel moved to creatively reimagine what *Movement* could be. May you always feel that possibilities are open to you, no matter where life takes you.

To my family, whose unwavering support has sustained me through the highs and lows of this project, and to my partner, Harry who has lived this thesis with me – probably from the day we met. Without you this work would not have made its way into the world.

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List of Abbreviations

ACC	Accident Compensation Corporation
CDS	Critical Disability Studies
CRS	Critical Rehabilitation Studies
MOH	Ministry of Health
NZ	New Zealand
SMA	Spinal Muscular Atrophy
OT	Occupational Therapist
U.S. FDA	United States Food and Drug Administration

Introduction

Spinal Muscular Atrophy and the Concept of *Movement*

Spinal Muscular Atrophy (SMA) is a neurogenetic condition that causes progressive muscle weakness and paralysis (Aslesh & Yokota, 2022; Willis, 2022). It is caused by the homozygous deletion of the SMN1 gene on chromosome 5q13, which dramatically reduces the production of Survival Motor Neuron (SMN) Protein, which is required for normal cellular processes to occur (Aslesh & Yokota, 2022). The loss of SMN is particularly impactful on the alpha motor neurons in the spinal cord, the loss of which disrupts the signal sent from the brain from reaching voluntary muscle fibres (Aslesh & Yokota, 2022; Willis, 2022). Reduced SMN levels are also thought to be impactful on cellular function across multiple body systems, including mitochondrial function (Zilio et al., 2022), muscular function (Habets et al., 2022; Montes et al., 2021) and the immune system (Deguise et al., 2020; Garcia et al., 2024).

While a common genetic cause has been identified, significant variation exists within SMA. The condition ranges from severe paediatric forms, where symptoms present <6 months (type 1) and <18 months (type 2), to milder forms that present in childhood after walking is achieved (type 3) and adulthood (type 4). Type 1 and 2 SMA are life-threatening, and left untreated, most will not live beyond the age of five years (Aslesh & Yokota, 2022). In milder presentations of SMA, a normal lifespan is expected (Aslesh & Yokota, 2022; Montes et al., 2015). The overall incidence of SMA is thought to be approximately 1 in 11,000 births (Sugarman et al., 2012; Willis, 2022).

While types 1 and 2 SMA reflect the overall majority of SMA cases[1] (Lally et al., 2017; Ogino, 2004), adults living with milder phenotypes are overrepresented in the community, accounting for more than 25% of the global SMA population (Verhaart et al., 2017). The disease burden in adults living with SMA is significant and multifactorial, impacting physical mobility alongside presenting significant emotional challenges, including anxiety, depression, fatigue and social isolation (Day et al., 2022; Wan et al., 2020). The approval of the first pharmaceutical treatments for SMA by the U.S. Food and Drug Administration (FDA) has offered hope to the SMA community internationally through the promise of limiting disease progression and improving functional outcomes (Yeo et al., 2022). However, these pharmaceuticals have also resulted in social and ethical challenges for the SMA community – including in Aotearoa New Zealand (NZ).

In 2022 and 2023, Te Pātaka Whaioranga – Pharmac, the government agency responsible for deciding which medicines are funded in NZ, approved funding for children under 18 to two pharmaceuticals for the treatment of SMA: Spinraza (Nusinersen) and Risdiplam (Evrysidi) (Pharmac, 2022, 2023, 2024a). New Zealand adults with SMA over 18, however, were exempt

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[1] Internationally, SMA type 1 and 2 are thought to account for 58% and 29% of SMA cases overall, while SMA type 3 is believed to account for just 13% (Lally et al., 2017; Ogino et al., 2004)

from funding provisions and currently remain without access (Pharmac, 2024b). This decision has, understandably, become a political issue for members of the adult SMA community in NZ, many of whom have now moved overseas to receive care (Espiner, 2021; Forbes, 2023).

While the lack of equity in treatment access is concerning, it is important to note that these pharmaceuticals are *not* curative (Yeo et al., 2022). Empirical evidence has shown treatments to provide only modest benefits in adults in improving or stabilising motor function (Hagenacker et al., 2024), and it has been questioned whether treatments actually result in increased subjective well-being or quality of life (Wan et al., 2020). The price of such treatments are also a significant barrier (Yeo et al., 2022), particularly at a time when spending on health by governments generally is under threat as they look to cut costs and reduce expenditure (Nicholls, 2018b; Robins & Nolen, 2023; Thomas, 2019). Within such socio-political environments, care provision to minority communities such as those living with disability is often deprioritised (Nicholls, 2018b; Tawfik et al., 2023).

In SMA, while genetics are a significant factor contributing towards functional decline, it tells only part of the story. For example, in adults, modifiable lifestyle factors such as disuse atrophy, contractures and comorbidities also play a mediating role in progression (Wan et al., 2020). Physical activity and exercise in particular have been highlighted in empirical research as important modifiable risk factors in SMA and protecting against progression (Ng et al., 2019; Voet, 2019), and this has resulted in physical activity guidelines for those living with SMA (Trenkle et al., 2021). Such research provides important insight into the physiological underpinnings of SMA, and supports therapeutic exercise being is prescribed in ways that is safe and effective.

There are shortcomings with the exclusive use of these approaches, however, as they often hinge on the argument that physical impairment is the leading cause of ‘disability’ and that by mitigating or reducing the impairments of the body, quality of life can be improved. While such arguments hold weight when we consider the day-to-day impact of disease, such approaches fail to consider how practices in society or the health system at large also contribute towards the ‘disablement’ of these populations.

Adults with SMA experience reduced psychosocial wellbeing (Wan et al., 2020), with the majority experiencing social stigma and challenges in integrating in and participating in mainstream society (Kruitwagen-van Reenen et al., 2018). In fact, one study cited that motor skills only accounted for 26% of the variance of restrictions in societal participation (Kruitwagen-van Reenen et al., 2018). Such findings highlight the fact necessity to look beyond bodily limitations to support well-being in SMA.

Internationally, there is a shortage of high-quality qualitative studies that examine the *experiences* of those living with SMA (Wan et al., 2020). There is also a lack of critical studies addressing the way that societal factors, the changing therapeutic landscape, and political issues (such as treatment access) impact the SMA community (Setchell et al., 2018; Wan et al., 2020).

As far as I am aware, this is the first qualitative study concerned with the SMA population in Aotearoa, New Zealand.

The lack of qualitative and critical research is concerning, as these methods explore the lived experiences of research populations and often work to identify and highlight the often unseen social structures leading to inequity, which when properly investigated could positively impact care provision, policy making and the choices families and individuals living with SMA make about how to live their lives in society more broadly (Setchell et al., 2018). Moreover, the use of critical research methodologies has the potential to open up alternative ways of thinking about what it means to live and move with SMA, which could positively impact quality of life.

Critical scholarship has highlighted *Movement* as a concept that is central to rehabilitation (Gibson, 2016c). Here, notions of *Movement* are often informed by the intrinsic values of biomedicine, through which *Movement* is often objectified and reduced to its mechanical components (Gibson, 2016c). Particular kinds of *Movement* – like physical exercise- are deemed to be 'acceptable' and 'beneficial', while others are ignored, devalued, not considered or prioritised (such as *Movement* for recreation or leisure) (Nicholls et al., 2018). In the case of SMA, *Movement* also provides the basis on which diagnosis is established, and upon which understandings of disease severity and progression are formed (Nishio et al., 2023).

Within social constructivist epistemology, concepts – such as *Movement* and *Movement Loss*- are not simply reflections of physical reality. The ways that language and discourse are used and the way that meaning is applied when we use it are indicative of the underlying distribution of power in society. Language not only provides the words with which to describe our reality, it shapes the way we think about and frame experiences and how we act (Burr & Dick, 2017; Gibson, 2016c). Because of this, critical researchers argue that there is a need to understand the impact of social constructions and how they operate (Gibson, 2016c).

This study aims to explore the ways in which New Zealand adults living with SMA understand and think about *Movement* and *Movement Loss*, and to consider how these constructions are impacted by interactions by the NZ health system and broader society. By increasing awareness of social constructions of *Movement* for this population, my intention is to generate discussion about the impact of language and discourse on disease experience and well-being. If healthcare is to continue to move forward in ways that ensure equity and quality of life for those it serves, it must move beyond a simplistic approach and consider alternative ways of understanding and working with disability and chronicity across the lifespan in ways that support individuals to live good lives (Gibson, 2016c; Setchell et al., 2018). Critical research offers a powerful modality by which this can be achieved.

Researcher Positionality

At the age of 10 or so, I remember wondering what life would have been like had I been struck by some terrible accident and become paralysed. It wasn't until many years later, in my early

20s, when I was diagnosed with the genetic neuromuscular disorder, Spinal Muscular Atrophy (SMA) Type 3, that I found out that —*technically*— I already partially was.

The irony wasn't lost on me. I had lived my life up to this point believing and being told by health professionals that I was completely 'normal', only to suddenly be told that one day that I wasn't.

As it turns out, the difference between 'normal' and 'abnormal' can be a really fine line and the story we tell ourselves about our bodies and what they can do *matters*. It's the difference between having an explanation for why you tripped and fell that time – or being stuck in limbo without any plausible reason for *why* a body might do that. It's also the difference between whether you believe you *can* achieve something – or whether you *can't*.

The experience of diagnosis set in motion a deep curiosity within me. What *was* this "normal" that I was being compared to in diagnostic experiments? Clearly, I had never experienced it. And how might someone given a life-changing, progressive diagnosis like SMA live the rest of their life? I still had aspirations and hopes for my future, and I was determined not to live my life in fear of the inevitable 'decline' that had been projected for me.

Within a year of my diagnosis, I decided to study physiotherapy in the hopes of answering such questions. In the long term, I hoped to support others who might have had similar experiences on their rehabilitation journey.

It has now been more than 12 years since my diagnosis, and within this time, the treatment landscape for SMA has changed immensely. What I was once told was an 'incurable' disease now has three USA Food and Drug Administration (FDA) approved drugs available for treatment. These changes have had profound effects on the SMA community both in Aotearoa, New Zealand and overseas. This has particularly been the case with families with children living with the more severe forms of the disease, where these treatments have drastically changed life expectancy and functional outcomes.

It has been my observation that these changes have also come with new challenges. While new treatments can help prevent progressive changes characteristic of the disease, they are *not* cures (Yeo et al., 2022). The ethical dilemma posed by these new therapies for SMA for governments is well documented (Robins & Nolen, 2023; Yeo et al., 2022), and for good reason. Pharmaceutical companies *Biogen* and *Novartis* have received criticism for their enormously expensive drug costs for Nusinersen (Spinraza) and Onasemnogene abeparvovec-xioi (Zolgensma). Nusinersen is priced at US$750,000 for the first year and US$375,000 thereafter. Onasemnogene abeparvovec-xioi is priced at US $2.125 million, and Risdiplam US $340,000. Competitor company Roche has thus far managed to avoid criticism by pricing Risdiplam competitively against the other two drugs, but the cost remains high (Yeo et al., 2022). These extortionate prices have led governments and funding bodies to grapple with whether the benefits of treatment to the individual are outweighed by the costs to society. In New Zealand, this has meant that funding has currently been granted by Pharmac for children under the age of 18, but adults with the condition continue to currently live without access (Pharmac, 2024b).

The lack of access to pharmaceutical treatment for SMA in New Zealand might not come as such a blow to the community if other non-pharmaceutical preventative treatments — such as physiotherapy or occupational therapy support — were readily available. However, because SMA is a chronic condition and not categorised as an 'injury' resulting from an accident, healthcare is therefore not provided for under NZ's well-funded Accident Compensation Corporation (ACC) scheme. Rather, care as it is currently funded for adults living with SMA is provided under Te Whatu Ora – The Ministry of Health (MOH). This system grapples with significant limitations in funding (Espiner, 2024; Hill, 2024), and current funding provisions fail to provide ongoing preventative interventions such as physical exercise which could help to reduce disease progression (Ng et al., 2019; Voet, 2019). Accessing services beyond these limits must therefore be self-motivated and funded privately or with the help of non-government organisations such as Muscular Dystrophy New Zealand (Muscular Dystrophy New Zealand, 2024). This shortage of care has posed a challenge for many adult New Zealanders and their families living with SMA, who now feel they are faced with a decision whether to stay in New Zealand or move overseas to receive pharmaceutical treatment (Espiner, 2021; Forbes, 2023).

My own relationship with this debate is complex.

In 2019, I attended the annual *CureSMA* conference in Florida, USA, where I was able to see first-hand and meet with individuals whose lives had been changed dramatically after receiving pharmaceutical treatment. Here, the SMA community was buzzing with success stories and hope for what might be possible as treatments progressed in the years to come, particularly for children born with the more severe forms of the condition. Hearing these success stories after so long being told that 'nothing could be done' was a beautiful, hopeful and humbling experience and one I continue to carry with me. At the same time, I have had to grapple with my feelings about treatment and its implications for how I understand myself as a person. When I was first informed that there was a treatment for my condition by my neurologist, my first thoughts and emotions were not of celebration or joy, but a question:

"You mean… I'm not enough as I am?"

At this point, I was studying physiotherapy, engaging in regular physical exercise, had made dietary changes, and overall, I had reached a point where I was confident that those things I *could* change I was working to change, and those things I couldn't change, I was able to accept. From this point on, finding acceptance has become more problematic. With the presence and expectation of treatment, it no longer feels sufficient to simply 'live one's life' or 'move one's body' as best you can. My imperfect SMA body was no longer 'enough' – not when there was technology that could improve or remove all those things I was 'lacking'.

The strange thing about the body is that it is part of *who you are* – the very fibres of your being. At what point do 'I' and whatever it is that is 'SMA' begin and end? SMA is etched into my DNA and expressed in every living cell. Who am I if I am not this? And who am I without it?

Sometimes, I like to think I can do improbable things. I have been told— more than once— that the very fact I can walk is something of a miracle. My quadriceps muscles are so weak that, technically, my body should crumble to the ground, and stairs should be impossible. But I *can* do these things, and I *do* do these things. *Movement* is something we take for granted every day, and yet how often do we think about how our understanding of *Movement* has been shaped by the societal forces around us? This thesis looks to answer that question.

Introducing the Research Questions and Aims of the Study

This research sought to answer the two following questions:

1. *In what ways do New Zealand adults living with Spinal Muscular Atrophy understand and think about Movement and Movement Loss?* And,

2. *In what ways are these understandings impacted by society and the New Zealand health system?*

The aim of answering these questions is to better understand the ways that adults with SMA in New Zealand think and understand *Movement* and the way that this is shaped by factors like a progressive diagnosis and the social-political context in which one lives. Given the centrality of *Movement* to well-being and health, I intend to draw attention to the impact language and discourse have on disease experience, and highlight the importance of considering alternative ways of understanding *Movement* to support adults living with SMA to live meaningful lives despite disease progression and treatment availability.

Structure of the Thesis

This thesis is structured in six chapters.

Here, in the Introduction, I outline the socio-political context surrounding the SMA community in Aotearoa, NZ and highlight why there is a need to consider how *Movement* is conceptualised by members of the SMA community. I also provide insight into my positionality to this research as an insider to the adult SMA community in NZ.

In the Literature Review, I outline the sociological origins of dominant notions of *Movement* and *Movement Loss* in biomedicine, rehabilitation and society and then go on to consider historical constructions of *Movement* within the context of a diagnosis of SMA. I then provide examples of alternative social constructions of *Movement* and consider the potential benefits of deconstructing notions of *Movement* and *Movement Loss* for the SMA community.

In the Methodology and Methods chapter, I first discuss the methodological lens used in this work (social constructivism) and the social and political theory informing the analysis (critical rehabilitation studies and critical disability studies). I then outline the methods used to collect and analyse the data.

In the Findings chapter, I outline the framework of *Movement* and *Movement Loss* that I developed in my response to the research question and the accounts shared by the study participants (question 1). I then consider how conceptualisations of *Movement* and *Movement Loss* shared by participants appeared to be shaped by broader processes and influences within the health system and society at large (question 2).

In the Discussion, I interpret my findings and consider how they relate to current qualitative research exploring the experiences of adults living with SMA. I then draw on critical research to highlight the importance of considering language and discourse in health, and broader society as avenues to support participation and well-being. I consider avenues for change, research impact, the strengths and limitations of this study. Finally, I share a personal reflection on how this research has shaped my understanding of *Movement* and *Movement Loss* as an insider to this community.

In the Conclusion of this thesis, I provide a summary of the aims of this study, methods and methodology and key research findings. I highlight the relevance of this work to the SMA community and the disability community more broadly and argue the need for further critical research in this area.

Language Conventions

In this thesis, language has been used which aligns to the social model of disability as interpreted by the NZ Disability Strategy 2016-2026 (Ministry of Social Development, 2016). Within this model, ‘disability’ is considered to be a process that happens when people living with impairments face barriers in society. It assumes that ‘disability’ is created by society, not by an ‘impairment’ or a problem with the functioning of or the structure of someone’s body. It is important to acknowledge that there are many words and terms that can be used to identify ‘disability’. While some members of the SMA community proudly identify as ‘disabled people’ in recognition that disabling barriers exist in society, not everyone in the community – including those interviewed in this study – identify with disability-focused language. The genetic etiology of SMA makes it a reflection of the broader diversity of the human genome, but there is also diversity within SMA and experiences as people. While the social model and language of ‘disability’ is imperfect, it has been used in this thesis to support clarity when differentiating between ‘physical impairment’ and socially generated barriers to participation.

A primary concern of this thesis is establishing how *Movement* and *Movement Loss* are socially constructed by members of the SMA community and establishing whether dominant discourses in health and society impact these constructions. As discourses operating in society and health are *both* socially constructed, I differentiate my discussion by referring to the 'biomedical discourse' as the dominant discourse operating in health settings, and 'broader social discourses' when discussing dominant discourses outside health settings.

The reader will note that I have capitalised and italicised the terms '*Movement'* and '*Movement Loss'* throughout the thesis. This has been done to indicate where I have used these terms as proper nouns and to refer to the socially constructed concept of 'movement' or 'movement loss', rather than in terms of their everyday usage.

In line with APA7 style conventions, I have not capitalised the names of diseases, disorders, therapies, theories, concepts or principles except where personal names appear in these kinds of terms (for example, Kugelberg-Welander disease)(American Psychology Association, 2019). I have also generally avoided using italics for emphasis (American Psychology Association, 2022). The exceptions to this are when italics have been used in the body of the text to make the meaning clear to the reader and in direct quotes from participants, where I have used italics to indicate where emphasis was placed in a sentence in the original interview recording to maintain participants' voice.

In the Findings section, I have omitted the use of gendered pronouns when describing participants' contributions in the body of the text and spoken on issues based on age or ethnicity in general terms only. As the adult SMA community in New Zealand is small, there was an increased likelihood that a participant may be able to be identified by an insider of the community if this information was provided. I have, therefore, tried to remove identifying information from participant accounts and quotes as much as possible while still maintaining the meaning and spirit in which it was said. Contributions from participants have been randomly allocated a letter from A to J and are labelled according to these codes in the body of this work (e.g., Participant A).

Chapter Summary

This chapter has provided a brief overview of the sociopolitical context for adults living with SMA in Aotearoa, NZ, and considered some of the reasons why understanding ways in which *Movement* is conceptualised by members of the SMA community is important. I have briefly explained my positionality, the research questions have been introduced, and the structure of the thesis has been outlined.

The next chapter, the Literature Review, will expand on the ideas shared here by delving into the sociological origins of dominant constructions of *Movement* and *Movement Loss* and the potential implications of this and considering the evidence base for alternative social constructions of *Movement*.

Literature Review

The purpose of this literature review is to provide context to the argument that *Movement* and *Movement Loss* are concepts that have been socially constructed over time and to locate the SMA community as one that has been impacted by this process. I also look to provide context by considering social issues posed by rehabilitation and pharmaceutical treatments for SMA. Finally, I consider the evidence for alternative social constructions of *Movement* and consider the relative value of these in light of the literature reviewed.

Sociological Origins of Dominant Constructions of *Movement* and *Movement Loss*

This thesis seeks to identify ways in which *Movement* and *Movement Loss* are conceptualised by the adult SMA community in Aotearoa, NZ, and identify the ways in which these understandings are impacted by society and the New Zealand Health System. Answering such questions hinges on the assumption that notions of *Movement* and *Movement Loss* are social constructs and that how we understand the body and its abilities are flexible, malleable and can change over time in response to social or political pressures.

The way we understand and think about *Movement* and *Movement Loss* in Aotearoa, NZ, today has its roots in its historical origins (whakapapa). This section contextualises dominant notions of *Movement* and *Movement Loss* in society and healthcare today in terms of sociological and historical origins.

Sociological Constructions of Movement and Movement Loss in Biomedicine and Rehabilitation and Society

In her book, *Rehabilitation: A Post-Critical Approach,* Gibson (2016c) describes several different approaches to the moving body, which influence the way we think about bodies in general, the relationships we have to and with them, and to what ends. These conceptualisations and relationships are important when considering the sociological construction of *Movement* and *Movement Loss* because these concepts are linked to our understanding of bodies. Gibson (2016c) draws attention to three specific constructions of the moving body. These are the ‘Body as Object’, the ‘Lived Body’, and the ‘Made Body’.

The Body as Object. The ‘Body as Object’ refers to approaches to the moving body that are typically taken up and held in biomedicine and rehabilitation, identifiable as the biomedical ‘discourse’ of *Movement* (Gibson, 2016c). Within this, *Movement* is conceptualised in terms of its material and mechanical properties, essentially restricting understandings of *Movement* to the field of kinematics and pathologies/diagnosis (Gibson, 2016c).

The ‘body as object’ and biomedical discourse are identifiable in healthcare settings in medicine and rehabilitation today through common practices. This includes the way that language is used, values that are upheld and the ways in which power operates within these spaces and places. For example, Nicholls et al. (2015) identified that biomedical discourse and practice is concerned with the ‘body part’ rather than the ‘person’ (Nicholls & Viera, 2022). This narrow view of *Movement* is communicated in language which is restricted to the description of levers and forces (e.g., flexion, extension) or the displacement of a body from A to B (Nicholls et al., 2015). While understanding the moving body in this way enables the ability to identify and treat pathology, it also has the effect of marginalising more wholistic ways of thinking, and locates the body as the centre of the ‘problem’, – rather than addressing other social or environmental determinants of health.

It is worth noting that the development of biomedical discourse and the ‘body as object’ can be traced back through history. The 19th century saw the conceptual separation of the body from its environment through sanitary science and the documentation of anatomy in medicine (Armstrong, 2002). This work was expanded upon in the 20th century through the exploration of the body’s movement (Armstrong, 2002). It was also at this time that notions about what caused illness and mortality became located within the physical body, localised as an illness, an abnormality of structure or function in the body, or a specific pathological lesion (Armstrong, 2002). Such diagnostic classifications offer benefits in the ways in which care and other resources are structured, provided and outcomes are measured within public health settings (Jutel, 2024a). They also provide clarity to a patient of the cause of their ailment, add credibility to suffering and absolves the individual of responsibilities or blame (Jutel, 2024a). Beyond this, however, classifications of dysfunction can often be problematic, resulting in social consequences such as the legitimization of some problems rather than others, an oversimplification of a person’s ‘disease’ experience (Jutel, 2024b). In this, the notion of ‘body as object’ and biomedical discourse begins to disrupt and divide individuals’ experiences of *Movement* rather than supporting them.

Engagement with *Movement* and the moving body in ways that move beyond these conceptualisations opens the possibility of understanding the body beyond its material qualities or attributes. It also allows us to consider the moving body (and *Movement*) in terms of how people live through their bodies in an embodied relationship with the world, or indeed, how bodies are socially constructed through language, concepts and categories, which are then produced and reproduced through health care and society (Gibson, 2016c).

The Lived Body. The ‘Lived Body’ refers to the understanding of the moving body, *Movement* and *Movement Loss* as a function of how people live *through* their bodies to have an embodied relationship with the world (Gibson, 2016c). This conceptualisation of *Movement* and *Movement Loss* departs from the mechanical and material focus observed in the ‘Body as Object’ by challenging the assumption that the mind and body are separate and distinct entities, where the mind is ‘subject’, and the body is ‘object’[2] (Gibson, 2016c). Rather, the ‘Lived Body’ blurs these

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[2] Also known as the ‘Cartesian Split’ (Gibson, 2016c)

distinctions: people live in a reality where they simultaneously *have* bodies (body is object) and *are* bodies (body is subject), and as we move through the world, we cannot separate the two (Gibson, 2016c). Understanding *Movement* and *Movement Loss* through the lens of 'The lived body' involves acknowledging the lived and sensate experiences of the body as central to living and being in the world (Gibson, 2016c). When an individual receives a progressive diagnosis, this is impactful both on the physical body, the person and the way they understand themselves and the world. This approach to the moving body and *Movement* is often associated with phenomenology and phenomenological research (Gibson, 2016c).

The Made Body. While the 'Body as Object' and the 'Lived Body' demonstrate a shift in understandings of *Movement* and *Movement Loss*, both conceptualisations remain fixed within a 'physical reality' (Gibson, 2016c). Despite their differences, both retain the assumption that the moving body is at least in part determined by its physical reality, and in the presence of pathology, both locate the physical body as the locus of the problem. In contrast, the "Made Body", the lens associated with critical research, refers to how bodies are socially constructed through language, concepts and categories, which are then produced and reproduced through health care and society. Such understandings consider the body not 'born' (such as through the advent of being born with a genetic anomaly), but 'made' through and by society (Gibson, 2016c).

Understanding *Movement* and *Movement Loss* through the lens of the 'Made Body' requires us to consider how particular types of bodies are constructed and culturally reproduced as 'fit bodies' or 'healthy bodies', while those that deviate from pre-established norms are constructed as 'patient bodies', 'dysfunctional bodies' or 'disabled bodies' and therefore made amenable to intervention (Gibson, 2016c). It also requires us to consider how the physical body might 'extend into other bodies', such as prosthetics, adaptive technologies, animals or relationships with people which create functional assemblages (Gibson, 2016c; Gibson et al., 2021; Gibson et al., 2012; Nicholls et al., 2016).

The process of construction and reconstruction of the 'Made Body' to achieve a particular social purpose can be demonstrated through sociological research. For example, Armstrong (2002) cites how in the early 20th Century, posture and exercise were used in the army, education and society at large to achieve political ends. *Movement* was something that required control, being viewed as having a strong mental and moral impact on the development of character. Controlling discourse about and around *Movement* was a way in which a population could be indoctrinated, and controlled. For example, the discipline of the armed forces was considered of critical importance to the expansion of the British Empire (Armstrong, 2002). However, social constructions can also have unintended consequences. For example, while diagnosis might have the effect of explaining a common set of symptoms, they also have social consequences such as stigmatising or attaching a prognosis to those who receive that diagnosis (Jutel, 2024b). As such, constructions of *Movement* and the body have transformative power on the identity and social outcomes of those who experience them (Jutel, 2024b).

Directly relating to disability, critical disability scholarship (CDS) has attempted to draw attention to the differential societal expectations of those living with ‘typical’ movement and those classed as ‘disabled’ through the notion of ableism (Gibson, 2016a). Ableism refers to discrimination based on perceived or actual physical or intellectual ability. It occurs when attitudes in society prioritise, validate and show preference towards bodies or minds that are considered ‘typical’ or ‘normative’. At the same time, those that fail to meet those standards are systematically excluded or marginalised (Stanford Encyclopedia of Philosophy, 2019). Ableism operates via networks of beliefs, social processes and practices (Campbell, 2001) and these practices operate both in day-to-day interactions within society and in boarder social and political structures (Stanford Encyclopedia of Philosophy, 2019) which prematurely close down aspects of the imagination that resist these ways of thinking (Campbell, 2008). Ableism has been documented to come in many different forms, including ‘structural ableism’ (inaccessibility of the physical environment which effectively denies entry and equal use of social resources) (Lundberg & Chen, 2024) and ‘internalised ableism’ (when the disabled person discriminates against themselves because they believe disability is something to be ashamed of and hide) (Campbell, 2008).

Dominant Social Constructions of Movement are Challenged by Lived Experiences

From accounts from communities of disabled people, we know that conventional understandings of the moving body and *Movement* in society or health care settings don’t always match what is desired or needed to live well with ‘disability’ (Bell & Brooks, 2023; Radio New Zealand, 2019). Our relationship to *Movement* determines how it is perceived and understood. It plays a role in wellbeing. It ‘does something’ to and within society. It is therefore important to identify and consider ways in which these constructions are made and reproduced through interactions in health care and society at large.

Social Constructions of *Movement* in Spinal Muscular Atrophy

SMA as Documentable Pathology

The notion of SMA as a documentable pathology has occurred relatively recently. The first case studies occurred in the 1890s, which documented the more severe forms of the condition that ran in families. Milder forms of SMA (what would now be classified as type 3) began to be formally documented in 1956 under the name of Kugelberg-Welender disease. Before this, these individuals were typically diagnosed with muscular dystrophy (Nishio et al., 2023).

These early social constructions of SMA were born out of documentable characteristics such as familial history and physical findings such as the presence of ‘flaccid paralysis’ and progressive proximal muscle weakness that was identifiable due to the loss of anterior horn cells in the spinal cord and muscle atrophy. The arrival of genetic testing in the 1990s meant that the vastly disparate presentations of the disease in severe and milder forms were able to be located at the same locus on chromosome 5q. At this point, the ‘disease’ was renamed Spinal Muscular Atrophy and the associated subtypes (1a, 1b, 2, 3a, 3b and 4) were defined (Nishio et al., 2023). From 1995–2016, a period of massive growth occurred in the base of genetic research looking to understand the mechanisms underlying the disease in the hopes of finding a ‘cure’ (Nishio et al., 2023). *Spinraza,* the first pharmaceutical drug to treat SMA, was approved by the U.S. FDA in 2016 (Yeo et al., 2022). Here, it can be seen how biomedicine has provided a diagnostic framework by which *Movement* in SMA is constructed and categorised in terms of pathology (Jutel, 2024a). Doing so has resulted in an subsequent epidemiological and evidence-based practice to arise (Jutel, 2024a, 2024b) enabling the ‘disease’ to valued increasingly in terms of its ‘curability potential’ in recent years (Yeo et al., 2022). These social constructions of *Movement* continue to be dominant amongst scientific literature and SMA social platforms and community groups (Tkaczuk et al., 2022), suggesting there may be a large uptake of these ideas by those living with the condition. At the same time, the lack of critical research looking to understand the implications of these social constructions on the community means that it remains unknown whether these constructions are universally beneficial or not.

Social Constructions of Movement Identified by the SMA Community.

Internationally, there have been very few studies looking to understand the subjective experiences of those living with SMA. A qualitative descriptive study completed by Lamb and Peden (2008) in the USA looked to understand the experience of adults living with SMA. While now over 16 years old, this study remains of value because it was completed before the advent of pharmaceutical interventions for SMA. As such, the study provides potential insight into the challenges currently experienced by the New Zealand adult SMA community. Participants in Lamb & Peden’s study reported challenges with the constantly changing experience of SMA and feelings of social isolation as they attempted to work through these challenges. Study participants also reported struggling with progressive movement loss and the consequent fear of losing independence. This is indicated in the following quotes from participants in the study:

> Two of the most significant symptoms of my condition are loss of muscle strength and curvature of the spine; the progression of muscle weakness impacts me the most… I struggle with the fear of what tomorrow, next week, next month, or next year might bring… I never thought I would struggle with feeding myself, and yet this is a reality I must face.
> (Lamb & Peden, 2008, p.253)

> The part that bothers me the most is the progressive nature. If I could just stay stable, I would be satisfied with my condition. However, just when I think I’ve stabilised, I go through another period of strength loss that ultimately results in the loss of function. At one point, I could transfer myself; I lost that. At one point, I could crawl; I lost that. At one point, I could roll over in bed; I lost that. At some point, I will

> become too weak to drive, feed myself, etc. That's the tough part of dealing with SMA.
> (Lamb & Peden, 2008, p.253)

Lamb and Peden (2008) highlighted the importance of living a life that was 'normalised' and 'mainstreamed' with society, socially rich and adopted creative and innovative approaches to symptom management. Participants also reported the importance of maintaining an "optimistic life view" and feeling they were in control of their lives. This often involved accepting limitations brought on by the disease rather than 'harbouring ill emotions' such as bitterness due to the disease's impact.

The challenges of dealing with progressive *Movement Loss* have also been documented by Yang et al. (2016), who explored the experiences of 'anticipatory loss' in families living with school-age children with types 1 and 2 SMA in Taiwan. Here, parents reported feelings of helplessness as they realised their children would never experience youth and middle age. They reported that their children also felt helpless and afraid of death, they showed anxiety about their age and lived cautiously. Parents often felt sad, frustrated, depressed and helpless as they engaged in a future that was both uncertain and necessitated an 'unavoidably limited life'. At the same time, Yang et al. reported that even though they understood that SMA was incurable, parents never gave up hope for their children. They tried different treatments to prolong their children's lives, and when these failed, they focused on parent-child relationships and cherishing the time they had together and looked to liberate them by making a 'colourful life' despite an 'inactive body'. In so doing, parents continued to provide their children with opportunities to grow, learn and develop their self-esteem and confidence despite the progressiveness of the condition.

The notion of acceptance as important in one's response to the course of disease is shared by SMA disability advocates. For example, in her article, Timms (2023) (a disability advocate who lives with SMA type 2) describes her first big experience of physical loss when she realised during early adolescence that she could no longer support her head while swimming. Reflecting on the impact of this event, Timms acknowledges the reality that everyday tasks that she can complete now may also become too difficult as the years pass. However, she also argues, "I've learned it's ok to grieve these changes, to miss what my body could do before, but also find ways to adapt and enjoy what I can do, and accept what I can't".

These accounts suggest that how individuals living with SMA (and their families) engage with *Movement* and *Movement Loss* are impactful in terms of the degree to which one can adapt and lean into positive experiences and live a life that is meaningful despite an SMA diagnosis.

Social Constructions of Movement in SMA in Response to Pharmaceutical Technologies

The arrival of new pharmaceutical technologies for the treatment of SMA appears to have been well received by the SMA community. At closer inspection, however, the complexity of the situation is greater than expected as new or different challenges have arisen or old challenges have intensified or remained unresolved despite the arrival of new technology. This is highlighted by the work of Farrar et al. (2020), an Australian qualitative study that looked to explore the perspectives adults and parents of children living with SMA and treating health professionals on the changing treatment landscape. The authors found that new pharmaceuticals offered members of the community hope and optimism for the future. This was particularly the case for parents making decisions for their children and the possibility of better albeit uncertain benefits and for health professionals who hoped to optimise and promote functional capacities in the context of disability. For adults living with the condition, optimism was mixed with feelings of apprehension and uncertainty, given their past experiences of accessing health care or new treatments.

Treatment was also framed by parents and adults as a means by which day-to-day activities could be continued, appreciated and cherished. There was also acknowledgement, however, that treatment was not the only means by which this could be achieved. For example, some parents who did not pursue treatment for their children spoke about living 'an amazing' day-to-day life rather than living a life that was longer but of low quality, which in their eyes "did not seem fair" (Farrar et al., 2020, p. 392).

Interestingly, for some adults living with SMA, the hope for new treatment and prevention strategies was experienced as conflicting with notions of the strength and equality of people living with disability. While they perceived treatments as important, they also felt they should *not* be the sole focus. They were *proud* of their identities, abilities and achievements and felt that they should not be defined by their illness or perceived limitations. They already considered themselves to be living lives that were "good lives" (Farrar et al., 2020).

The implementation of prevention strategies such as pre-conception screening was also considered challenging by adults living with SMA:

> …when it's talked about in society [pre-conception screening] is the utter rejection of the kind of life that we live. I kind of feel a bit offended…. We're not seen as strong people living good lives.
> [p010 adult SMA 3] (Farrar et al., 2020, p. 395)

At the same time, participants also acknowledged that screening enabled reproductive choice, and they would want that choice if in the same situation.

Another interesting finding of the research was the reported feelings of pressure and judgement that members of the SMA community felt about their treatment decisions. For example, parents who had chosen supportive care over pharmaceutical treatment reported feeling that they would not be as welcome in the community if they *didn't* take Nusinersen. Similarly, some adults with the condition reported feeling pressured to emphasise their negative experiences to access to new therapies and to present themselves in ways that conflicted with a positive self-identity:

> I wrote a submission the other day... and I felt like I was writing a lie because I had to – I wrote it in the way of how SMA has affected me negatively. I wrote all this stuff

> – but that's not really how I feel. Because I feel I have a really good life and it's made me a better person and it's made me stronger in my heart and in my mind. My body's weaker but I'm strong [cries].
> [P011, adult, SMA2]. (Farrar et al., 2020, p. 395)

These findings suggest that while the changing treatment landscape holds opportunities for the SMA community, navigating this changing landscape can also have implications in terms of what is expected of members of the community, their feelings of social inclusion about their treatment decisions, the degree to which individuals feel they can positively embrace their abilities and identities. Or, in other words, simply providing treatment does not solve the social problem of 'disability'.

The Case for Considering Alternative, Non-biomedical Constructions of *Movement*

The aforementioned social constructions of *Movement* and *Movement Loss* are problematic. First, dominant biomedical constructions of *Movement* are often underpinned with assumptions that they are apolitical in how they operate. Despite this outward appearance, how these constructions operate within society can have profound social and political consequences for groups of individuals within society at large. This is illustrated in Saxton (2018), which looks at how the political interests of neoliberalism have overlayed *Movement* in terms of engagement in physical exercise and explores the paradoxical expectations requiring individuals to engage in exercise to benefit their health while simultaneously being socially excluded from spaces that enable that. Saxton's argument is significant because it suggests that while mainstream arguments for engagement in exercise within rehabilitation and society might be framed as being within the 'interests' of the individual, such arguments may also be serving a conflicting political purpose. While disabled people might be actively encouraged to 'take care of their health', barriers are simultaneously constructed that prevent them from doing so.

This argument also poses questions when considering the rapidly changing treatment environment for SMA – both in New Zealand and globally. For example, many of the arguments for access to pharmaceutical treatments for adults living with SMA are based on ideas such as the reduction of disease burden, the potential to support participation in meaningful pursuits, increasing the likelihood of being able to maintain full-time employment, or simply minimizing the severity of symptoms such as fatigue, muscle loss or falls (Biogen, 2024; Forbes, 2023; Genentech USA, 2024; Yeo et al., 2022). Yet, the price point of these medications simultaneously prevents members of the community from accessing them.

Dominant notions of *Movement* are problematic because of what they potentially do to the person. This has been demonstrated in other neuromuscular populations. For example, Jachyra and Gibson (2016) completed a qualitative study exploring the socio-behavioural mediators of sports participation in young men living with Duchenne Muscular Dystrophy as they reached adolescence. The authors found that the quest for excitement in physical activity, pleasure of movement/ flow, connectedness and identity were factors that supported boys' involvement in physical activity. This contrasted with the biomedical or social preoccupations with "fitness, fatness and body image" and social practices such as bullying which were cited as reasons why the boys decided against physical activity. These findings highlight that the relationship one has with *Movement* within the context of living with a chronic neuromuscular disorder is important in determining whether one chooses to engage in it. While some individuals might continue to engage in *Movement* despite poor experiences, biomedical and social expectations *do* shape what people choose to engage in and what they choose not to.

What might help someone living with SMA to engage positively with *Movement* and *Movement Loss* might be counterintuitive to what the biomedical model argues for. This is highlighted in Gray et al. (2021), a critical rehabilitation study, which considered how the practice of clowning in children's rehabilitation settings could promote relationship, inclusion, laughter, and emotional reprieve from that which is difficult and unable to be immediately changed in ways that contrasted to the seriousness of the biomedical model. The study highlighted that what might help someone in the face of difficult life events might be counterintuitive to the inherent values of the biomedical model. It also highlights the importance of being open to exploring alternatives and exploring multiple means of engaging and providing care.

Non-biomedical Understandings of *Movement*

Due to the challenges presented by biomedical notions of *Movement* and *Movement Loss,* this final section touches on some alternatives.

There are several instances of non-biomedical understandings of *Movement* that can be identified within critical disability and critical rehabilitation scholarship. Such examples include 'crip theory' from critical disability scholarship (which looks to reclaim the derogatory term 'crip' into a positive affirmation of crip identity) (Thorneycroft, 2024); the 'connectivity model' from critical rehabilitation studies (which is a philosophical approach in rehabilitation that looks to intentionally support those living with disability to build relationships with others, technology or animals that acknowledges co-dependence) (Nicholls et al., 2016), post-human (Gibson et al., 2021) and other post-modern or post-structural scholarship, such as the work of Paul Virilio, Erin Manning, Gilles Deleuze and Félix Guattari (Nicholls et al., 2015). Such scholarship looks to reframe the relationships individuals have with *Movement*, others and their environment.

Indigenous scholarship and models of disability also provide a valuable window into alternative notions of *Movement.* The Whānau Hāua model, which is informed by te ao Māori, provides a Māori perspective on disability (Hickey & Wilson, 2017) is one example of this, as is indigenous scholarship highlighting the significance of *Movement* in informing cultural identity and relationship to whakapapa (Heke, 2022).

These examples highlight that non-biomedical notions of *Movement* and *Movement Loss* already exist and circulate within society. Such alternatives are important, particularly when we consider the fact that disabled people have historically been underserved by health systems and within society, and these social and cultural inequities continue to play out (Hickey & Wilson, 2017; StatsNZ, 2020). It is also significant when we consider how the rapidly changing treatment landscape is challenging the traditional 'bounds' of care and the corresponding need for governments and societies to envision what kind of healthcare provision is valuable for their future (Nicholls, 2018a). Finally, while disabled people are key stakeholders in these decisions, they are often unrepresented within sociopolitical decision-making that fundamentally affects their lives (Hogan et al., 2019).

Chapter Summary

In this chapter, I have identified *Movement* and *Movement Loss as* social constructs that have historically been subject to sociopolitical influences, and that this process continues into current day. The notion of 'Spinal Muscular Atrophy' as a clinical diagnosis is in and of itself a social construct created within the biomedical discourse. This discourse views the SMA body and the way it moves in particular ways and guides the types of advice and treatments individuals and families living with SMA are recommended and receive. Navigating this social-political landscape poses an ongoing challenge for individuals and families living with SMA, and this is documented in recorded in qualitative research and personal accounts of adults and families living with SMA overseas. It is of interest to explore and document how *Movement* is being constructed by New Zealand adults living with SMA given the current barriers to receiving rehabilitation management and lack of access to novel pharmaceuticals. In the next section, I describe how this was achieved in the study by outlining the methodology and methods I utilised.

Methodology and Methods

This chapter outlines the methodological lens and theoretical positioning of the study and documents the practical steps taken to carry out the research. To do so, I first outline the epistemological lens of the study, Social Constructivism, and consider its critiques and relevance to this research. I then outline additional social and political theory/scholarship that has contributed towards the theoretical positioning and lens used in this research. These theories include: Critical traditions within qualitative research, Critical Disability Studies and Critical Rehabilitation Studies. I also consider reasons why drawing on these particular theories and scholarship is relevant to this research. I then outline the method taken to carry out the research. To do so, I describe decisions made regarding the research study design, data collection, and data analysis. Finally, I outline key ethical and cultural safety concerns identified during the planning stages of this research and how these concerns were addressed.

Methodology

The methodological approach used in this study is based on a Social Constructivist epistemology and informed by Critical Social Theory, in particular, Critical Disability Studies (CDS) and Critical Rehabilitation Studies (CRS). This research uses Braun and Clarke's (2022b) method for Reflexive Thematic Analysis. This methodological lens and methods were chosen because of the underlying aspirations and intentions of the study to generate social change in health and social settings for adults living with SMA. By critically questioning dominant understandings of *Movement* and *Movement Loss* within the context of SMA, I hoped to provide a research base from which outcomes for the SMA community might be improved long-term.

Social Constructivism

Social constructivism carries with it a set of assumptions around 'being', 'what is' and what the nature and structure of reality is (Crotty, 1998b), and is often associated with a relativist ontological position (Braun & Clarke, 2022b). An epistemology of social constructivism argues that that which we consider 'true' and 'real' in the world is generated or constructed by the language and discourse we use in society. While phenomena in the natural and physical world do exist, *meaning* is ascribed to these phenomena through language and social discourse (Burr & Dick, 2017; Gergen, 2015). This meaning-making is constantly changing and evolving with society but shapes our perceptions of reality in important ways.

Social constructivism has several key tenets that are important when considering this epistemological position and its implications for research. Burr and Dick (2017) describe that the way we understand and think about the world is dependent on the language and social discourses we use to describe things. *Who* has power in a particular culture or society can determine why some aspects of the world are 'more important' than others and how meaning is ascribed to those phenomena. In this sense, ‘reality’ is constantly being ‘generated’ by the social mechanisms of language and social discourse.

‘Discourses’ refer to sets of ideas or broad meaning systems (Speer, 2005)and social constructivists are interested in these meaning systems because of their productive power, their ability to influence what we do and how we act (Burr & Dick, 2017).

Discourses also have disciplinary effects (McHoul & Grace, 2015). Individuals desire to conform to the norms within society, and so discourses can also determine the consequences if deviation from the norm occurs. Socially constructed meanings and discourses are set within a particular time, place and culture, and it is also possible for more than one competing discourse to occur or be in play at any one time. Interestingly, the more one discourse works to normalise one mode of behaviour and being, the more counter-discourses are produced that resist that approach (McHoul & Grace, 2015).

Social constructivist research looks to identify and critique language and social discourses, the power they hold and the supporting structures that enable them to continue to have power in society. It enables the taken-for-granted ‘truths’ and assumptions by society to be deconstructed and demonstrates how these can be socially ordered (Crawley, 2019). By uncovering these discourses, we can consider other ways of understanding or thinking about this problem. We can consider where certain discourses have value, where they have limitations, and what alternatives might be available (Crawley, 2019).

The epistemology of social constructivism has implications for how qualitative research is done. Because of the assumption that social realities are ‘generated’ and ‘constructed’, this assumption carries forward for the researcher interacting with their data. Rather than themes simply ‘emerging’ from the data, ‘ready’ for the researcher to ‘discover’, the social constructivist position argues that meaning is actively constructed when the researcher interacts with the data. In this sense, the researcher plays an active role in creating, constructing meaning, generating data and producing particular cultural realities (Terry et al., 2017).

Critiques and Limitations of the Social Constructivist Position. Several critiques come with the social constructivist position. For example, relativism, a consequence of social constructivist philosophy, argues against a single definitive ‘truth’ and that the value of any one discourse cannot be proved against another. This means that to take a social constructivist position, we must also accept that there are multiple perspectives on any given issue or experience and that whose perspective is accepted as ‘correct’ is more about politics and power than it is the attribute of the perspective itself (Burr & Dick, 2017).

Another limitation of the social constructivist perspective is that the focus on the constructive power of language can also lead to the neglect or denial of key aspects of personhood or experience, such as what a person subjectively feels, hopes or fears. Often, these experiences can be framed by social constructivists as ‘side-effects of discourse’ or aspects of ‘performances’ during interactions rather than experiences real in and of themselves. There have been attempts to progress thinking in this area by social constructivists, to disrupt the constructed divisions between the body, the mind and the world of language, and to understand the person wholistically as a complex, embodied, psycho-social-linguistic entity (rather than removed from one's body as is often the case with mind-body dualism) (Burr & Dick, 2017).

Crawley (2019) argues that one of the critiques of social constructivism is that because the theory is not grounded in 'reality' ('brute facts'), it cannot be used to do critical work as it has the potential to deny 'facts'. Interestingly, Crawley argues that this limitation *can* also be ameliorated through researcher reflexivity on positionality. Reflexivity, a practice described as "bend[ing] back upon oneself" (Sparkes & Smith, 2014, p. 20) is a practice whereby the researcher examines and observes how factors such as their background, experiences, emotions and underlying assumptions in relation to the subject that they are researching (Trainor & Bundon, 2021). It is a practice of introspection and self-awareness (Sparkes & Smith, 2014). The purpose behind reflexivity is to 'deconstruct' the impact that one has on the research process (Hill & Dao, 2021), and openly engage with how the researcher is an active agent in the production of knowledge (Trainor & Bundon, 2021). When reflexive practices are followed, it provides clarity to the constructivist argument by making it *clear* how knowledge was produced and the researcher's impact on that process. Doing so supports the validity of using the Constructivist lens without denying the concurrent existence of 'practical' realities (Crawley, 2019).

Relevance of Social Constructivism to this Research. Using an epistemological position of social constructivism is both *relevant* and *necessary* to the completion of this research. This is because the *research questions* underpinning this research specifically look to investigate, first, the *constructed realities* of adults living with SMA (as it relates to notions of *Movement* and *Movement Loss)* and second, to identify ways in which those constructed realities have been shaped by social forces within health care society at large. Such questions can *only be answered* when we start to consider what is *normalised* or generally considered to be 'true' in society as constructed realities. Language and discourse work to generate these realities, and there is potential for institutions with power to use these tools to create social realities that support them.

Such questions *could not* be answered using an alternative lens, such as positivism or post-positivism, where a single, objective reality that can be discovered through systematic, detailed observation, experimentation and verification is assumed (Grant & Giddings, 2002). This is because these paradigms often assume that social realities are stable and based on preexisting patterns and order (Grant & Giddings, 2002). Subsequently, a study based on a Positivist or Post-positivist approach would fail to provide the ability to assess social realities at all, let alone consider these realities as flexible, changing, nuanced and connected to notions such as equity or well-being.

The case for the social constructivist approach also appears timely as the industry for therapeutics targeted at treating the symptoms of SMA has recently become increasingly widespread and accessible globally, but social constructions of *Movement* remain unquestioned and unchanged, leaving individuals to grapple with the following paradox: at the time where medical advances allow the greatest opportunities to alleviate the physical symptoms of ‘disease’, one is simultaneously unable to engage with *Movement* creatively and to its fullest extent. One is unable to *Move* as they might ultimately wish or desire to.

Theoretical Positioning

Critical Traditions in Qualitative Research

In addition to a social constructivist epistemological position, the methodology of this study has been influenced by critical scholarship embedded within critical social, critical disability and critical rehabilitation traditions.

Crotty (1998b, p. 113) describes critical inquiry as:

> … a contrast between a research that looks to merely understand and that which challenges… between a research that reads the situation in terms of interaction and community and a research that reads it in terms of conflict and oppression… between a research that accepts the status quo and a research that seeks to bring about change

Critical methodologies are ‘transformative inquiries’ that look to bring about social justice and social change (Denzin & Giardina, 2016), and share the common assumption that we live in a world that is stratified along predictable lines such as ethnicity, gender, class and disability (Grant & Giddings, 2002). Critical inquiry works to highlight these power relationships and expose the forces of hegemony and injustice that create them. In doing so, it works to invite researchers, participants and audiences to become open to new ways of thinking and understanding about these issues and work towards change (Crotty, 1998b).

The Origins of Critical Inquiry

While there have always been social critiques, Karl Marx remains a key figure in the modern critical tradition. His works *The Communist Manifesto (1847)* and *Das Kapital (*1867–1894), fundamentally set in motion a form of critical inquiry that is seen today (Crotty, 1998). The marxist critique addresses many issues similar to those typically raised by social constructivism, however, these issues are contextualised within the broader political economy and the social relations of production within a competitive market society (Arfken, 2017).

Marx was followed by the neo-marxist (post-marxist) academics of the Frankfurt School of critical theory, which was dubbed ‘critical theory’ from the 1950s (Crotty, 1998b). This movement included theorists such as Max Horkheimer (1895–1979), Theodor W. Adorno (1903–1969), Herbert Marcuse (1898), Walter Benjamin (1892–1940) and the leading figure of the second generation, Jürgen Habermas (b. 1929) (Celikates & Flynn, 2023). The Frankfurt school utilised many competing epistemological positions to do critical work despite their common marxist heritage (Crotty, 1998). In this sense, there are many ‘strands’ of critical theory that have emerged as a response to reflective engagement with the emancipatory goals of different movements, including feminist, queer and crip theories, critical disability theory, critical race theory and others (Celikates & Flynn, 2023). This critique extends to theorists more commonly associated with post-structuralism, such as Michel Foucault (Celikates & Flynn, 2023).

Critical Disability Studies (CDS)

Critical disability studies (CDS) refers to a diverse set of theoretical approaches that work to analyse the concept of ‘disability’ as a cultural, historical, social and political phenomenon (Stanford Encyclopedia of Philosophy, 2019). In doing so, CDS methodology works to scrutinise social norms that define and label particular ‘attributes’ as ‘impairments’, as well as identifying contradictions in society that ultimately see stigmatised attributes being concentrated in particular populations (Schalk, 2017). CDS looks to contribute to social change beyond academia by producing knowledge that supports justice for those communities who live with stigmatised bodies and minds (Minich, 2016). In this sense, CDS is seen to work in solidarity with these communities (Minich, 2016).

Relevance of a CDS Approach to this Research. A CDS approach is appropriate to the research question because we are interested in the ways that meaning is attached to concepts such as *Movement* and *Movement loss* by the SMA community. Like ‘disability’, these concepts are embedded with social, political and historic meanings. SMA movement has historically been labelled as deviant from normal movement within biomedicine by virtue of diagnostic criteria that have established it as a recognisable ‘pathology’. Similarly, social norms about what kinds of *Movement* are acceptable can present barriers to participation in movement, particularly when the way in which one moves is ‘atypical’ (Saxton, 2018). This research is also aligned with CDS goals in that it looks to work in solidarity with the New Zealand SMA community and beyond and looks to support representation and justice for this community.

Critical Rehabilitation Studies (CRS)

Gibson (2016) outlines what she describes as a ‘post-critical approach’ towards rehabilitation and broadly aligns with what is now commonly viewed as ‘critical rehabilitation studies’. This approach draws on and is informed by both critical and post-modern scholarship from a broad range of traditions that historically emerged at the ‘relational’ or ‘post-modern turn’. These include philosophers such as Immanuel Kant, Karl Marx, Georg Hegel, Friedrich Niestzche; social theorists such as Michel Foucault, Jürgen Habermas, Jacques Derrida, and Gilles Deleuze; and feminists such as Luce Irigaray, Donna Haraway, Judith Butler and Margrit Shildrick, among others.

A central feature of these approaches is their critique of the dominance of positivism in Western Society. Positivism can be traced back to the 17th century Enlightenment and the division of mind and body as separate substances by Descartes (Gibson, 2016c). Together, these approaches work to question the notion of objectivity in science and work to highlight the importance of social context and structures in mediating and determining what we think of as ‘true’ (Gibson, 2016c). It is worth noting that health disciplines within biomedicine and rehabilitation have traditionally been aligned with positivist or post-positivist research methods (Nicholls, 2018a), and these approaches have resulted in a dominance of understandings of the ‘body as an object’, rather than more wholistic ways of thinking. There has been a call for more critical research within rehabilitation, particularly as practitioners trained in traditional models of care find themselves inadequately prepared for the complex social, cultural, economic and ethical issues they face in the workplace (Setchell et al., 2018). Critical rehabilitation research looks to address these social, political and material aspects of rehabilitation to provide ethical and deliberate professional practice (Setchell et al., 2018).

Relevance of a CRS Approach to this Research. A CRS approach is appropriate in the case of this research as medical professionals and the SMA community grapple with the ethical, social and political effects of a changing treatment landscape. While such rapid transformation has the potential to be ‘liberating’ for the community, critical research remains important in this space if such changes are to continue to provide ethical and relevant care for those they serve (Setchell et al., 2018).

Section Summary

The broad methodology for this study was critical qualitative inquiry. Critical qualitative inquiry is understood here as qualitative inquiry that is theoretically underpinned by critical social theories and aims to prompt outcomes that are oriented toward social change (Koro-Ljungberg & Cannella, 2017). The framework that informed decision-making about the approach to study design, data collection, data analysis and interpretations was drawn from the critical theoretical positioning introduced above.

Methods

Overview of the Study Design

This study gathered qualitative data from NZ adults living with SMA who were 18 years or older in semi-structured interviews. The data gathered was then analysed using Braun & Clarke’s six step framework for reflexive thematic analysis (Braun & Clarke, 2022b).

Semi-structured interviews were chosen data collection methods because they enabled the collection of rich, qualitative data, where the study participants could openly discuss aspects of their lived experience that were important to them without being confined to answering in particular ways (Braun & Clarke, 2022a; Braun et al., 2021). Braun & Clarke's six step framework for reflexive thematic analysis was chosen because it enabled interpretations to be drawn from the critical theoretical and epistemological positioning of the study (Braun & Clarke, 2022a; Terry et al., 2017).

The study originally included an online survey with similar questions to complement the interviews. The intention of the survey was to 1) collect demographic data on the New Zealand SMA community (the most recently published data on this was in 2017) (Rodrigues et al., 2017) ; 2) to ask preliminary questions which can then be used to inform the in-person interviews; and 3) to support the rigour of the research by allowing later reflection on the relationship between the demographic data and the data gained through the interview process (Braun & Clarke, 2013). On completion of the survey, however, it was found that this was not how it actually functioned.

In this section, I describe the processes for both semi-structured interviews and online survey, and later, I will discuss the contribution of the online survey.

The study design was informed by consultation with stakeholder groups, including Pūnaha Io the New Zealand Neuro-Genetic Registry and Biobank, Muscular Dystrophy New Zealand and AUT Mātauranga Māori Committee. Prior to completing the ethics application for this project, I also discussed research ideas with others living with neuromuscular conditions for their input and feedback on the study.

Ethics Approval

The research received ethical approval from the AUT Ethics Committee on 14th September 2023 (Reference Number 23/228). The application was approved for three years until 14 September 2026. At this stage, further consultation with the AUT Mātauranga Māori Committee to support Māori engagement in the research was undertaken. With the advice received, further amendments to the research design were made (see pg. 39 for details of these amendments). Following review by the AUT Ethics Committee of these amendments, ethics approval was granted on 17 October 2023. Evidence of ethical approval can be found in Appendix A and B.

Ethical Considerations

In preparing the ethics application, particular attention was given to the following concerns:

Informed and voluntary consent. For potential participants for the semi-structured interviews, verbal or written consent (e.g. via email) was provided before the interview to indicate the potential participant's interest in partaking in the research. The potential participant was provided with an information sheet about the research and interview process to read before the interview took place (appendix C). Finally, before the interview, the researcher and participant verbally discussed and completed the consent form (appendix D). This consent form could be completed in hard copy or digitally.

For the online survey, participants were initially sent an information flyer via email providing brief details about the survey (See Appendix E), and if interested, participants could click a link in this email which sent them to the survey. An information sheet and consent form was embedded at the beginning of the online survey (see Appendix F). In completing the survey, participants agreed for their information to be utilised in the study.

Confidentiality and Anonymity. It was not always possible to retain anonymity between myself and the participants because I live with SMA, am part of the New Zealand SMA community, and this is a small community in New Zealand. Attempts were made to maintain as much confidentiality for participants as possible despite these inherent challenges. For example, the online survey was designed so that it was able to be completed anonymously without revealing the identity of the participant. Online survey data was gathered and held separately from interview data to retain the anonymity of the participants.

In the case of the interviews, confidentiality was maintained by completing the transcription of interviews myself and substituting identifiable names or places during this process with codes or pseudonyms to protect the anonymity of the participant. An effort has also been made in the writing of this thesis to remove identifiable features within the quotes. The participants and information gathered during the interviews will be kept confidential to the research team and treated with respect and dignity both within and outside the research environment. It is acknowledged that the SMA community in New Zealand is small, and so the researchers may come across some participants socially. In this case, I would not be discussing any interview data. The decision was made never to publish the raw data generated from this study in a data repository or similar.

Cultural Sensitivity of the Research. As a non-Māori researcher identifying as Pākehā or Tauiwi, I acknowledge that historically, Māori have not been well served by Pākehā research, and this has contributed negatively to health and equity outcomes for Māori. I also acknowledge the legal obligation of researchers to consider the ethical positioning of their research for Māori under Te Tiriti o Waitangi.

To my knowledge, this study is the first qualitative study on SMA completed in the context of Aotearoa, NZ. While this research did not look to specifically target Māori as the sample population, I did wish to support Māori participation and engagement in the study and ensure Māori were well served by the research that was produced. SMA is an inherited neurogenetic disorder. While unpublished demographic research has indicated that Māori may have a lower prevalence of SMA than non-Māori, the genetic nature of SMA means that it is significant to Māori because of its ties to whānau and whakapapa.

This research utilises a social constructivist epistemology and critical theory to question the narrow understandings of *Movement* held by the Western biomedical model and rehabilitation at large. Indigenous perspectives provide valuable insight into alternative ways of understanding concepts such as *Movement* and ‘disability’, and I believe tāngata whaikaha and Māori have valuable knowledge base from which the status quo in the New Zealand health system may be questioned and generate insight into how to facilitate change that is meaningful for Māori. Including and accounting for these perspectives also has the potential to provide foundational evidence to address current health inequities for Māori and provide a knowledge base to support future Kaupapa Māori Research in this area.

I consulted with the AUT School of Clinical Sciences Mātauranga Māori Research Review Committee and with Māori representatives of the muscular dystrophy community before settling on the design of this study. My application letter to the committee and its recommendations from the consultation process can be found in Appendix G and H. This feedback was integrated to the extent allowed by the scope and time constraints allowed of master’s thesis framework, and this involved:

- Providing a video introduction of the research for 'recruitment’ of potential participants.
- Invited participants to include their whānau as part of the interview process if they wished and for researchers to follow preferences on this.
- Utilisation of a purposive recruitment strategy aiming for 50% Māori/ 50% non-Māori participants in the semi-structured interviews.
- Gaining consent for a separate cultural analysis of data to be completed at a later date
- Providing Māori participants with the choice to review their transcripts before the data analysis phase began.
- Kaitakitanga (guardianship/taking care of) of the implicit Māori cultural lens expressed in Māori data.

Management of Researcher Insider-Experience. Management of the impact of this research on me was also considered, given my insider experience in this community as someone who has a family history of SMA and lives with SMA. To minimise the emotional impact of working with individuals with the same condition, I kept a reflective diary throughout the research and attended regular professional supervision sessions with an external professional supervisor in addition to research supervision meetings with my research supervisors.

Data Collection

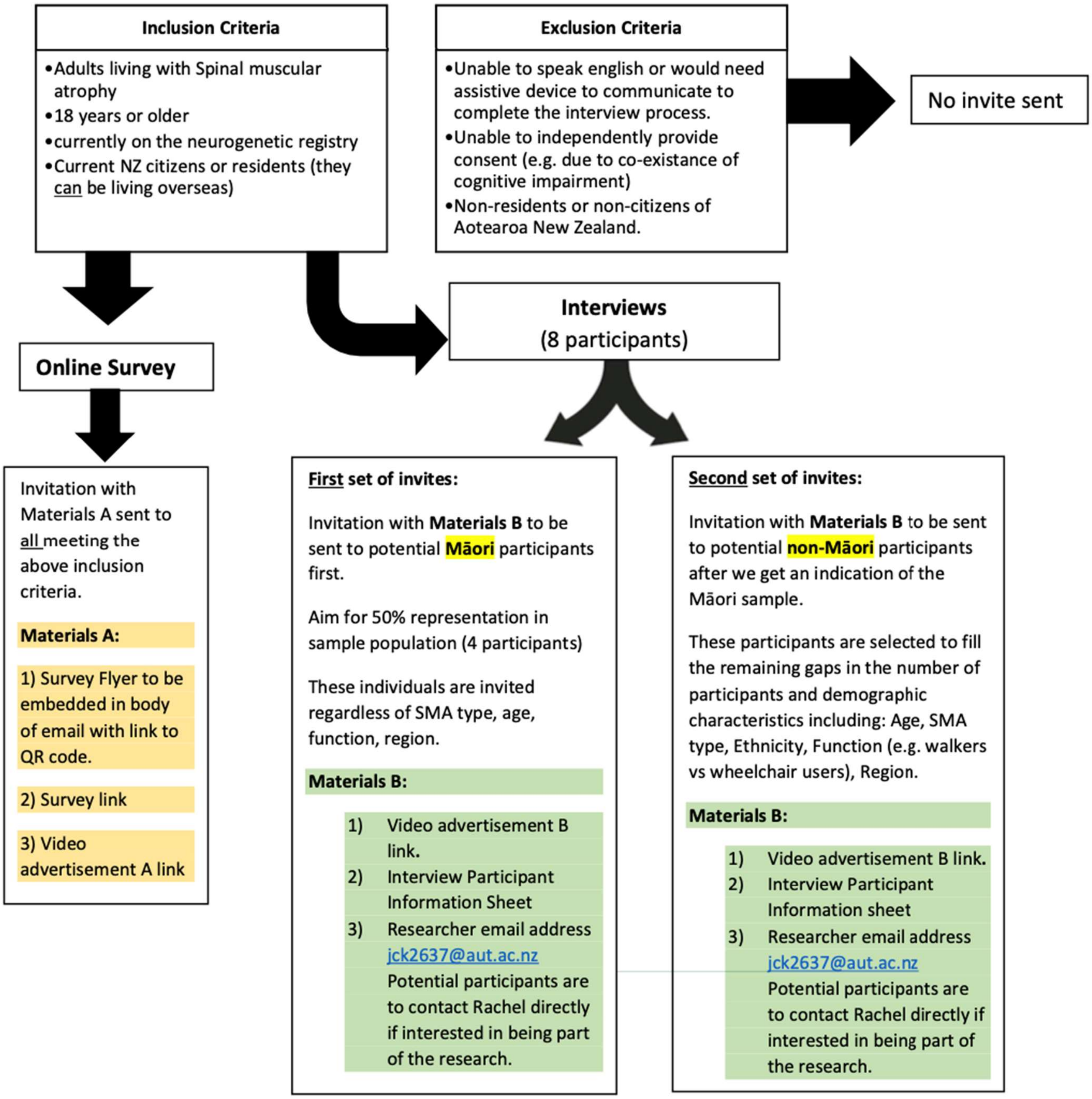
Participants. This study looked to include adults living with SMA who are New Zealand citizens/ residents currently living in New Zealand or overseas (if receiving treatment overseas). Our inclusion criteria for those participating in the study were those individuals with Spinal Muscular Atrophy who are: 1)18 years or older; 2) Currently on Pūnaha Io– Neuro-Genetic Registry and Biobank or known through personal and professional networks; and 3) A current New Zealand citizen or resident. I looked to give priority to potential Māori participants to participate in the study, looking to achieve up to 50% of the sample population where possible. Best efforts would otherwise be made to include a range of other ethnicities, SMA types (1–4) and capacities across the SMA movement spectrum.

Potential participants were excluded if they were: 1) Unable to speak English or use an assistive communicative device to complete the online survey or interview process. 2) Unable to independently provide consent (e.g. due to co-existence of cognitive impairment); 3) Non-residents or non-citizens of Aotearoa, NZ. This exclusion was necessary for this study for the data being collected to be appropriately understood and interpreted by the researcher and to ensure that individuals can make informed decisions about whether or not to participate in the research. I chose only to include citizens and residents of Aotearoa, NZ, because this status will affect access to publicly funded medical care in New Zealand.

Participant Recruitment. An application was made to Pūnaha Io–The New Zealand Neuro-Genetic Registry and BioBank to utilise the register for participant recruitment (see Appendix I). Initial contact with participants was made by a representative of the register, who was also responsible for identifying individuals who meet the inclusion criteria. Email contact was made asking for the participation of potential participants in the Online survey. Attached to this initial email contact was an information pack provided by the research team, which included an advertising flyer for the online survey (see Appendix E), a link to the survey, and a video advertisement explaining the research and its purpose (see Appendix J).

When recruiting for the semi-structured interviews, the register representative made either email or phone contact with potential participants. Potential participants were then sent a video advertisement explaining the research and its purpose (see Appendix J) and an information sheet about the interviews (see Appendix C). Figure 1. below demonstrates the process of participant selection from the Neuro-Genetic Register.

The study was also advertised through our personal and professional networks. If potential participants were interested in the research, they were able to contact the research team directly.



Inclusion Criteria

- Adults living with Spinal muscular atrophy
- 18 years or older
- currently on the neurogenetic registry
- Current NZ citizens or residents (they can be living overseas)

Exclusion Criteria

- Unable to speak english or would need assistive device to communicate to complete the interview process.
- Unable to independently provide consent (e.g. due to co-existance of cognitive impairment)
- Non-residents or non-citizens of Aotearoa New Zealand.

Invitation with Materials A sent to all meeting the above inclusion criteria.

Materials A:

1) Survey Flyer to be embedded in body of email with link to QR code.
2) Survey link
3) Video advertisement A link

First set of invites:

Invitation with **Materials B** to be sent to potential **Māori** participants first.

Aim for 50% representation in sample population (4 participants)

These individuals are invited regardless of SMA type, age, function, region.

Materials B:

1) Video advertisement B link.
2) Interview Participant Information Sheet
3) Researcher email address jck2637@aut.ac.nz Potential participants are to contact Rachel directly if interested in being part of the research.

Second set of invites:

Invitation with **Materials B** to be sent to potential **non-Māori** participants after we get an indication of the Māori sample.

These participants are selected to fill the remaining gaps in the number of participants and demographic characteristics including: Age, SMA type, Ethnicity, Function (e.g. walkers vs wheelchair users), Region.

Materials B:

1) Video advertisement B link.
2) Interview Participant Information sheet
3) Researcher email address jck2637@aut.ac.nz Potential participants are to contact Rachel directly if interested in being part of the research.

Figure 1. Flow diagram of participant selection from the Neurogenetic Registry. Materials A and B can be found in Appendix E (Survey flyer), Appendix J (Video advertisement used for both the survey and semi-structured interviews), and Appendix C (Interview information sheet). The survey link cannot be provided as it is no longer viable.

Online Survey. The voluntary online survey was distributed to adults (≥18yo) who are registered as having a diagnosis of SMA on Pūnaha Io the New Zealand Neuro-Genetic Registry and Biobank. Participants were able to participate if they were currently living in New Zealand or overseas. A copy of the questions from the online survey can be found in Appendix K.

The online survey was completed using Qualtrics software, and was proposed in the study design for the purpose of collecting demographic data, to provide supplementary data that could be used alongside the in-person interviews, and to support the rigour of the research by allowing later reflection on the relationship between the demographic data and the data gained through the interview process (Braun & Clarke, 2013). The data from the online survey was collated on the Qualtrics online platform and later exported and uploaded to the secure research centre on Microsoft.

While the online survey was planned and carried out, ultimately, the decision was made *not* to use this data in the final analysis. This decision was made in part due to a low response rate to the online survey and the fact that data gathered during interviews was rich enough to make the findings of the online survey redundant. Despite these setbacks, incorporating an online interview remained useful within the broader context of this project, particularly in considering the types of questions that would be valuable to ask participants within the semi-structured interviews and allowing participants to look at some questions in advance.

Semi-Structured Interviews. I planned to complete between 8–10 semi-structured interviews with New Zealand adults living with SMA. These interviews would last between 60–90min. Participants were given a choice as to whether the interview would be conducted in person (at AUT North Campus) or using an online platform chosen by the participant (via Microsoft Teams, Skype, or Zoom). A copy of questions used in the semi-structured interviews can be found in Appendix L. Participants also completed a demographic survey prior to interview. This can be found in Appendix M.

I completed and recorded the interviews using a digital voice recorder provided by the Person-Centred Research Centre. I then transcribed the recordings by hand with the assistance of a computer programme called Express Scribe Transcription Software. This software was used to control the speed and playback of the recording while it was being typed out by hand (as opposed to generating the transcript from the recording through the use of AI technology). The data generated was also anonymised at this time through the removal of identifying names and places from the transcript. These transcripts were then uploaded to the secure research centre server on Microsoft.

Analysis

Reflexive thematic analysis of the data sets was completed using Braun and Clarke's six phase approach of analysis to generate meaningful themes from the data (Braun & Clarke, 2022b).

Reflexive thematic analysis allows interaction between the data, the researcher, and their research question to offer the best possible story of the data through iterative phases: Reading and familiarisation, coding, searching for themes, reviewing themes, defining and naming themes, and writing/finalising analysis (Braun & Clarke, 2022b; Terry et al., 2017). Regular supervision sessions (which were also recorded), reflective notes and a reflection diary were kept to support ongoing reflexive practice throughout the project.

The Six Phases of Reflexive Thematic Analysis

Phase 1: Familiarisation. This phase involved becoming deeply and intimately familiar with the data set through the process of immersion. This was achieved through first listening to the audio recordings of the interviews and then through the process of transcribing the interviews by hand. Finally, the transcriptions were read, reread, highlighted and annotated with brief analytic ideas linked to answering the research question. Engagement with the data at this stage was relaxed, with the overall intention simply to note items or points of interest that could inform a response to the research questions later on in the analysis. For this reason, data items considered ‘important’ at this stage were intentionally very broad to be open to participant experience as much as possible. This approach reflects the theoretical positioning of social constructivism through its openness to the meaning constructed by participants and not being too attached to pre-existing notions of *Movement* and *Movement Loss* or the social factors that might have shaped them.

Phase 2: Coding. This involved a more systematic and focused engagement with the transcript data. Having gained a general overview of the data, the intention now was to begin coding the data more formally to capture single meanings or concepts. This involved re-reading the transcripts for a third time, this time in Microsoft Word, and using the comment function within Microsoft Word to highlight relevant sections of text and to attach reflective notes and codes to specific sections of data.

Developing a coding system that captured what was considered to be subjectively important to participants and addressed the research question was an iterative process that was refined as successive interviews were coded. The iterative nature of coding also meant that it was necessary to “recode” several transcripts that had been coded earlier in the coding process to ensure consistency.

Codes were made identifiable from descriptions or reflective notes by applying a hashtag immediately preceding the broad topic/question or a key area of interest identified in the data (E.g. #Movement is…; #The SMA Body). A table of early data codes used across different interviews and their descriptions/definitions can be found in Appendix N.

The process of coding requires the researcher to begin to deconstruct the meaning put forward in the raw data and begin constructing new meanings as they interact with that data. This process follows a social constructionist epistemology in that the researcher plays an active participant in the process of drawing meaning from the data (Terry et al., 2017).

Phase 3: Generating Initial Themes. The process of generating initial themes is an active process of pattern formation and identification as the researcher builds on the earlier engagement with the data during Familiarisation and Coding (Terry et al., 2017). In this phase, I began to link shared patterns of meaning across the data set. Interview data codes were printed into hard copy form and then sorted into “initial themes”. This stage aimed to allow comparisons to be made across the data sets, so to start, initial themes had a strong correlation to the codes developed in phase 2, using many of the same codes as initial themes.

The research questions were used as a guide for what data segments were considered relevant to bring together potential clusters of patterned meaning. This meant, for instance, in considering research question one, prioritising and bringing together data segments specifically discussing conceptual definitions of *Movement* and discussing experiences of *Movement Loss.* In the case of research question two, it meant collating data segments from a wide range of participant experiences of accessing and navigating health care and social spaces and looking for very basic patterns within these groupings.

Reflective notes and diagramming were tools used during the process of pattern and meaning-making at this stage. Reflexivity was supported through the use of journaling practices.

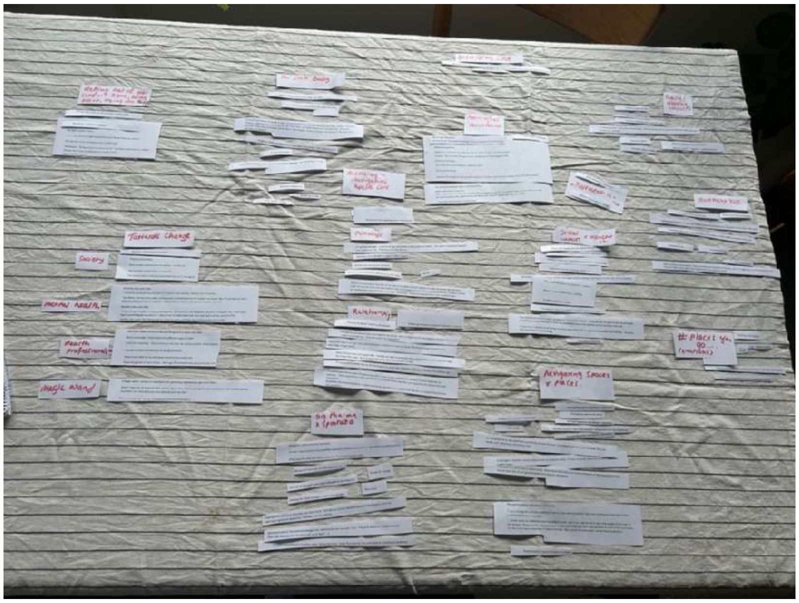


Figure 2. Early theme development**.** Participant coded data was printed, cut out and sorted into categories (indicated by the red headings). These categories were guided by what was considered subjectively important to the participants during the interviews, and the research questions. This picture shows early attempts to categorise the data codes generated from a single interview using visual mapping techniques.

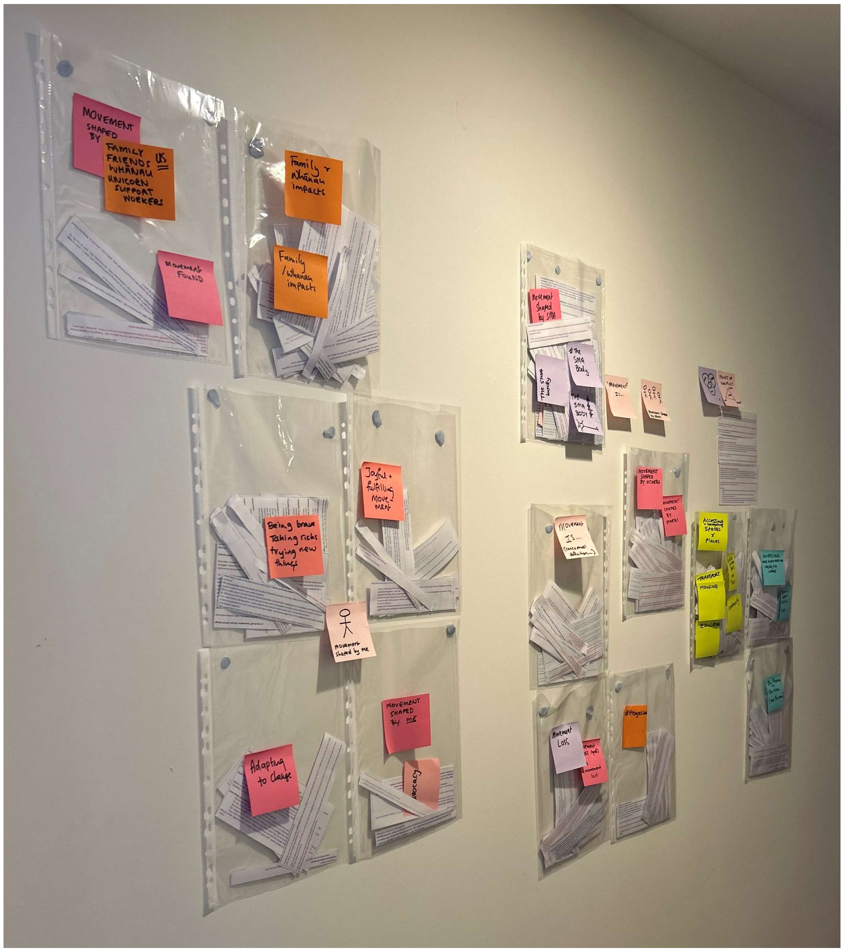


Figure 3. Initial theme development. As the sorting process progressed, understanding the relationships between larger concepts became important. This picture shows how the large number of codes generated from the interview data were sorted into categories for later review and refinement.

Phases 4 and 5: Refining, Defining and Naming Themes. After the process of bringing together initial themes, the next step was to review and refine these themes. This stage of reflexive thematic analysis is important as it allows themes to be shaped, clarified or rejected as the researcher works to ensure that the initial themes are reflective of the coded data, transcript data and the research questions (Terry et al., 2017). This is an important step in ensuring coherence in the lines of meaning being drawn between working datasets utilised by the researcher and making sure that the themes generated *are* reflective of participants' accounts and experiences (Terry et al., 2017).

In this project, the process of theme refinement, definition and naming themes was an iterative process that continued well into the process of writing the thematic analysis report and the drafting of the findings of this thesis. At each new iterative stage, there was an intention to shift thinking and meaning-making away from a "summative position" (where themes are essentially lists of codes and collated data) to an increasingly "interpretive position", where the final report tells a ‘story’ that is based on and about the collected data through pattern making and sense-making (Terry et al., 2017).

Figures 4, 5 and 6 are examples of thematic maps that were drawn during this process. Figure 4, an earlier iteration, bears similarities to my final response to question two in this report, but much of the supporting evidence remains very close to early data lists created during the coding process. Figures 5 and 6 reflect increasing deviation from these lists towards a more interpretive understanding of *Movement* and *Movement Loss* for study participants.

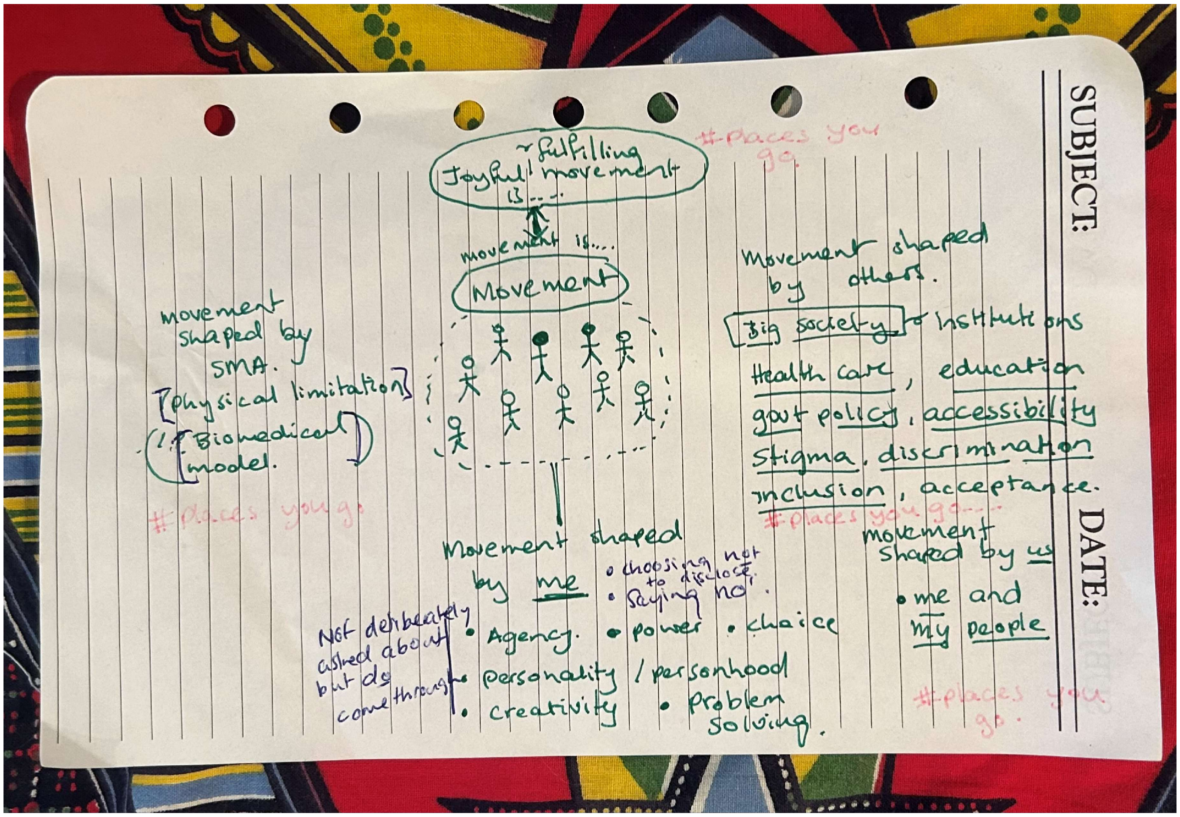


Figure 4. Example of a thematic map drawn early on in the refinement process. This thematic map was drawn up after initial data codes were collated and sorted as demonstrated above.

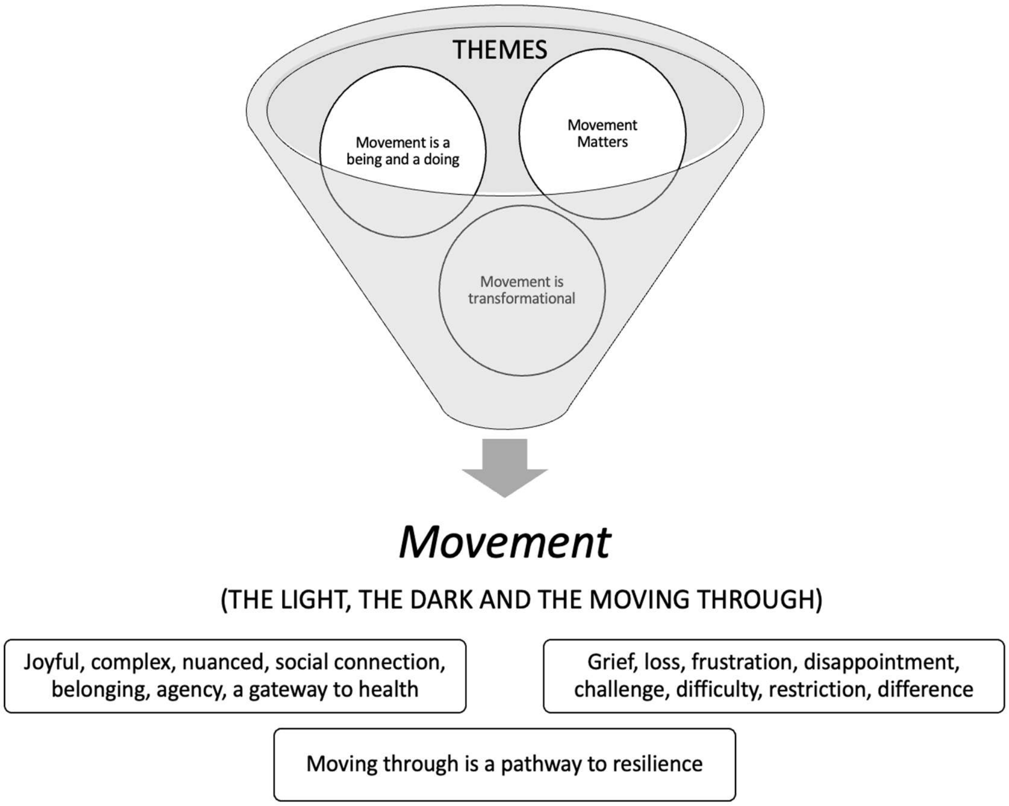


Figure 5. An example of a thematic map drawn later in the refinement process.

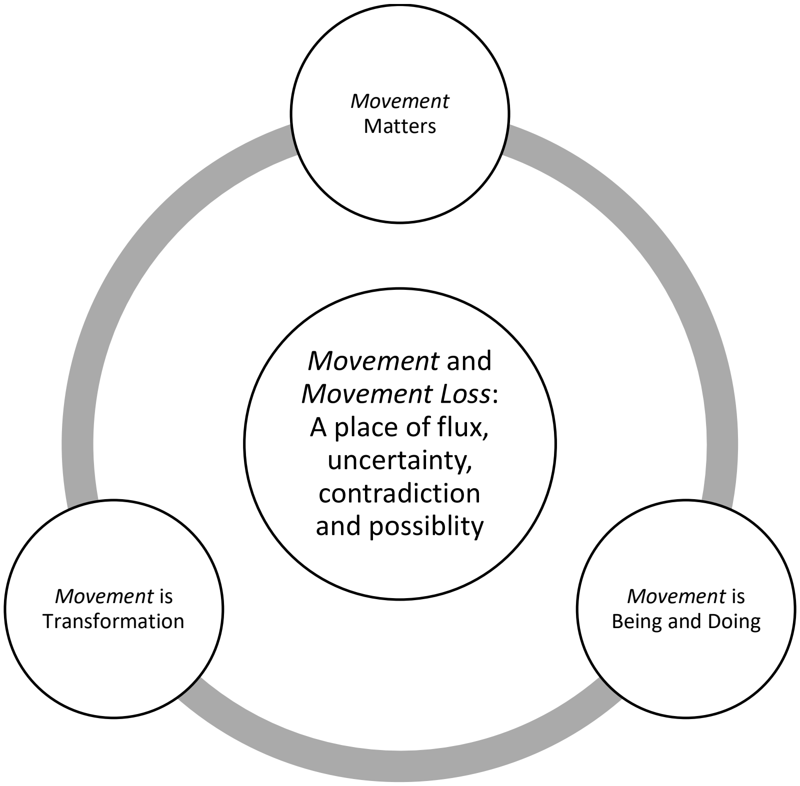


Figure 6. Refined (finalised) thematic map for *Movement* and *Movement Loss.*

Phase 6: Writing the Thematic Analysis Report. In reflexive thematic analysis, the writing process is considered a distinct and final period of focus and refinement, whereby the researcher draws together data, analysis and scholarly literature to answer their research questions (Terry et al., 2017). At this point, the focus of the researcher shifts again to consider their data not only from an analytical point of view but also in terms of the bigger picture of the overall project and its aims (Terry et al., 2017)**.**

In the case of this research, writing was completed in three stages. The first stage involved writing a report of the initial themes identified in the data and a list of coded data and quotes, which were grouped according to common topics. This enabled the researcher to identify links across the data while also being able to link findings back to original interview transcripts. This played an important role in ensuring coherence between interview transcripts, coded data and patterns and meaning being drawn by the researcher during analysis in Phases 4 & 5. This report was used to review the validity of early thematic maps (such as Figure 4) and consider alternative ways in which the data could be viewed that would enable a more interpretive position to be taken when writing the thesis.

The second stage of report writing began as sections of this thesis began to be drafted, reviewed and refined. This process refined my awareness of the research questions, the theoretical and methodological lens of the research, and what bringing together the two would mean for establishing and naming themes. The Findings section of this thesis reflects the final iteration of this process, which is detailed in the next chapter.

The third and last stage of writing involved writing the Discussion section of this thesis. This involved considering how the themes and concepts discussed in the Findings section related to the broader field of social constructivist research, critical disability research and critical rehabilitation research. In addressing the narrative taken in the writing of the Discussion, I also reflected upon my own clinical experiences as a physiotherapist and as an adult living with SMA in Aotearoa, NZ, and what I perceived to be the most important takeaway messages from the research to generate social change.

Chapter Summary

In this chapter, I have discussed the methodological and theoretical lens utilised in this study and have discussed the methods used to analyse participant data using Braun & Clarke’s (2022) six phase approach to reflexive thematic analysis. In the upcoming chapter, I will detail the findings that were generated through this process.

Findings

This chapter outlines the key themes and patterns of meaning identified across collated interviews that were brought forward through the process of reflexive thematic analysis. To do so, I first discuss the characteristics of the study participants and the interview process and how this met aspirations set out in the initial study design. I also discuss the rationale behind the decision to exclude data from the online survey from the final data set.

Following this, I provide a brief overview of the themes for both research questions and provide a conceptual framework for understanding. I then address research question one in depth by setting out core themes relating to the ways participants conceptualised *Movement* and *Movement Loss,* with supporting evidence from interviews. To address research question two, I highlight ways in which participants' experiences and interactions in health care and society influence how they described their experiences and understanding of *Movement.*

Finally, I discuss ways in which participants were able to resist dominant discourses/notions of *Movement* within societal and health discourse and the implications of doing so for these participants. In line with RTA, findings are drawn from themes across the participant interviews. Findings are supported in different ways in the reporting. Sometimes an illustrative direct quote is provided while in other places a descriptive summary was most appropriate.

Characteristics of Study Participants

While 11 responses to invitations to be interviewed for this research were received, I was only able to complete ten interviews due to time constraints in the data collection phase. The interviewed participants came from a range of geographic locations, including urban and rural regions within New Zealand, as well as several participants who were currently living abroad to receive treatment. As expected, participants utilised a range of ways of getting around their community and reflected a range of SMA types and functional presentations.

Ethnic diversity within the collated sample was limited, with eight participants identifying as New Zealand European, one as New Zealand Māori, and one other ethnicity. This occurred despite the decisions made in the study design, which looked to recruit potential Māori participants first (to make up to 50% representation within the sample) and to otherwise include a range of ethnicities. All participants chose to complete their interviews using an online platform (Teams/ Skype/ Zoom) rather than in-person at AUT North Campus. Four of the participants lived in one of the six major New Zealand urban centres (Auckland, Christchurch, Wellington, Hamilton, Tauranga, Lower Hutt, and Dunedin). Three participants resided outside these centres and were therefore classed as 'rural'. The majority of the participants were female (n=8), with only two male participants and no other gender identities. Ages ranged from 21 – 64 years, and most of the participants used a wheelchair for community mobility (n=7), with two walking and one using both a wheelchair and walking.

It will be noted that participant contributions are coded in the body of the text according to randomly allocated a letter from A to J (e.g., Participant A). I have also omitted identifiable data (such as names or places) from contributions, including the use of gendered pronouns. When discussing issues based on participant's age or ethnicity, I have aimed to do so in general terms only. These descriptions are deliberately cautious as the adult SMA community is small, potentially easily identifiable community in NZ.

Table 1. below provides summary details of the participants' demographics and characteristics. Background information was collected before interviews took place, and any amendments to the forms were discussed prior to or during the interview.

Characteristic	**Subgroup**	**Participants**
SMA type	Type 1	0
	Type 2	3
	Type 3	7
	Type 4	0
Community mobility	Walking only	2
	Wheelchair and Walking	1
	Wheelchair only	7
Ethnicity	New Zealand European	8
	New Zealand Māori	1
	Other	1
Gender Identity	Female	8
	Male	2
	Other	0
Age range	21–64 years	
	median age	36.6 years
Geographical location	New Zealand Urban	4
	New Zealand Rural	3
	Overseas	3
Interview format	In-person	0
	Online via video call	10

Table 1. Participant demographics.

Interview Processes

During interviews, participants were invited to discuss their experiences living and moving with SMA generally and were then invited to provide a conceptual definition of *Movement* that reflected their experience of *Movement* as opposed to generally agreed upon definitions provided by broader society.

Understandings of *Movement Loss* were gathered across interviews as a whole, where the participants felt comfortable sharing their experiences rather than explicitly being brought up or questioned by the interviewer. This decision was made early in the data collection phase as it became apparent that *Movement Loss* was an emotionally charged topic for many participants and associated with grief and/or past trauma experiences. The online platform of the interviews posed challenges in terms of picture, time delay and sound quality depending on the quality of the internet connection and had the potential to disrupt the ability of the interviewer to read and respond to verbal or non-verbal cues signalling a participant's discomfort in responding to a question. In light of this, priority was given to the process of building rapport and promoting an emotionally safe online environment for participants by allowing them the freedom to speak to topics and experiences that felt important and relevant to them. Interestingly, most participants continued to self-initiate discussion around *Movement Loss* as a core aspect of their experiences living and moving with SMA. It was this data that was used to discuss both *Movement* and *Movement Loss* in the findings outlined below. An overview of interview prompts used can be viewed in the appendix I.

Overview and Conceptual Framework of the Themes

The first research question aimed to examine how adults living with SMA conceptualised *Movement* and *Movement Loss*. My analysis of participant data found that participants tended to talk about *Movement* in three diverging ways. First, *Movement* was described as complex, joyful and nuanced. It was linked to positive social experiences such as connection and belonging. Participants felt they had agency and control over their lives, and *Movement* was a means by which opportunities to live good lives were opened up. Second, *Movement* was described as a place of grief and loss, frustration and disappointment. Here, both *Movement* and *Movement Loss* were marked by experiences of challenge, difficulty, restriction and social difference as participants attempted to conform to social normative standards and struggled when these options were not available to them. And third, moving through the challenges of *Movement Loss* was a pathway to resilience: Being able to maintain one's identity and adapt to change was a means by which participants were able to continue to live good lives despite experiences of *Movement Loss*.

Within these overarching descriptions, three themes relating to the conceptualisation of *Movement* and *Movement Loss* were identified. These themes were: 1) *Movement* matters, 2) *Movement* as 'being' and 'doing', and 3) *Movement* is a place of transformation.

Together, these themes painted a picture of *Movement* and *Movement Loss* as a place of flux, uncertainty, contradiction and possibility. A conceptual framework detailing how these descriptions and themes relate can be found in Figure 7 and Table 2.

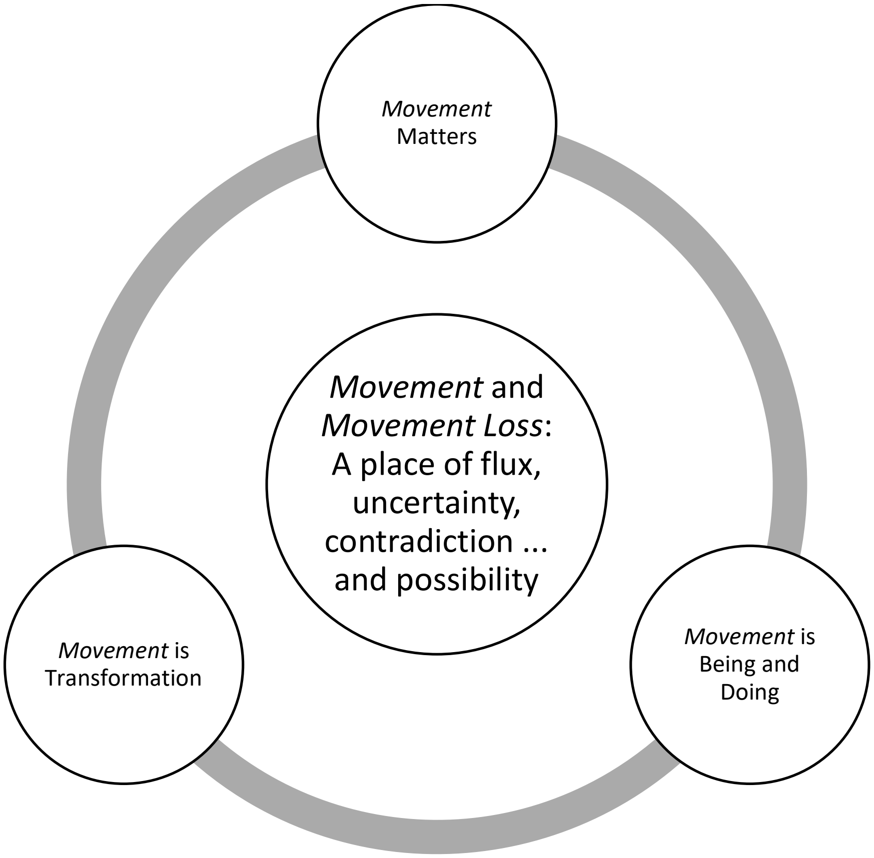


Figure 7. The concepts of *Movement* and *Movement Loss* as they relate to overarching themes

Theme One: ***Movement* Matters**	**Theme Two:** ***Movement* is Being and Doing**	**Theme Three:** ***Movement* is Transformation**
Movement is… complex, nuanced, rich, agency, control, connection, belonging		
Movement is important and valued. A taken for granted resource Movement is what makes one unique and links one to the broader SMA community *Movement* is independence *Movement* is freedom *Movement* is agency, intention, willpower, choice. *Movement* is a gateway to wholistic wellbeing	*Movement* is the ability to experience and do *Movement* is the act of 'being moved', of being 'done to' *Movement* is in 'moving in space' as well as 'in your body' *Movement* is having strategies for getting things done.	*Movement* is stimulation to the brain that disrupts *Movement* is transitional (e.g. across life stages) *Movement* is a moment-to-moment state of being *Movement* is a place of joy, fulfillment and release. Movement is a place of exploration and learning. Movement is a place curiosity, connection and belonging.
Movement is… Grief, loss, frustration, disappointment, challenge, difference, isolation		
Movement is invisible, unseen *Movement* is fortune, luck *Movement* is a marker of achievement *Movement* is tenuous, an uncertain future	*Movement* is 'strength' *Movement* is 'restricted' *Movement* is marked by a disconnect between what 'should' be possible and reality	*Movement* is marked by difference *Movement* is a 'dichotomy of being grateful for it and being scared of it.' *Movement* is a place of anxiety, distrust and conflicted identity
Movement Loss is…Grief, loss, frustration, disappointment, challenge, difference, isolation		
Movement loss affects all parts of you *Movement loss* is inevitable *Movement loss* is intolerable	*Movement Loss* is insidious, silent. *Movement loss* is deterioration *Movement loss* is a threat to life and livelihood	*Movement loss* is a barrier to joy. The threat of *Movement Loss* is just as impactful as loss itself. *Movement loss* is symbolic of something bigger that has been lost.
Moving through the challenges of *Movement Loss* is a pathway to resilience		
Movement Loss is a gateway to gratitude and meaning. *Movement Loss* is a gateway to acceptance. *Movement Loss* is a means by which one can gain clarity with one's values and act in ways to support those values. *Movement Loss* is a means by which you become closer to experiences of community and connection.		

Table 2. Representation of themes relating to *Movement* and *Movement Loss.*

The second research question looked to explore how conceptual understandings of *Movement* and *Movement Loss* were impacted by the NZ health system and society. To do this, I looked at instances where participants explicitly linked their understanding of *Movement* and*/*or *Movement Loss* to dominant discourses in health and society, *or* there appeared to be an implicit link based on the experiences they shared of accessing and navigating healthcare and society in general.

In health care settings, the influence of biomedical discourses on participants' understanding of *Movement* and *Movement Loss* was demonstrated when:

1. Participants provided conceptual definitions of *Movement* that conformed to and upheld the values of the biomedical discourses.

2. Participants reported interactions with the NZ health system or health care professionals shaped the messages they were receiving about *Movement* and/or *Movement Loss.*

3. The biomedical messaging participants received about *Movement* and/or *Movement Loss* when accessing or navigating health care was impactful on the participant (e.g. social, mental/emotional, physical, and spiritual well-being).

In the case of social settings more generally, the influence of broader social discourses on participants was demonstrated when:

1. Participants provided conceptual definitions of *Movement* that conformed to and upheld the values of broader social discourses (such ableism and neoliberalism)

2. Participants' experiences accessing and navigating spaces and places shaped the messages they were receiving about *Movement.*

3. Participants self-reported that their conceptual understanding of *Movement* had been "shaped by others"

4. The messages participants received about *Movement* or *Movement Loss* when accessing or navigating social spaces and places were impactful on the participant and/or their family (e.g. social, mental/emotional, physical, and spiritual well-being).

An additional diverging theme in the interviews was the sense amongst participants that *they* also could shape *Movement,* particularly when supported by trusted others - an *Inclusive Allied Community*. Factors such as one's attitude towards the changing SMA body, family culture, the inclusiveness of social spaces and communities as well as being able to draw upon one's strengths were important here. The degree to which one was able to resist or operate outside dominant notions of *Movement* had implications on the well-being of participants and the ease with which they were able to accept their diagnosis and the changes that come with it.

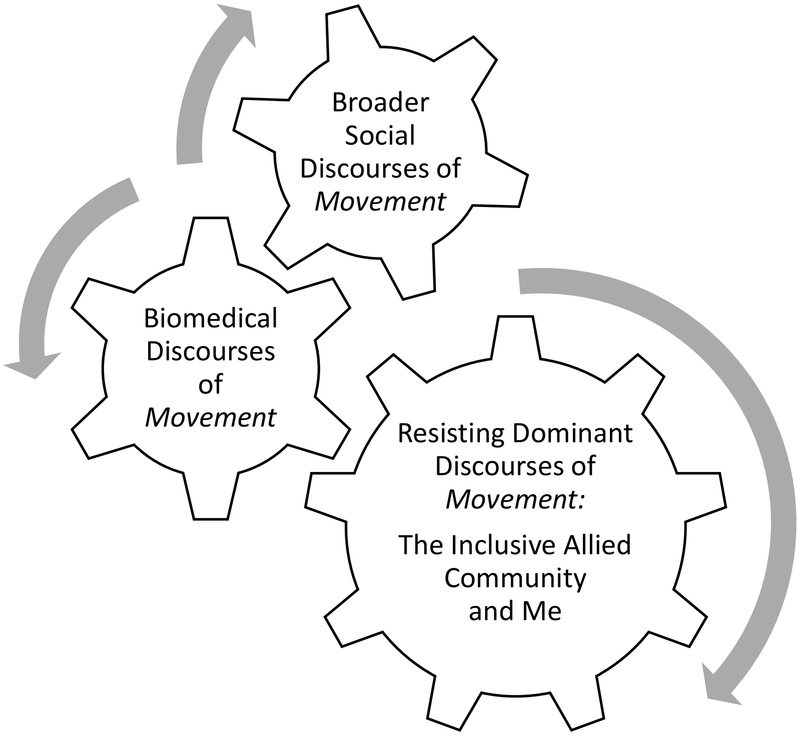


Figure 8. The key influences shaping *Movement are* biomedical discourses, broader social discourses, the Inclusive Allied Community and the Person.

Having provided a general overview of my overall approach to the data and research questions, the following sections of this chapter look to provide further detail and extracts from the interviews to illustrate this argument.

Conceptualisations of *Movement* and *Movement Loss*

Here, I address research question one by setting out core themes relating to the ways participants conceptualised *Movement* and *Movement Loss.*

Theme One: Movement Matters

The first theme, '*Movement* Matters', describes the idea that *Movement* is an important and valued experience for adults living with SMA even though participants often felt that the importance to them was often underestimated in healthcare settings or broader society. The theme is important because it draws to our attention that *Movement* and *Movement Loss* are constructs that 'matter' because they are linked to one’s ability to maintain and access other experiences such as dignity, independence, autonomy, self-determination, and health over the lifespan.

***Movement* is important.** *Movement* was unanimously viewed as an important and valued experience by participants. It was a gateway through which wholistic well-being could be reached, allowing the body to stretch itself out, be upright, stand, walk, build strength by engaging in sport or exercise, or support mental, spiritual and emotional well-being through engagement in meaningful activities, community or the environment. The individual characteristics of one’s *Movement* were what made one special and unique while also connected to the broader SMA community.

Movement was precious and often described as a scarce and unpredictable resource that was often taken for granted by society at large. Activities that might be considered relatively ‘simple’ or ‘routine’ to others— such as brushing one’s hair or teeth, getting up in the morning, or taking a shower— significantly impacted participant’s lives, particularly when those routines were disrupted in ways that often went unnoticed or unacknowledged. The experience of *Movement* in a body with SMA was described as arduous: “heavy” and “restrictive”, an experience akin to having “heavy sandbags” attached to one’s limbs or “being tied down”. Daily life was characterised by fluctuations in energy (power, endurance) and fatigue, which participants had to manage, plan or be responsive to as they went about their day. Moving in the SMA body was also punctuated by sensate experiences such as pain (or the unnerving absence of it), sudden loss of control (such as falls or when a muscle ‘gives way’ mid task), tightness and pressure, muscle twitches and tremors. Participants also often described the need to dedicate significant mental/cognitive effort to move, and it was common for participants to report utilising cognitive strategies (such as visualisation) that enabled them to move more effectively.

The concept of *Movement Loss* was also deemed significant by participants. The experience of diminishing physical ability impacted all parts of the individual: their identity, well-being and their ability to participate in social roles (e.g. as parents, partners, employees) and within society. The expectation of impending progressive loss also led participants to question their ability to *do* the things they wanted to do or be in the future. The uncertainty of what abilities might be lost, what adaptations might need to be made, or what experiences they might miss out on was a source of ongoing worry and distress for participants. Paradoxically, while the uncertainty of the future was acknowledged, participants often viewed *Movement Loss* as a stable, inevitable and unavoidable part of living with SMA, indicating a potential thought bias towards a downward trajectory of the condition.

The burden of living with the physical restrictions caused by SMA was also significant to participants because of the impact they had on one’s internal lived reality and the way they understood themselves and the world:

> SMA is a lot of physical things, but we are trapped inside the body the whole time, we don’t have a break, like ever, and you do that for years on end, and that’s going

> to, like, cause some serious pressure on your personality, your mood, your aspirations, how you… interact with the world, how you perceive the world heading towards you…
> (Participant C)

This highlights the fact that the physical manifestations of SMA are significant because of the way these 'physical realities' directly impact emotional and psychological well-being and quality of life.

***Movement* offers Agency, Freedom, Control and Autonomy.** A common view amongst participants was that *Movement* was important because of its ability to offer independence, freedom, agency, control and autonomy. For some individuals, *Movement* offered independence through the ability to complete physical tasks themselves and with ease, and these experiences positively impacted their mental well-being:

> *Movement* means I can do at least some things independently… I'm in a better state of mind when I'm able to… move my arms, like, brush my hair and, like, brush my teeth without getting exhausted.
> (Participant B)

The importance of exercising agency and control over one's environment led some parts of *Movement* to be considered more valuable than others. For example, Participant J, a wheelchair user, described the importance of being able to use their arms because of the freedom it gave them to be able to engage in artistic pursuits:

> I want to say some things are more important than the 'big things' for me, like... being able to do small movements [with my hands and arms]… they're, like, more important to me… because my legs, like, I can move them, but I can't walk. And I, I have something to *help* that, I have my wheelchair… it's, like, *dealt* with... But being able to move my arms? There's nothing that can really support that... that is the hard part.... Like, not being able to move my arms? Become too tired to do [art,] my favourite hobby? Like, you know, that's – that's bigger to me than being able to.... to *climb a ladder!*
> (Participant J)

Interestingly, even individuals living with milder physical manifestations of SMA continued to feel that their freedom, independence and ability to exercise control were under threat if they lost the ability to complete physical tasks in the future:

> *Movement* is incredibly important to me. Like, I want to keep doing what I'm doing, and I want to have as much freedom to, you know, be in control. And I know I'm lucky, I can stand— if I need to go to the toilet I can stand up and I can take myself, I don't need to wait for anybody, so it is, it is at this point in time, I'm not handcuffed, but I know that if I lose that movement I get more and more chained, because you're restricted and there's all sorts of things you can't— that you can't do…
> (Participant A)

For others, the physical abilities of their body were just one aspect of their experience and did not necessarily limit agency or independence:

> Obviously, I'm in a wheelchair. I can't do a few things. I can't lift my hands above my head… and things like that. Everything else is fine… SMA means I can't do a few things but… I can live an independent life.
> (Participant I)

Movement was not necessarily limited to the physical abilities of the body if one could exercise agency, willpower and intention in the world in other ways. Participants often described this in the context of intentionally setting habits or routines in which they built their lives, such as allocating regular time to swim, walk, or exercise. But agency, willpower and intention were also expressed through the intentional cultivation of supportive relationships (e.g. family, friendships, formal relationships with health care providers, support workers, employers and colleagues), which could support participants to do the things they needed and wanted to do. This suggests that *Movement* is something that can transcend the limits of the physical body when one has other means to self-determine, shape and manipulate the world around them:

> I'm a bit of a risk taker... I feel like I calculate risks quite well, and when I am having a tough time and I'm frustrated... it's like I want to run away from being stuck right here, like this [gestures to self]. So, I'm like, 'what big thing can I do that will drag me away from being so stuck?' yeah? Even if things aren't right, I'm like 'I don't care. I'm doing it' Even if I have like, major anxiety, I'm way out of my comfort zone, I would rather do anything rather than experience what I am experiencing right now... so *I like to throw myself into the fire.* Kind of like to just, you know, shake it up you know? Switch it up? …You know? Not too stale and stagnant...
> (Participant C)

Theme summary. *Movement* and *Movement Loss* 'mattered' to participants because of their perceived ability to enable independence, freedom, agency, and health over the life span. This conceptualisation was informed by participants' experiences of living and moving with SMA and the day-to-day challenges that it brought. It was also informed by participants' experiences of *Movement Loss*, which not only impacted physical ability but also perceived ability to participate in the social roles that were important to them.

Theme Two: Movement is 'Being and Doing'

The second theme, '*Movement* is being and doing', refers to the notion that *Movement* and *Movement Loss* are defined in large part by one's physical interaction with the world. In the context of the conceptualisation of *Movement* and *Movement Loss* put forward in this framework, the theme is significant because it locates these concepts as being subject to the laws and forces of the physical world. One's embodied experience of *Movement* and *Movement Loss* cannot be removed from physical reality or one's interactions in physical space and time.

***Movement* is Active.** It involves the physical body— and expands beyond it. On a superficial level, *Movement* was defined by participants in terms of one's physical ability to 'experience' and 'do'. It was a way in which one was able to interact or engage with, shape or manipulate the world. This often involved active engagement in activities or hobbies that were meaningful to the person, such as work, child care, sport, exercise, creative or recreational pursuits or participating socially in their community:

> For me it is really important to go swimming and be out of my chair… and even though I think visually to people, it looks like I'm not doing anything much in the water, because I can't swim… I can walk. So, I walk up and down, and I try to keep that movement going and… I can stand in water and… to me it's so important to stretch the body out…
> (Participant F)

While engaging in these activities was important to participants, they often reflected upon the fact that much of their movement or efforts to create/generate it went unseen or invisible to the naked eye:

> So, I'm just trying to keep... everything moving. So that's just passive exercise really? But because I don't have much – any movement in my legs, so, but I'm.... pushing and pulling, you know what I mean? With my muscles? Even though there's not sort of, evidence of it!
> (Participant D)

Because of this, there was a sense amongst participants that their *Movement* was underestimated and undervalued within health care and, more broadly, within society, particularly as they often failed to meet or achieve normative movement standards.

Interestingly, among participants with greater physical restrictions due to their SMA, the 'being and doing' and 'active' components of *Movement* expanded to include acts of 'being moved' or 'being done to' in cases where external supports (caregivers, family members) were needed to support movement or experiences to occur. This is exemplified in the following quote from Participant C:

> My parents are amazing, and they took me *everywhere* when I was a kid, done everything... they strapped me to this, strapped me to that... took me with them, chucked me out in the ocean... Everything. So, I experienced everything you could experience, plus probably a lot more than some kids, yeah.

This finding is interesting because it shifts the 'being and doing' of *Movement* from an individual pursuit into something that is held by a collective and supported by relationships of inter-dependence between people. *Movement* transcends the traditional boundaries between 'body' and ‘non-body’ into the world of social connection. It is the many components of the collective that enables *Movement* of the whole.

Where close family members, friends and trusted support workers were seen to support *Movement* in positive ways, participants also reported experiences of vulnerability when they were dependent on others — particularly strangers — to have their needs met:

> We're at the mercy of what they [carers] can give us... we take what we can get sometimes. Sometimes we get treated so badly... But we just go, ‘ok, well, as long as they take me to the toilet, I’ll put up with this behaviour’ — where no one would put up with that behaviour in the real world… we just go, ‘you know what? I need to go to the toilet. I need to have a shower. So, I’m just going to suck it up, just so that I can be... I can get what I need from that person.’ So that is, like, *the* number *one* struggle.
> (Participant G)

Such experiences highlighted the cost of *Movement Loss* to participants and the potential for physical vulnerability to seep into social realities.

Continuing with the notion that *Movement* can expand beyond the physical body, it was interesting to see that *Movement* was also conceptualised as “moving about in space as well as in your body”. This brought up issues of physical accessibility as participants navigated their lives in society more broadly. This included participants’ feelings of restriction in spaces and places where “typical” movement was assumed, preventing them from accessing facilities, or experiences:

> [University] was really bad…. it’s, like, hard to talk about… I was running into so many problems, mainly to do with accessibility that I was stressing so much about that, that I could barely focus on my work. Like, when it came to my classes, again, obviously, no wheelchair seatings where I could, you know, park in so I was forced to be in the middle of this stair at the bottom. And there was this massive screen in front so I’m like this (participant tilts their head upwards so their neck is fully extended), for like, three hours sometimes. It was so *horrible*. Like, I would be exhausted. I would have headaches… there was only one [accessible] computer [in the library] that had the adjustable desk, but most of the time it wasn’t operating…
> (Participant B)
>
> I stayed at a hotel… that advertised a disabled room, and we went in and the first thing we saw was the bath on the floor. So! A disabled unit with a bath! (laughs) Ah! yeah! I actually said something to them, ‘cause I said ‘you can’t advertise this room as for disabled’ – that’s all there was, was a bath! So, I said ‘you can't be advertising this as disabled because you know, it’s not!’ We were only there for a night or something, but I thought it's very *easy* to say. You know, they’re like ‘oh, but we’ve got a ramp at the door’ but that doesn't make it a ‘disabled unit’.
> (Participant D)

Interestingly, physical accessibility was also an issue for participants with milder forms of SMA, traditionally classified as more ‘able’:

> You’re *constantly...* you’re *constantly,* like, *aware*... I work in the corporate space and so often the receptionist will be like ‘take a seat’, but I'll look at that seat and I’ll

> go ‘can I get out of that?!’... or you go to like, you know, a dinner? You know there’s a couple of times where, like my legs have like, you know, sort of made me drop and I’m just like ‘oh gawd!’ that’s so *mortifying! …* most people could probably catch – catch themselves... But, you know, I, like, I *can’t,* when that happens… (Participant A)

Contrary to what one might expect, these findings show that *Movement* in social spaces and places present challenges for adults living with SMA across the spectrum of physical ability, albeit in different ways. This would suggest that SMA is impactful on one’s understanding of *Movement* and *Movement Loss* regardless of the ‘objective’ level of physical limitation experienced subsequent to the condition.

The ‘Being and Doing’ of *Movement Loss*. When considering *Movement* in context of their physical interactions in the world, participants conceptualised their bodies as ‘restricted’ and ‘lacking strength’. There were feelings of disconnect between what their bodies rationally ‘should’ be able to achieve and their body’s reality. At times, this was highlighted by things like the difference in physical function between one’s self and one’s peers or feeling the desire to raise one’s arms expressively during a conversation— only realising later that this is not physically possible. In other cases, participants reported feelings of isolation, disruption and dislocation from their body as it changed in ways beyond their control:

> I feel like I’m just a head at times… and everything below my head, I’m like, ‘what the *heck* is going on?’... Like, it’s really an out of body experience… my body is not my own… like, I don’t *identify*— it took a long time for me to connect to my mind with my body… it’s… not having control over what is going on! How my body’s changing… It took me a long time to accept my body for what it is… it’s a hard one… to learn to love the body that you’re in. I think most people struggle with that… I can’t change what’s going on. I can’t go to the gym and fix this. (Participant G)

This quote highlights the ongoing challenge of integrating the ‘doing and being’ of moving with SMA, particularly when that involves physical changes that are not within your power to control.

Participants’ understandings of *Movement Loss* were often related to SMA’s insidious and silent ability to impact life and livelihood over time. Alongside increased social vulnerability, *Movement Loss* brought with it increased susceptibility to health issues requiring medical intervention, ongoing monitoring, or, in severe cases premature death. Participants were often highly aware of their medical vulnerability, and this often led them to deeply consider their options regarding symptom management and the uptake of lifestyle interventions to manage their SMA.

While medical vulnerability was viewed as important, the components of *Movement Loss* perhaps most keenly felt by participants were the loss of hobbies and activities that were joyful or meaningful to them and contributed towards their sense of self and identity:

> I used to do photography…I actually saved a lot of money to buy a really professional, proper camera, and then I started deteriorating and I couldn't use that camera any more. And that made me super depressed... even now, I just don't see myself returning back to photography because it's the triggering thing for me... because it just represents how…. Cause that was my only outlet at the time, my only creative outlet, and once I lost that ability I feel like… I lost my only ability to, like, express myself.
> (Participant B)
>
> I played guitar until I was like… I don't know?12?... I can't play guitar [now] because I actually can't strum the chords. It got to the point where I actually had to sell my guitar…it's, like… I know *how* to do it, but I *can't* actually do it?... I wish I could just take that up and play it because I know *how* to and I *love*— and I *love*— I *love* playing guitar… but I just *cant*.
> (Participant J)

Dealing with the physical realities of *Movement Loss* had an emotional cost. Participants expressed feelings of frustration, disappointment, grief, loss and social isolation as they navigated these experiences.

Theme summary. The theme '*Movement* is being and doing', highlights that while *Movement* and *Movement Loss* are defined physical interactions with the world. Counterintuitively, this analysis found that while physical capabilities were important, understandings of *Movement* were able to expand beyond the limits of the body to include interactions and relationships between others and the environment.

Theme Three: Movement is a Place of Transformation

The third theme, '*Movement* is a place of transformation', refers to the notion that *Movement* in and of itself can change, shift, modify, alter, shape, and transform us. This theme highlights that *Movement* and *Movement Loss* are not universally good or universally bad: Moving with SMA involves acknowledging the existence of uncertainty, flux, contradiction and the possibility of failure. While experiences of *Movement Loss* have the potential to negatively impact people's lives, this is not necessarily the case. Experiences of *Loss* also can open up new opportunities, possibilities and ways of being in the world.

***Movement* opens opportunities**. *Movement* is a place of transformation refers to the notion that *Movement* in and of itself can change, shift, modify, alter, reshape, and transform us. This metamorphosis has the capacity to enrich life as *Movement* opens opportunities to experience joy, fulfillment, release, exploration, and learning, connection and belonging with others.

During interviews, participants were asked to reflect upon activities that they enjoyed or found meaningful despite their SMA diagnosis. While responses to this provocation were varied, and there was acknowledgement amongst some participants that *Movement Loss* associated with SMA had made it increasingly difficult/challenging to find activities they found fulfilling or brought them joy, all participants were able to provide several examples of such activities, and a collation of these activities can be found in Appendix O. Interestingly when discussing these activities, many participants appeared to be liberated from the ‘weight’ of their diagnosis, and there was a sense of openness and possibility towards engaging in the world which might have previously been challenging:

> You know, I actually, you know, I don’t… I don’t know if there is anything that doesn’t, you know, bring me joy?
> (Participant A)

Another interesting point here was the way in which technology, relationships with others and the environment often integrated to enhance opportunities available for participants:

> …and cooking, I love cooking! So, I do a lot of movement in my left arm because I’m cooking a lot. My wheelchair can elevate which is awesome! So, it can go up to the stove top level, and I’m like, *stirring the pot*! [makes enthusiastic stirring motion to camera with left arm] doing *stir fries*! So, I think that’s helped with my left arm strength!
> (Participant G)

Participant G goes on to detail how their relationship with their Occupational Therapist (OT) enabled this experience through the addition of a height adjustment function on their wheelchair. Such examples highlight not only how *Movement* opens up opportunities to engage in meaningful activities, but also draws attention to the many factors and relationships that come together for those *Movement* opportunities to come to fruition.

***Movement* is Moment-to-Moment State of Being.** In addition to being transformative in its ability to open up opportunities, *Movement* was also referred to by participants in terms of its ability to bring one’s attention into the moment, into the sensate experiences of the body or one’s connection with the world. Participants cited experiences such as music, art, the feeling of weightlessness when swimming, feelings of connection and belonging when going out with friends or the challenge and focus when engaging in sport. *Movement* offered a means by which the daily challenges and frustrations of the physical body could be transcended, bringing renewed vitality to the experience of living. This is aptly expressed in this quote from Participant C:

> *Movement…* makes you feel more alive and human and individual… [it is] stimulation to the brain...which can help disrupt the... monotony and the repetition of being *so* disabled.
> (Participant C)

The moment-to-moment state of being and moving with SMA was also highlighted as participants reflected upon their lives as a series of transitions over time. For example, participants reflected on the impacts of transitioning between childhood and adulthood, changes the body experienced over time, the flux and flow of how their bodies responded to loading in daily tasks. ‘Moving well’ with SMA required one to be able to recognise and engage with these fluctuations, knowing that ‘SMA leads to *Movement Loss’* — while also being open-minded towards the opportunities and experiences that remained possible.

Transformative emotions in response to *Movement* and *Movement Loss.* The notions of *Movement* and *Movement Loss* were also transformative in the sense that they had the capacity to drive or elicit emotional responses from participants. On the one hand, *Movement* had the potential to transport participants to a range of positive experiences and emotions such as joy, fulfillment, triumph and connection.

It also, however, could transport participants to a place of fear and anxiety, a place of distrust towards one's body, and conflicted identity. Such responses are highlighted in the following quotes as participants looked to maintain their engagement in activities that were meaningful to them while the physical limits of their bodies made this challenging to achieve.

Participant H expresses fear and anxiety about mobility fatigue:

> I get a lot of anxiety about mobility fatigue. This fear of humiliation, of falling is something I've always had and I've been really trying to work past it because it would be so much easier to be disabled, if I didn't care what people thought, um, so I'm working on that…

Participant A expresses conflict between the type of person they perceive themselves to be— and the physical limits of their body:

> …I'm such a sporty person and I love sport… And I can't – I can't *do* a lot of that sort of stuff… [it's as if] my *brain* is like 'I'm this kind of person' but my *body* is like 'No, actually, you're *this*! You're *this* kind of person'

Experiences of *Movement Loss* and disease progression were similarly transformative, as participants lost access to activities they once enjoyed, or lived with the ongoing threat disease progression:

> …when you've lost [the ability to eat and drink], that is probably the most difficult thing I've had to come to terms with. I can't even – I can't really explain to you what the brain does when one day you're eating and drinking to next – Nothing. It's like your brain goes into... a panic. Like, you're supposed to eat to survive, but you're not eating... I've even been diagnosed with PTSD from that time because of like this constant anxiety, the panic... like... and when you take away the pleasure from *tasting*. 'Cause taste actually contributes a lot of, um, joy into your day, so to take that away as well... uh... it's the worst.
> (Participant C)

Interestingly, while the challenges of living with *Movement Loss* were impactful and long lasting, the ability to 'move through' these challenges was unanimously viewed as a pathway towards resilience. While *Movement Loss* was a place of isolation, frustration, disappointment, difference and grief, it was also a gateway though which participants were able to find gratitude, meaning, acceptance, gain clarity about their values and learn to act in ways that supported those values. Experience of *Movement Loss* also could offer participants with opportunities to experience community, connection and belonging as they navigated the physical challenges of living with SMA:

> …I feel like… me having— yeah, having a good mindset and being able to *accept*, you know… the '*having to adapt continuously'* is something that has helped my health. Like, I'll just have to learn that everything I'll have to adapt to… coming to terms with that has helped me a lot. Yeah.
> (Participant B)

> Living a good life with SMA...[means] focusing on the things that you can do. Acknowledging the things that you can't do – cause I don't want to say don't think about it, because... your gonna think about it. Hey, I can't brush my hair any more... and it's like grief over losing abilities, and we *have* to acknowledge this… you can be sad about it, and grief is a process… [but now] let's focus on what we can do. Because for me personally, I like to keep going and not be stuck in that negative mindset, cause… if I don't organise my cares, organise this, this and this, no one is going to do it for me. I have to do those things in order to just continue, like, living... So, I have to switch on, put a smile on my face and just get on with it, right? Um... so that's what it means to me I guess, to 'live a good life' is like, focus on the good, acknowledge the bad, its ok to grieve... but get out of that. Yeah, don't get stuck in that. That's what I would say.
> (Participant G)

These responses highlight the need to straddle paradox and uncertainty when engaging with *Movement* and *Movement Loss*. It also suggests that engaging positively with the fluidity, flux and uncertainty of SMA was necessary for growth after diagnosis. This finding is supported by this quote by Participant H, reflecting on their experience of being diagnosed with SMA, and the advice they would give others in hindsight:

> I'm not sure I believe this- if someone had told me [at diagnosis], but I think to say 'things are going to look very different, and that's going to be ok'… because it was so scary to… even now it's scary to think 'this is how I wanted to live my life, and this is how I have to live my life. I've found that – that push pull is quite scary… just so: "It's going to look different… but you're going to grow and learn and change with it, and there will be a place in society for you, we just have to help you find that"
> (Participant H)

Theme Summary. This theme is important in understanding *Movement, Movement Loss* and how these concepts are conceptualized by New Zealand adults living with SMA. This is because it highlights that *Movement* and *Movement Loss* are not universally good or universally bad: Moving with SMA involves acknowledging the existence of uncertainty, flux, contradiction and the possibility of failure. While experiences of *Movement Loss* have the potential to negatively impact people's lives, this is not necessarily the case. Experiences of *Loss* also can open up new opportunities, possibilities and ways of being in the world.

Section Summary

Three overarching themes were identified that were able to capture the ways participants conceptualised *Movement* and *Movement loss*: *Movement* Matters, *Movement* is Being and Doing and *Movement* is a place of Transformation. These themes identified *Movement* as an experience that was meaningful and valued by participants, an experience that was situated in the 'being' and 'doing' of the body but also expanded beyond it. *Movement* was transformative for one's identity, and mental, physical, emotional and spiritual well-being.

These results illustrate the complex, varied and nuanced relationships adults living with SMA have with *Movement* and *Movement Loss* and the potential challenges faced by participants as they navigate the fluctuation and uncertainty of associated with the SMA body. Interestingly, despite the physical challenges of living with SMA, participants continued to live rich *Movement* lives and remained open to the possibilities that *Movement* could offer.

Influences on the Social Construction of *Movement*

Here, I address research question two by exploring how participants' experiences and interactions in health care and society influence how they described their experiences and understandings of *Movement* and *Movement Loss*.

The Influence of Biomedical Discourses on Participants' Understanding of Movement

Definitions of *Movement* Conformed to Values of the Biomedical Discourse. The conceptual definitions of *Movement* provided by several participants linked '*Movement'* to their experiences in medical and rehabilitation contexts. For example, several participants identified *Movement* as 'exercise' that one might complete as part of a therapeutic rehabilitation programme prescribed by a physiotherapist or occupational therapist.

Participant G describes 'what *Movement* means':

> So, every night before I go to sleep, I do a series of stretches and some exercises with my support workers. So, stretching— um, just pushing my legs down... and then… bending the knee up and down… a quick squeeze squeeze squeeze of my legs, up and down my legs to get the circulation going. And then we do stretches on my arms. So that's very basic, and it takes 10 mins... I do that before I sleep and when I wake up in the morning before I get out of bed… In terms of *Movement*… I'm currently researching what other movements I can do to help with my core... that's work in progress... at the moment I don't know what exercises I *should* be doing, but I'd like to do more.

Participant I describes 'what *Movement* means' in terms of priorities for rehabilitation:

> ...obviously head movement is really important, keeping that stable. Arm movement is good as well. Obviously, in my opinion like leg movement and things [is] a bit

> harder to work on… in my life, I focus more on my upper body than my lower body, um, just cause that's what I – what I think would help me in the future, would be having a stronger upper body than lower body.

These definitions identify *Movement* as a practice of stretching and strengthening the body, which requires prioritisation and long-term engagement for preserving function. These understandings of *Movement* also appeared to be layered with moral undertones often employed within biomedicine and rehabilitation: that exercise is something one '*should'* do and be continuously invested in if one wants to mitigate the risk of progressive *Movement Loss* associated with SMA.

Conceptual understandings of *Movement* articulated by participants also conformed to and upheld biomedical discourses in the way several participants linked their understanding of *Movement* to disease progression and viewed their bodies through a lens of reductionism. By this, I refer to medicinal reductionism, which is concerned with the body's systems and structures rather than the person as a whole (Nicholls & Vieira, 2022).

For example, for some participants, *Movement* was defined by features or characteristics they perceived themselves to be lacking and the experience of *Movement Loss* over time:

> Movement to me has connotations of like, fluidity, like gentle flow... that sort of... action...which I don't really have… maybe I did in the *past,* but... everything [now is] a bit more *rigid* and *stuck* and... *not exactly where it should be…* my movement is quite *limited* unless I'm in the pool…I don't sort of move around very much so,... Movement for me is quite... *restrictive* really.
> (Participant D)

Medicinal reductionism was also expressed more generally across participants as they described their experience of moving in a body with SMA by referring to the clinical features of the condition. This included features such as their perceived level of impairment, symptom severity, rate of disease progression, or the age at which they experienced particular shifts in mobility and function (e.g. transitioning to using a wheelchair, scoliosis surgery). During this process, participants often drew comparisons between themselves and others living with SMA, considering, for example, how 'strong' they were for their type of SMA and how far they perceived themselves to be along the path of progression.

Many participants were well informed of the pathophysiological underpinnings of SMA, and they used this language to describe their experience of *Movement.* Several participants described their experience of *Movement* as 'restricted' *because* of muscle weakness and a 'lack of strength', putting forward the idea that *Movement* challenges experienced in SMA were reducible to *this* critical functional impairment. These understandings mirror accounts of the SMA body identified in clinical diagnostic frameworks, which identify pathological features such as the deterioration of anterior horn cells and muscle atrophy as causes for movement impairment in SMA.

Alongside utilising measures of clinical features to aid the description of SMA, some participants utilised biomechanical metaphors to describe their experience of their body and *Movement:*

> I think of my body as a machine, and I need to… um, take care of this machine in order for it to be running at optimal… speeds! [laughs] And, and so, for me, I've decided 'ok, if I want to do these things in life, if I want to keep working full time— a job that I love… If I want to keep travelling, if I want to keep living my life the way I have been living, then I need to take better care of myself, I need to learn the triggers that will lead me to… sickness?'... So, in terms of my diet, my exercise, just health and wellbeing, just all of it needs to be considered every single day… and I cannot make a mistake. If I make a mistake anywhere along that chain, um, then of course I pay for it.
> (Participant G)

The use of this metaphor highlights the participant's awareness of the cause-and-effect relationship between daily actions, habits, routines and the physical functions of the body. There is an assumption that the triggers to sickness can be learned and mitigated through lifestyle factors but that there is little margin for error if the status quo was to be maintained – like maintaining 'the machine'.

Healthcare Access and Interactions Shape the Messages being Received about *Movement.*

Healthcare Access. Healthcare access avenues, processes and procedures indirectly impacted messages participants received about *Movement*. Healthcare access was an issue that was considered to impact not only the adult SMA community but the NZ disabled community at large. Participants and their families and whānau were required to navigate multiple complex systems to receive the funding and care they needed. Stringent rules around what equipment could be publicly funded and a lack of transparency around alternative funding avenues meant that equipment enabling physical access or assistance with the maintenance of their condition often had to be co- or self-fund. The stress and uncertainty associated with navigating complex processes significantly impacted participants and their families/whānau, often leaving them feeling frustrated and exhausted.

Participants reported a range of barriers to healthcare services or funding. At times, services were not offered at all, and they described instances where access to care was withdrawn or declined due to resource shortages. Participants noted that public health services were often only provided once symptoms had met a severity threshold. This left little or no scope for preventative management, such as preventative physiotherapy to manage the symptoms of their SMA.

When care was able to be accessed, quality of care was insufficient to meet the participant's needs. The funding of disability support hours was a frequently cited example of this, where there was a shortfall between the number of hours required by participants and the number that they were able to get funding for. The result of this shortfall was that family, friends and whānau were often needed to fill this gap, or additional disability support hours had to be self-funded, placing additional responsibility on participants to have enough paid work to fund the deficit or rely on family/whānau to meet this need.

Several participants reported experiencing declining healthcare access, resourcing and continuity of care for as they aged. This was most notable in the transition between childhood and adult services as participants moved from well-funded and resourced paediatric services to adult neurological services. For example, several participants described that as children, they and their families/whānau had built longstanding therapeutic relationships with their care team, and that their physical function was routinely monitored and supported through regular neurological reviews and respiratory checkups. As they became adults, access to these same services became increasingly disrupted (with frequently changing neurologists, for example), declined or stopped altogether. One participant described that they had not been seen for neurological review in 10 years and had recently been told that their scheduled review had been cancelled. Another participant described that they had never been reviewed by respiratory services as an adult despite living with respiratory compromise. Participants in their 20s also described the challenge of diminishing access to funding for supportive equipment while also being faced with the challenges of transitioning to living independently within the community.

Participants reported that the health problems they faced because of their SMA didn't just 'get better' or 'go away' when they turned 18, yet they received vastly less support. They experienced feelings of frustration and isolation as they were confronted with managing the continuing disease processes while the support provided through the health system for monitoring and managing their symptoms fell away. Participants with milder SMA phenotypes diagnosed in adulthood were also affected. While they might have been able to 'get by' with relatively few health resources in early adulthood, several found that their needs increased as they entered their 40s and 50s but they lacked the health support systems to support them at this stage. These findings highlight the need to consider health resourcing for SMA across the lifespan.

Contrary to popular belief of better resourcing for traumatic injuries, which receive funding under NZ's ACC funding scheme, participants living with SMA but also recovering from traumatic injury reported significant shortfalls in the ACC system to meet their acute health needs. This suggests a need to address healthcare resourcing under both systems if healthcare needs are to be met.

The continued lack of access to novel pharmaceutical treatments for adults living with SMA in NZ was a significant issue for participants. Three participants had left NZ to receive treatment overseas, but all other participants had either been involved in advocacy campaigns or were aware of these campaigns. While participants acknowledged the high cost of pharmaceutical treatments as a contributing factor towards lack of access, they also identified the absence of treatment as a human-rights issue. Participants who had moved overseas to receive care had done so for a range of reasons, including rapidly deteriorating physical or mental health and/or as a means of mitigating the risk of deterioration over the long term, and supporting their family/whānau to live quality lives.

Some areas of accessing and navigating healthcare services were seen as positive. For example:

- Paediatric services were seen to be well-resourced and supportive, particularly by younger members of the study cohort.
- Adult respiratory services were considered very supportive and helpful for those requiring ongoing respiratory management and were highly spoken of by participants who engaged in these services. Inconsistency in access to these services was noted depending on the geographical location in which a participant lived.
- Provision of care through private avenues was often more timely, and participants expressed greater satisfaction with these services.
- When care was provided that utilised more ‘mainstream’ specialist pathways – such as orthopedics or respiratory care – care was well received.

Issues of healthcare access were impactful on the social construction of *Movement* and *Movement Loss* by participants because of how access became an indicator of one’s ‘value’ and ‘worth’ to society. This is demonstrated by Participant J and Participant E as they reflect on the impact of not having access to pharmaceuticals such as Spinraza and Risdiplam:

> I just...feel like I’ve been waiting for something my entire life…We went to parliament when I was like, seventeen?... It just feels like it's all gone to, like, you know, waste? I’m still sitting here waiting, and I’ve just missed like the cut off… It’s just... I want to… be *worth* it…in the end.
> (Participant J)
>
> Why aren’t over 18s as important as under 18s?... because there are only a few of us... I know [Spinraza is] not a cure… I just don’t… I don’t know how you can just kind of say “Ok, under 18s are, you know? More ‘viable’ than over 18s.”
> (Participant E)

Healthcare Relationships. Participants reported challenges with interpersonal relationships in healthcare settings as they attempted to have their needs met. Challenges arose when participants’ bodies were objectified without consideration of the impact this process had on the person and their family/whānau. Instances of objectification included during the clinical assessment process (e.g. being “pummeled” by doctors to find a knee jerk reflex), the process of diagnosis (being reduced to a label and a prognosis) and the teaching of medical students (e.g. considered a “guinea pig” of a new type of operation, or an example of a “problem to be solved”).

Participants also reported instances where clinicians had held unhelpful beliefs about SMA, which then impacted the way their condition was subsequently understood, talked about and acted upon. For example, when clinicians considered SMA only as a ‘chronic progressive’ disease, this impacted the treatment options that were offered:

> Like, rather than give us lung exercises they [health professionals] just tell us that ‘you probably will need a ventilator to sleep with’ and it’s like, [with sarcasm] ‘well.... how about we try the lung exercises?’ — you know the things that [we can do], or whatever! It’s that— I think there is that kind of whole ideology of ‘oh, it’s a... a ‘degenerative disease’ and so it’s just degenerating. And I think that calls back to my um point at the beginning with, you know, doctors don’t always just look at you just as a [person], they just look at you as ‘oh you’re degenerating and how can I just give you a comfortable life?’ They’re not really worried about.... anything else… I’m looking at a *healthy life!*... It’s, it’s a different perspective!
> (Participant F)
>
> What I found a battle was that there has never been that feeling of being proactive. Like I remember asking ‘you know, can I get a referral for, um, some physical therapy, you know, to keep my muscles as strong as they possibly can be. I want to see someone that’s going to understand, you know, how my body works. And then being told ‘well, there’s no point because once the message has stopped going through, they’re not – they’re not going to work’
> (Participant A)

These interactions highlight instances where alternative, ‘active’ treatment options supporting *Movement* for participants were ‘shut down’ because of the assumption that progression was inevitable and that efforts to maintain or manage symptoms were futile. This left participants feeling lost and disempowered in their efforts to preserve *Movement* —or simply to move in ways which were meaningful and safe for them.

Some healthcare interactions were seen as positive by participants. Participants often reported feelings of comfort and safety when they knew they were going to be seen by someone who knew about their condition and who was able to give them appropriate advice and help. Participants often had trusted health professionals with whom they had long-term relationships and returned to because they were knowledgeable about SMA, their past medical history, appropriate medications, and had therapeutic partnerships whereby management plans and advice could be openly discussed. Participants expressed most satisfaction when they felt supported, that their condition was being managed proactively and that while it was not possible to change the SMA diagnosis, efforts to mitigate it were in place.

Individual clinicians were viewed by participants as being able to play a fundamental role in supporting participants to navigate the complexity of the health system. These clinicians came from a broad range of medical and allied health professions (including GPs, neurologists, nurses, physiotherapists, occupational therapists, exercise physiologists, ENT specialists, counsellors, and psychologists). The clear distinction here was that participants located these clinicians as ‘allies’ within the challenges of managing their condition and the broader challenges of navigating a complex health system that was inherently stacked against them. Clinician allies frequently demonstrated active listening skills, believed participants’ accounts of what they needed and were able to provide meaningful interventions to address this were valued by participants. Interestingly, clinicians with lived experience of ‘disability’ were cited as providing services that were more appropriate to participants’ needs because they were able to understand participants’ experiences.

The quality of interpersonal relationships with clinicians in health care settings was impactful in terms of the way *Movement* and *Movement Loss* were understood. When health professionals held beliefs that SMA could be positively impacted (e.g. through lifestyle interventions, the provision of referrals or medication), participants were able to maintain a more positive outlook about their diagnosis, their body and their *Movement.* When health professionals held limiting beliefs about the ability to positively impact the trajectory of SMA, this led to participants either taking up those limiting beliefs themselves or disengaging from services.

Biomedical Messaging about Disease Progression Shapes Conceptualisations of *Movement*– and the Person. Within the backdrop of healthcare interactions, it is worth discussing the impact that notions of disease progression had on participants and their understandings of *Movement* and *Movement Loss.*

As discussed in the previous section on research question one, participants often described their understanding of disease progression in SMA with a high degree of certainty, which meant they understood *Movement Loss* as an unavoidable part of their future without access to pharmaceutical interventions. At the same time, the rate of progression, what might be lost or what adaptations might need to be made remained uncertain. Interactions with health professionals strongly informed and influenced this understanding. This can be shown in the recollections of participants with later onset SMA, who were diagnosed in their teens or adulthood, who reported being told by clinicians that they would become increasingly weak over time and that there was nothing that could be done to prevent this:

> [T]hey said ‘yeah, it was SMA’... and [they] basically said, you know, this is what it is, and you know, over time, *you’ll just... uh, feel weaker and... and that's it*. *And off you go*. And I wasn't worried, because – it really... it didn’t really impact my life for... until 10 years… And then slowly, it was my fingers... and then... I remember I couldn't hang out nappies on the line… and it really wasn't until I kind of hit *40* that it... it, it kind of took off, you know, a lot a lot faster… Or more noticeable. Mmmm…. I went through a specialist… [who wrote] up this big report of everything I already *knew* and there was, you know*, nothing they could do to help*. They offered me a physio, I went and saw the physio, but... I just didn't feel like there was any... there*, there was nothing they were, you know, offering to... you know, to help...* (Participant E)

While ‘progression’ was often constructed as a stable and certain future reality when living with an SMA diagnosis, it was interesting to note that there was significant variation in the degree to which participants reported *experiencing* progression. At one end of the spectrum, some participants had experienced significant, slow, steady progression over their life, while others experienced fluctuating periods of loss interspersed by plateaus in function, and others for whom their SMA had ‘not progressed a lot’. These findings suggest that while SMA is classed as a ‘chronic progressive disease’, there is variation in the degree to which this plays out for specific individuals over time. The portrayal of progressive *Movement Loss* as a stable and certain characteristic for *everyone* living with SMA, therefore, appears problematic.

The messages that participants received from their prognosis were also impactful on the person. For some participants, the expectation of progressive *Movement Loss* led to increased salience, awareness and surveillance of daily fluctuations of movement that could equate to disease progression over time. Here Participant J reflects on their experience of progression as an adult:

> It always the small things, like ‘oh, um, I don't... put my own hair up as much as I used to’ or... small things like that I *can* do it, but... I get my friend to do it a lot of the time… its always the small things and I’m like ‘oh’ (disappointed) ‘I don't do that as much as I used to’… or... I don't... Enjoy make—up as much as I used to, or I don't… get myself dressed as much as I used to, I get other people to do it… It's always like the small things…

For other participants, the certainty of disease progression led to anticipatory feelings of grief and loss. These feelings pertained not only to what this could mean for themselves but also for how it would affect life decisions, such as finding a partner or choosing to have children, how their decline in function would impact their families (whom they believed would become their caregivers). Feelings of anticipatory loss also led participants to view the progression as something to be feared, fought and resisted:

> I could have hope for how things will go, but then it’s also not having answers... to be honest it is genuinely petrifying because I don't know... how much more limited I’m going to be... in in ten more years and... …being able to accept that and move past that because the, the kind of paralysis I feel with the kind of progressiveness is so scary, I feel like slowly my agency and and my mobility are being taken away and the idea of - especially living a life that's been pretty mobile for the last five years, the idea of that shrinking down to me having to be showered... it it’s not a life that I want to live. So, I’m trying to find ways to be ok with that, and also to kind of *fight* it, like I want *treatment* or *help*, I want to make a *change* and I feel like it’s really hard to....
> (Participant H)

For participants who lived with significant physical and/or respiratory compromise due to their SMA, anticipatory loss led them to consider their mortality and deeply consider what was important in life. Often, these participants had lived with the knowledge that they had a progressive, potentially fatal diagnosis since childhood. Interestingly, these participants engaged with the uncertainty of progression and existential threat with a high level of awareness. Because of this, they were able to resist reactive responses to notions of progression and instead focus on the things that mattered to them: their work, travel, family/whānau, friends, creativity and the day-to-day activities that allowed them to keep going and survive.

Evidence Supporting the Case that Broader Social Discourses Shape Participants' Understanding of Movement

Conceptual Definitions of Movement were Provided that Conformed to and Upheld Values of Broader Social Discourses. While there was variation in participants' response to 'what movement meant' for them, it was interesting to see several of the conceptual definitions of *Movement* provided conformed to and upheld notions of broader social discourses.

For example, one of the most frequently provided definitions of *Movement* linked it to notions of 'freedom' and 'independence'. Such notions feed into Western neoliberal values, which highlight the perceived importance and value of individualism over notions of inter-dependence. It was interesting to see that when participants reflected on *Movement* in terms of inter-dependence, such as the act of 'being moved' or 'being done to', experiences fluctuated between states of deep interpersonal trust (such as when they were assisted by a trusted family member or friend) and intense vulnerability of being dependent on others such as support workers for daily needs to be met, or the perceived burden that care would place on family members. *Movement Loss* within this context is often linked to increasing physical restriction with social vulnerability and burden. It is also interesting to note that conceptualisations of *Movement* as 'independence' and 'freedom' were often linked to additional markers of social success, including 'achievement' and 'success', 'fortune' and 'luck'. This suggests that concepts *Movement* and *Movement Loss* are shaped by the values embedded more deeply within our society and culture, including how we define accomplishment, success and productivity.

Another definition brought forward in the interviews that appears to uphold the idea that broader social discourses are influencing the way adults with SMA understand and think about *Movement,* was the idea that moving with SMA was defined in part by its deviance from able-bodied *Movement* norms and the fact that these differences were outwardly noticeable in society. Interestingly, participants could hold conflicting views of their *Movement* that both upheld personal feelings of confidence in their brain and body's adaptability to find balance and meet a vast array of task demands (despite living with SMA) – while simultaneously experiencing doubt when aspects of their body are branded as 'different' or 'deviant':

> I think *Movement*, um, to me is is my brain knows what it needs to do any given situation… if you can't do that, let's try it this way, lets modify it, and you know, I swear I have a bit of a 'duck bum', but like, I, I can still walk. But my body will balance itself out where it all sort of sticks things into different, different places and like, I've had photos done recently… and it's, they're sort of like 'can you lift this shoulder up? You're, you're crooked.' And It's like, yeah, I am crooked! Like…You know? I don't even know it! Like, but I but I am.
> (Participant A)

The juxtaposition of these two sentiments is worth drawing attention to because it highlights how *Movement* was defined by participants both by what it *was* and by what it *was not.* It is indicative of a comparison to able-bodied norms and the pressure to present as 'normal' so that even when the SMA mind and body can adapt to challenges, this is simultaneously undermined by feelings of social difference.

Subjective Reports that Movement was 'Shaped by Others'. One of the question prompts utilised during interviews related to whether participants viewed the conceptual definitions of *Movement* they had provided as being shaped by their experiences of living with SMA and by their interactions within society at large. Participants responded to this provocation in a variety of ways.

At a very basic level, they described that factors within the physical environment, such as accessibility and supportive technology, enabled them to move more freely in some spaces than others. This impacted their feelings of freedom, autonomy and restriction in their homes and society at large.

They also identified that understandings of *Movement* were shaped by their relationships in social spaces and places including education, the workplace, family/whānau, healthcare providers and the broader SMA community. SMA was considered to have a social stigma attached to it, which could negatively impact social interactions, and for some participants, this led them to be discerning about whom they shared their diagnosis with:

> If someone has said to me in the past… 'Why? Is there something wrong with your hand?' Or 'something wrong with your arm?' and, if I said, 'Oh, yes. I've got SMA'. Number one, they'd go *'What*?' — like, cause… *no one* knows what it is. And I go, 'oh, it's a muscular dystrophy' …they still really don't know... but if I say… "I was involved in an accident and it's affected the nerves..." – [their response is] 'Oh! Alright!' You know? They just treat me just completely differently than a 'disability'... it's like… we're just 'different levels' than them, I'm down there. Whereas, you know, if you have an '*accident'…* you're still their equal… they don't '*sympathise'.*
> (Participant E)
>
> It's funny, with my condition, I never tell people what I have, I just always think, 'you don't need to necessarily label me to actually help or support me'… I find the label not so helpful because people just put you in boxes. With SMA, it's usually the 'too hard' box, I'd say. You get that question of 'why are you still alive?', you know? Rather than anything else…, so when people ask, I say, 'Oh, it's something I'm born with', like, I just fob it off because, like, at the end of the day... even health professionals don't understand. I've had health professionals say to me, 'Oh, you're making it up.' It's like, "*No. Literally*. I can't do that…Look it up. It's real.'… So, because there's no understanding even from health professionals, I don't even go there with other people.
> (Participant F)

Participants were also aware that their understanding of *Movement* was 'shaped by others' when they experienced social pressure to conform to able-bodied *Movement* norms. This was reflected when participants encountered situations when there was social pressure for them to perform, and they had little agency to resist these social expectations. The workplace and schools were common settings where this was seen:

> I had PE teachers who would just say, ‘Oh, just try your best,’ and I did, because I didn't... have the language to say ‘No. I’m disabled. That’s going to hurt me. I don't want to do it.’ I was fifteen and a people pleaser, and this was an authoritative figure telling me what to do, and I felt that I had no disabled voice or... representation to say ‘nah — [they] can just sit this one out and read a book’, you know?
> (Participant H).

Here, it is clear that the participant felt unsafe and powerless in response to pressures from authority being exercised within an education setting. Such experiences within education were not unique, with one participant reporting being excluded from sports at high school because they used a wheelchair, while another participant reported that their teachers ignored their parents’ pleas to limit exercise at school because they were unable to build muscle and it was ‘hurting’ rather than ‘helping’. Social pressure to conform to able-bodied norms was also felt within the workplace:

> [W]ork had a thing years ago, it was like an amazing race... I was quite young, and it was just... Cause it was, like, you’ve got to run to this spot? And so, I would almost change persona and be like, ‘Oh, let’s cheat!’ —or something — ‘let’s get in a taxi!’ ...Which is not something I would normally do! Cause it was so... so *competitive*, and I was, like, ‘I’ll stay behind, and I’ll research the next stop, and then you come and meet.’ But, you know, I’d make all these excuses, but the reality was that I just couldn't... yeah.
> (Participant A)

This example draws attention to the fact that social pressure to perform normal movement continues into adulthood and adult spaces and places – like the workplace. It also draws attention to the *cost* that such social pressures have on individuals, here leading the participant to act outside their values fit in.

Participants also highlighted that health professionals were a sector within society that had impacted their understanding of *Movement*. For example, some participants reported supportive relationships with health professionals that had enabled them to better understand, interpret and work with the SMA body in ways that supported motor control:

> I think my understanding of *Movement* has probably more come from... my own awareness of what I can and can’t do...And then trying to understand.... Is there a way that I can cheat with those messages?...I *know* that if I try a few different ways of trying to connect with that body part and it doesn’t work, then it’s just completely switched off. And sometimes there are ways to, to sort of *trick* it, and to get around [it]… [In talking with] personal trainers and an exercise physiologist that I've seen… I’ve been able to sort of understand *how* my body cheats and *why* it cheats but then also recognizing where my greatest weaknesses is.
> (Participant A)

For Participant A, understanding the SMA body through a biomedical point of view has helped them to understand the underlying reasons why their body moves the way that it does and identify techniques that have enabled them to move better.

The influence and residue of the biomedical point of view can also be seen in conservative understandings of the SMA body and its limits, which are then taken up and internalised by participants as they navigate the world:

> I don’t know what I don’t know sometimes… So, I’m limited by my knowledge of what I can... I can do, like, in terms of my movement. So, the way I ask people to lift me, that’s impacted by my knowledge and understanding... of what I can do or can’t do… For example, I’m always looking for better ways of doing things. And I sometimes go ‘oh nah... I can’t do that. I’m not going to be able to’ and that stops me in the path of trying things… So there was this hoist… its made by a New Zealand company… its so *compact,* and just looks so *elegant,* and I just thought ‘there’s no way’. You know, ‘I require *complex machinery* to *move* this *thing’…* ‘my body is just not going to be able to cope with that’….And… my understanding of movement actually *stopped* me from approaching people about this…. it took a *long* time for that mind block to clear.... over a year I pondered…And it wasn’t until last year or early this year that I went ‘you know what? Just give it a go.... if it turns out to be a failure, at least you tried! You know? What have you got to lose?’ So I tried it – AND IT WORKED! And the provider was able to customise the, um, the lifting to suit my body…. I almost *cried* when it – you know, when it worked. And I use it *every day* now with my caregivers… it has added *sooo much... ease [and] huge* value into our lives… ah!!! I could write an essay about that equipment…it's about trying new things... and don’t let your understanding of movement stop you from trying new things.
> (Participant G)

This account from Participant G highlights the complexities of living with SMA when *Movement* is impacted. While it might be important from a biomedical point of view to understand the limits of one’s body, those same expectations can lead participants to be overly conservative in their expectations of what their bodies can or cannot do. It is important to be able to be open to different and new ways of moving if you are to open up new freedoms or new possibilities for individuals living with SMA.

Finally, societal ideas about *Movement* appeared to have a lasting impact on the person. This was highlighted in Participant B’s reflection on their experiences of discrimination and stigmatisation of *Movement* whilst at school:

> It made me more in my shell. I was— I hated myself even more, and I feel like the only time I came— like for the first time ever, like, fully accepted who I was and my disability and my… chair and I wouldn’t have it any other way was moving *here.*
> (Participant B)

This quote highlights the impact that disability can have on individuals in terms of their identity and their feelings of social acceptance in society. While this can have significant emotional impacts on individuals, change *is* possible. Participant B indicated that in their current living situation, the physical environment is accessible, there are more wheelchair users out and about in society, and the disability community is connected and united. These factors have contributed towards

Participant B being able to move through the challenges of living with SMA and into a place of acceptance towards their physical limitations.

Experiences of Access and Interaction in Society Shaped the Messages Received about *Movement.*

Physical Accessibility. Issues relating to physical accessibility generally in society included concerns about access to supportive equipment or technology that would enable participants to participate as fully and independently as possible in their homes and communities. This was considered important to participants in minimising the day-to-day challenges associated with the physical limitations caused by SMA. Here, participants highlighted the cross-over between the allocation of disability funding and one's ability to access and participate within the community. For example, when funding for accessible vans or wheelchairs that would enable community access was withheld, it directly impacted participants' ability to access and participate in their community:

> [Y]our *health,* it's your *life.* You know, if someone's not coming to help you up in the morning and take you to the toilet and stuff, it has a…major effect on your life…. The funding from, you know, the Ministry of Health is always quite constrained… I mean, they talk about… community living and encouraging disabled people… but the money doesn't – the resources don't back up that at all. And in fact, a recent experience was getting a new wheelchair and, um, I was talking with the OT and, um, I said, 'Oh well, what about this wheelchair?' and she said, 'Oh, well, we really constrained by funding and, um, we only need to provide you with a wheelchair that you are able to get around inside the house.' And I said, 'Well, what about going out in the community? Like, doctors' appointments and stuff like that? That's actually written, she sent it to me, a directive from the Ministry of Health saying only funding providing for accessibility within the house. So... they talk about community involvement, [but] they're not giving you the resources of a wheelchair to, to be *able* to go out!
> (Participant D)
>
> [S]o there isn't the funding there and I think... that's one of the tough areas, is like, you know, everyone talks about 'living a good life', but a good life actually involves having the supports you need, and having the independent supports that you need— you know? And yes, they can be quite high, but, um, that is kind of what we *need* in order to have a good life.
> (Participant F)

Appropriate means of transport were also identified as a key issue for participants. For example, participants often expressed difficulty in accessing funding for accessible mobility vans that would enable them to access their communities:

> [I]t's been so hard just like to get funding for stuff... I mean, I didn't get, like, an accessible van until I was, like, 13… I don't know why they just wouldn't give me one. They just wouldn't fund it…. there's a big thing about... your participation in the community, to get one. So obviously, when I was like, younger, they were like 'you're not like, *doing anything*, so you don't [qualify]' … getting access to things and

> funding for things, it's just... ... extremely hard for no apparent reason! (Participant J)

Correspondingly, when accessing public transport, participants were reluctant to use these services due to safety concerns (e.g. subjecting the body to pain, being put off balance by sudden movement of busses, dependency on passersby to tether one's wheelchair and concerns about whether this will be done correctly). These limitations in transport ultimately led participants to have reduced abilities to participate in their communities to the extent to which they might have wished.

Finally, participants reported issues with being able to access housing that was appropriate for their needs. Participants were often required to prioritise some aspects of physical accessibility in their houses (such as an accessible bathroom) at the expense of others (e.g., accessibility in the kitchen). While some types of equipment supporting accessibility were funded by the Ministry of Health (e.g., a shower chair), others were not, and this required participants to self-fund solutions that would not have been required by others living with 'normal movement'.

Education institutions (schools, universities) were cited by participants as places where physical accessibility was supported to varying degrees but appeared to have improved over time. Three participants within the upper age bracket of the study reported needing to attend specific schools deemed 'physically accessible' to receive their education. In one case, this required the family to travel long distances to a school outside the area where they lived, eventually requiring the family to move house due to excessive fatigue from the long trips. In contrast, three participants within the younger age bracket cited school as a place where physical accessibility had been well supported, particularly through the implementation of the Ministry of Education's Ongoing Resource Scheme (ORS) funding, which supported participants to engage in the school curriculum. In these cases, participants reported feelings of gratitude for the funding that had enabled them to have experiences with their same-age peers, and provided them with a sense of normalcy and inclusion within this space.

The provision of assistive technology and the accessibility of physical and built environments contribute towards social constructions of *Movement* and *Movement Loss* because they communicate to participants about what types of *Movement* are valued, expected and 'normal' in society. In the absence of spaces and places that are physically accessible, it denies individuals the opportunity or possibility to be in those spaces or requires significant effort or burden on the individual to do so. When physical accessibility is funded and supported, this correlates to a positive relationship towards *Movement* in society and signals to individuals that they are welcome and included within these spaces. It also reduces the physical and emotional 'cost' of participation.

Social Inclusion. Accessing spaces and places within society also brought up issues of social inclusion and exclusion, which impacted the degree to which participants felt they were accepted, valued and belonged. Cultures of openness, flexibility and inclusion towards difference were identified as important as participants navigated social institutions such as education, the work place, sport and recreation activities. When participants felt accepted and included within these settings, this contributed towards a positive sense of self-esteem and belonging. In contrast, when participants felt excluded, this impacted them adversely.

Social inclusion in education settings appeared to be significantly impactful as these early interactions often had lasting impacts on how participants saw and understood themselves (and their *Movement*) later on in life. It was pleasing to see some participants report experiences of school where they were well supported by teaching staff and students, and adaptations were made so that they could be meaningfully included in ways that supported self-esteem and a sense of belonging:

> I was always, like, included in like primary school and high school sports and things like swimming and swimming days and athletics days… [my] swimming isn't really like 'swimming', its more just like 'floating around'...I can, like, *slowly* swim… pretty much what they did was that one of my mates would be in the other lane than me, and they'd just like speed me up, kind of as we swam along, so I wasn't, like, too slow, you know what I mean? (smiles) Yeah. It was a good experience… (Participant I)

For other participants, education presented challenges to feelings of inclusion and belonging. These challenges presented themselves in interactions with particular teachers or individuals. However, they could also be presented by cultures held more broadly across organisations, that led to particular ways of thinking to be normalised:

> When I first came to New Zealand, I didn't find it very inclusive— as inclusive as I expected it to be... I went into a school where they had quite a big special needs unit… I didn't like it because all the students just said 'Oh, you should be in the unit, you shouldn't be mixing with us' … my peers didn't want to realise that I actually belonged with them… that whole school culture and dynamic around 'oh special needs go to the special needs unit... and don't mix with us' was a culture I didn't want, so then I changed schools, and I went to a school where… nobody who had been in there in a wheelchair for years… I had to go around with an OT, and they had to organise for ramps to be installed and to make it accessible, um, but in some ways that was good because none of the other kids had any preconceived idea about what somebody with a disability was supposed to be like, and so I could set the bar of, well I have a physical impairment, but intellectually, I'm your peer, you know, like we're on a parr, so that was really cool and I felt more accepted… (Participant F)

At times, the social stigma attached to moving 'differently' led to participants being excluded from activities that were meaningful to them. An example of this was one participant's experience being excluded from participating in their school's kapa haka group despite their Māori whakapapa because being in a wheelchair "wasn't traditional". Other participants reported being excluded from sports activities or being pressured to participate in activities that felt unsafe.

Such experiences are significant because they signal to participants that moving differently is not valued and supports the idea that excluding people who move differently from society is an acceptable practice. Social messages about *Movement* and *Movement Loss* were also impactful on the person and their social, mental, and emotional health. When participants experienced challenges within the social environment, it often led to experiences of stress and anxiety relating to mobility, fatigue, the fear of being found out, or their movement being misunderstood or misinterpreted by others. Participants found it an ongoing challenge to assert their boundaries in response to the social prejudice they experienced.

Resisting Established Notions of Movement and Movement Loss

Thus far, I have addressed how dominant discourses in health and social settings have shaped and impacted the way that participants understood and thought about *Movement* and *Movement Loss*. It is, however, important to highlight that dominant discourses did not go unnoticed or were passively taken up by participants. In fact, in many instances, they fought to resist them.

Resistance to established notions of *Movement* and *Movement Loss* took many forms. Many participants and their families were actively involved in patient advocacy work, community groups, and sports teams, had participated in clinical research, or had worked in professions where they had been able to make a positive social impact on the SMA community and beyond. While it was recognised by participants that engaging in advocacy roles had the potential to place additional stressors on themselves and their families, this was considered a worthy sacrifice to provide a legacy for others and an important part of generating social change from the experiences they had gone through. This sentiment is expressed in the following quote from Participant H reflecting on the way their experience living with SMA has informed the values they bring to their workplace:

> Coming into this job [my experience with SMA has] given me so much empathy for… all these different contexts, like depression and anxiety, I have experience with because of my disability... I feel like... I have such an awareness and a – an insider knowledge to kind of offer… and I'll always be there to advocate for those people because no one did that for me, so... the empathy that it's given me... I'm really, really grateful for because I wouldn't have that same level if I hadn't have been through kind of what I have.
> (Participant H)

Participants also resisted dominant notions of *Movement* and *Movement Loss* in their relationships and interactions in the public sphere. This was often done through the use of selective and intentional communication patterns when interacting with others. For example, some participants were selective about how and with whom they disclosed information, such as their diagnosis, as the stigma associated with SMA and its progressive prognosis could change the way the person was viewed and treated. This is demonstrated in the following quote:

> I don't think many people know that… I have [SMA]...I mean, people I do know and the people that love me, I suppose…it's probably a pride thing? Or it's I don't even

> feel I need to... if I *have* to tell somebody, I, you know, I will.
> (Participant E)

During medical interactions, several participants described the importance of learning medical jargon, the names of medications, their uses and side effects, and researching their condition and potential treatments before consults so they were in a position to advocate for what they needed when they met with clinicians:

> I know what works for me, I know what doesn't. And in order for the GP to trust me… we have to have that *relationship…* its forming relationships with your health care providers. You can't go in there with guns blazing… that doesn't get you anywhere. You're angry about something? Fine. What are you angry about? What do you want the doctor to do? Ok, Don't just sit there are go to the doctor 'do something!' — they don't know! They don't know what to do— they're as lost as you are!...So, for me, with healthcare providers, it's working together.
> (Participant G)

It was also important for participants to reflect on interactions critically and to identify the influence of dominant notions of *Movement* when they arose so they could seek care that supported alternative understandings of *Movement:*

> [Y]ou constantly get told 'you can't do this, you can't do that', 'you'll need oxygen' or however the specialist talks about things and I was just like 'well, you don't *know* that, you're just *assuming* that. You know? … I think luckily, I've got a very proactive family and so we're always looking at other options before we have to resort to... medical intervention as such, so... but I think if you *weren't* that way inclined, then your movement could go downhill a lot quicker because of the expectations of the medical world.
> (Participant F)

Such statements highlight the fact that while adults living with SMA were required to navigate dominant notions of *Movement* during their daily interactions in society- these discourses were also actively *resisted.* Participants' ability to draw on their lived experience, values, and beliefs enabled them to set clear intentions in the ways they conducted themselves and with others in society and enabled them to critically evaluate social discourses when one's sense of identity, dignity and autonomy was threatened.

The idea that *Movement* can be shaped by the individual is a powerful one, as it demonstrates that resistance to dominant social discourses is not only possible but that it is a process that is actively happening in society and medical settings already.

It is also worth noting that while participants might have resisted dominant discourses of *Movement* as individuals, they were also supported and aligned with a close support network, which I will call the 'Inclusive Allied Community'*.* While this community might also support with 'care', their primary function was to insulate against and act as a buffer against negative experiences and/or social stereotypes. Within this community, participants felt emboldened to take risks, try new things, and push the limits of *Movement* a little further. As one might expect, family, whānau and friends were critical cornerstones within the Inclusive Allied Community. But it also included trusted health professionals, support workers, sports teams, workplaces and team cultures that were supportive and open to difference and committed to exploring new options and creative problem-solving to support participants in their endeavours. These communities understood that participants' intrinsic value lay beyond the physical limits of their body and that while they might require support in some areas, they had much to offer others.

This is not to say that members of the Inclusive Allied Community always 'got it right' with their communication or support of adults living with SMA. But there was a sense that, with the Inclusive Allied Community to draw upon, participants were able to draw on their strengths and resources more when navigating social environments. For example, if they were self-described 'risk-takers', they could lean into and express that. Similarly, if they were competitive and loved sport, creative and enjoyed artistic or musical pursuits, or adventurous and had a love of travel, they were more ready and supported to make adaptations as their bodies changed to enable them to continue to engage in the activities that brought their lives meaning and gave them a sense of identity and purpose.

The Inclusive Allied Community provided the steady base from which dominant discourses could be resisted and alternative notions of *Movement* and *Movement Loss* explored. They were also important places of support as participants navigated feelings of grief and loss associated with *Movement Loss* and learned to adapt to and navigate new physical realities while continuing to assert one's identity and agency.

In some instances, Inclusive Allied Community also included members on the SMA community who had died or passed away, but these individuals continued to strongly impact participants' approach to *Movement,* loss and life:

> I know it sounds really cliché…but, I count my blessings….all the things that are good in my life. You know.... I have seen... witnessed so much suffering in life. I have lost so many good friends to SMA... to MDA and I'm still here. Yeah? That awareness is what keeps me going... yeah, yeah. And you know, I've... yeah, I've lost some really good friends to SMA…. I take that in, and I'm like... 'I'm still here.' um, you know I'm grateful to be still here, to be able to do what I do… I'm thankful. My crooked body... at the end of the day, [its] just superficial. And my friends [who have passed away], they would easily trade places with me. Yeah? So having that awareness helps get me through every day.
> (Participant G)

Overall, resisting dominant notions of *Movement* and *Movement Loss* was important to participants because it enabled them to grapple more fully with the paradox of their diagnosis: Not only was one living in a pending reality of loss, but it was also necessary to acknowledge this to fully engage with life.

Section Summary

This section seeks to identify ways in which participants' understanding of *Movement* and *Movement Loss* are shaped by their interactions within the healthcare system and society. While one is unable to establish causality (which would not be congruent with the research paradigm), there was a clear relationship between biomedical constructions of the SMA body (and the way that it moves) and the ways ability and disability is constructed more generally within society and the ways that adults living with SMA understand and think about their *Movement,* along with how they intentionally choose to and aspire to construct themselves.

These findings highlight the multifaceted and complex ways in which dominant discourses can be taken up and the long-term impact they can have— while also highlighting the ongoing possibility and necessity for the Inclusive Allied Community to resist.

Chapter Summary

This concludes the Findings chapter. The broader implications of these findings will be examined in the Discussion.

Discussion

Introduction

In this chapter, I address the proposed research questions in light of my analysis of participants' responses reported in the previous section. First, I summarise conceptualisations of *Movement* and *Movement Loss* demonstrated in the Findings chapter and the ways in which these constructs appeared to be shaped by participants' interactions within the health system and society. The significance of these findings will be discussed with reference to critical scholarship in the fields of CDS and CRS. I then evaluate and reflect on the significance of these findings and their implications for adults living with SMA, family and whānau, their clinicians and support networks. I then consider the limitations of this research and provide suggestions for further research. Finally, I consider the place of this research within the context of broader literature looking to support the SMA community internationally, and provide a personal reflection on the research.

Overview of the Findings

This research looked to address two research questions: 1) In what ways do adults living with SMA understand and think about *Movement* and *Movement Loss*? And 2) In what ways are these understandings shaped by interactions in society and the New Zealand health system?

Addressing these questions had two fundamental requirements: First, there was a need to formulate a conceptual definition of *Movement* and *Movement Loss,* which reflected the contributions of the research participants. Such a definition was important in its ability to demonstrate whether understandings of *Movement* and *Movement Loss* reported by adults in the New Zealand SMA community reflected the realities presented more broadly within society. Second, addressing research question two required exploration of the relationship between participants' interactions with health care or broader social systems and how participants understood and thought about their condition. In the Findings section, this was achieved by identifying points in the transcript where participants linked their experiences and the interpretation of these experiences to the healthcare system or their interactions in society more broadly. Examining these linkages highlights how social constructivism is actively working within society and impacting the lives of adults living with SMA in real and tangible ways.

Conceptualisations of ***Movement*** and ***Movement Loss***

In the conceptual framework of *Movement* and *Movement Loss,* which was drawn through my process of reflexive thematic analysis, I identified three overarching themes explaining the ways in which study participants understood and thought about *Movement* and *Movement Loss*. These themes identified *Movement* as 'mattering' deeply to participants; that it was central to the act of "being and doing" in the world in ways that used the physical body or expanded beyond it; and that *Movement* had "transformative" qualities either in its ability to open up possibilities, and enable participants to transcend the challenges of daily life – or in the case of *Movement Loss,* take those experiences away.

Participants experienced a range of emotional responses to *Movement* and *Movement Loss* and the degree to which they felt in control over their environment and their ongoing ability to adapt to change. On the one hand, *Movement* was complex, joyful and nuanced. It was linked to positive social experiences such as connection and belonging. Participants felt they had agency and control over their lives, and *Movement* was a means by which opportunities to live good lives were opened up. On the other hand, *Movement* and *Movement Loss* was a place of grief, loss, frustration and disappointment. Both were marked by experiences of challenge, difficulty, restriction and difference as participants attempted to conform with normative social standards and struggled when these options were not available to them. Moving through the challenges of *Movement Loss* was considered to be a pathway to resilience whereby the ability to positively adapt to the changing SMA body was a means by which participants were able to continue to live good lives despite their progressive diagnosis.

Concordance of Findings to Existing SMA Qualitative Literature

To start, it is worth highlighting that many of the emotional experiences expressed by participants in response to *Movement* and *Movement Loss* reflect findings expressed in SMA qualitative literature more broadly.

For example, Wan et al. (2020), a scoping review of health, well-being and lived experiences of adults with SMA identified that factors like autonomy, competence, social participation, resilience, determination, hope and optimistic view on life were important in supporting well-being for adults living with SMA. These factors are very similar to those linked to conceptualisation of *Movement* within the framework provided in this thesis. Particularly with factors like autonomy (expressed in theme 1, '*Movement* Matters'), the strong link to social participation throughout the research, and the importance of one's attitude towards *Movement* and *Movement Loss* in determining one's ability to accept and adapt to the changes associated with SMA rather than fight them. Secondly, the possibility of living a colourful, meaningful life despite restrictions (Yang 2016), and the necessity of having a flexible approach to change involves adaptation, moving through grief towards acceptance (Timms, 2023).

The impact of *Movement Loss* is well documented in the SMA literature. For example, the physical manifestation of symptoms such as fatigue has been shown to increase subjective feelings of depression (Wan et al., 2020), while the challenges associated with physical decline in the changing SMA body have been shown to lead to emotional distress (Lamb & Peden, 2008; Wan et al., 2020). This literature gives weight to the findings in this study that the physical manifestation of symptoms with SMA is impactful on the person and gives cause for participants' subjective considerations that one's understanding of *Movement* and *Movement Loss* are shaped by one's experience living with the physical manifestations of SMA.

Interestingly, fear of functional decline and death has been expressed by adults in several studies of adults living with SMA (Ho et al., 2016; Kruitwagen-van Reenen et al., 2016; Lamb & Peden, 2008). While this doesn't tell us about how these participants conceptualised *Movement* or *Movement Loss*, these findings do act as an indicator of the emotional impact associated with the knowledge and expectation of disease progression and indicate that grappling with this knowledge is prevalent in adults living with SMA internationally, highlighting an unmet need to address this. International SMA literature has also shown concordance in the major emotional challenges faced by people with SMA, including coping with frustration, guilt, stress and desire for independence (Wan et al, 2020).

The concordance of these findings is significant because it highlights that struggles related to *Movement* and *Movement Loss* are experienced internationally by adults living with SMA. This leads us to consider that issues around the social construction of *Movement* and *Movement Loss* are impactful beyond the NZ context. It also suggests that new ways of understanding and thinking about *Movement* and *Movement Loss* may be impactful internationally.

Points of Difference

There were several findings about *Movement* that were not picked up by existing qualitative SMA literature. One of the obvious points of difference was that this was a critical qualitative study using an epistemology of social constructivism. From the social constructivist view, meaning is not discovered: It is *created* (Crotty, 1998a). 'Meaning' is not inherent within an object or a body, simply waiting to be discovered. Rather, 'meaning' arises when people actively and consciously engage with the object (Crotty, 1998a) and is represented through language (Burr & Dick, 2017). In this, while the SMA body *does* have physical properties that determine what that body can do, within the lens of social constructivism, the real question lies in *why* certain properties— like *Movement*— assume particular importance, as it is these properties that are then used as the basis for evaluation in health and broader society (Burr & Dick, 2017).

In this research, I identified three themes pertaining to *Movement* and *Movement Loss.* These themes identified *Movement* in terms of its importance in enabling functional independence, freedom and participation within society, and that when *Movement* was lost, this correlated with experiences of difficulty, restriction and challenge in being able to achieve those same things. *Movement* was transformational because of how it could enable access to experiences of community, belonging, meaningful occupations, physical, emotional and spiritual well-being. But when *Movement* was lost (or anticipated to be lost), access to these experiences and opportunities was withdrawn, it threatened one's ability to engage in meaningful occupations or achieve wholistic well-being.

This reading of the data suggests that there is an underlying binary logic impacting how *Movement* is being understood by adults living with SMA: Either one can move and is granted freedoms to participate in society and belong in it, *or* one is unable to move and these freedoms and rights are withdrawn. This categorisation paints '*Movement Loss'* as an inherently negative experienc*e,* proliferating the idea that it must be *resisted* at all costs.

Many aspects of this binary also resonate with participants' experiences living in their body and society, particularly where they described the challenges presented by their physical limitations and the barriers they experienced to accessing and navigating spaces and places in health and society. However, the binary failed to reflect some of the participants' most deeply held beliefs about what it meant to live well with SMA. For example, while participants acknowledged that their day-to-day experiences of *Movement* were challenging, fluctuating and uncertain, participants described that living well with SMA required the ability to accept and work with these realities rather than resisting them, and it was only in doing so that participants were able to find a sense of amity, harmony and goodwill towards their body rather than being locked in a perpetual fight against it.

Living well with SMA also required being open to the possibility of what one's body could achieve and do— while also recognising and being open to the possibility of failure. The ability to step into this place of vulnerability could only happen when participants were able to view *Movement* beyond binary notions of *Movement* and *Movement Loss* as success and failure and were open instead to the multiplicity and expansiveness of what *Movement* could be and mean to them.

Social constructions of *Movement* and *Movement Loss* were impactful on participants' emotional response to their condition, their thoughts and beliefs about it. For example, when participants reported experiencing emotions such as grief, loss, frustration, disappointment, anxiety, and depression they generally did so when there was dissonance between their perceived ability and desire to move and the perceived reality of *Movement Loss* that was generated by this binary. These emotions and beliefs ultimately determined the behaviours participants engaged in and their choices. This included decisions such as whether or not to engage with healthcare services, the type of services they engaged with, and whether or not to participate in social activities or events. This suggests that notions of *Movement* do not simply 'describe the world', or 'what a person can do', they have the 'productive' power to influence how we think and how we act (Burr & Dick, 2017). This is significant, particularly as we look to research question two to identify ways in which dominant discourses about *Movement* in health and broader society might be transmitted to participants via their interactions.

Social and Health Impacts on Constructions of *Movement* and *Movement Loss*. Crotty (1998a) describes social constructivism as:

> The view that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world and transmitted essentially within a social context.
> (Crotty, 1998a, p.42)

This definition highlights the specific *ways* in which social constructs are generated and shared within society. In the participant data gathered to answer research question two, it was clear that dominant discourses in health and broader society *were* being transmitted to participants because they expressed and drew on these discourses as they provided their definition of *Movement.* In the case of health discourses, this involved talking about *Movement* as "exercise" or rehabilitation, viewing and understanding the SMA body through the lens of diagnostic characteristics, pathology and reductionism, or understanding the body in mechanistic terms such as viewing the "body as a machine". These understandings of *Movement* are reflective of existing descriptions of biomedical discourses of the body that are utilised in medicine and rehabilitation contexts (Nicholls et al., 2015). In the case of broader social discourses, this was shown when participants discussed *Movement* in terms of freedom and independence, and the distinction between "ability" and "disability", sameness and difference, inclusion and exclusion. These understandings highlight the influence of Western neoliberal values of individualism over notions of collectivism or inter-dependence, and are indicative of broader neoliberal notions of the moral citizen (Gibson, 2016b). It also highlights the influence of differential societal expectations and prejudice about *Movement* for those classed as 'other' through the process of *Ableism* (Brittain et al., 2020; Gibson, 2016a).

It was apparent in addressing research question two that the transmission and uptake of meaning was not occurring within a vacuum. Rather, it was informed by the human interactions and practices — both direct and indirect— that impacted how participants understood themselves and their *Movement* in the world.

Transmission of Biomedical Discourses about Movement. In the case of healthcare, biomedical understandings of *Movement* were directly transmitted to participants through practices such as diagnosis, clinical testing and teaching. During these instances, the SMA body and *Movement* were understood in terms of its objective, mechanistic, diagnostic and pathological features. *Movement* was valuable to health professionals when it met objective diagnostic thresholds or a particular level of "disability", enabling diagnosis or requiring intervention (Gibson, 2016a).

Biomedical discourses were also transmitted through the beliefs and opinions expressed by healthcare professionals as they provided care. The impact and stigma of the "chronic progressive" label attached to SMA was one factor that participants repeatedly brought up as being influential in shaping healthcare interactions, particularly in driving care towards palliative rather than 'active' care pathways, or to justify inaction because 'nothing could be done'. Such beliefs communicate that *Movement* is only valuable when identified problems can be 'fixed' and a state of 'normality' can be returned (Gibson, 2016a).

It is important to note that in healthcare interactions, participants reported that they did have some positive interactions with health professionals. In these cases, participants reported satisfaction because their clinicians were knowledgeable both of the person and their medical history, but also about SMA and the variations in its presentation. Participants reported satisfaction with their providers when they felt seen and heard, and clinicians were curious to learn about what mattered and was important to them and were able to provide them with meaningful, ‘proactive’ support. Within these interactions, participants felt that their experience of *Movement* was accepted and acknowledged and that while their body might deviate from able-bodied norms, interventions did not necessarily have to be aimed at ‘normalisation’ (Gibson, 2016a). Rather, through compassionate interaction, the socially constructed division between ‘normal’ and ‘disabled’ could be disrupted, dismantled and reformed within the context of health. This enabled new possibilities for *Movement* to eventuate.

Participants’ indirect interactions within healthcare were also a means by which social constructions of *Movement* were communicated. For example, when health needs remained unmet, or care provisions and funding fell away as participants aged, this indicated to participants that their *Movement* was not valued or viewed as worthy of investment by society more broadly. This treatment contrasted dramatically with healthcare pathways that were better resourced, such as paediatric services, mainstream care pathways (respiratory, orthopaedic), and private services. To participants this conveyed the idea that protecting and supporting *Movement* was only valuable when a problem was experienced by a population majority or a sector of society that is deemed ‘important’. This contrasted with the substantial and multidimensional impact that SMA had on participants’ lives, and the challenges in health they experienced.

Transmission of Broader Social Discourses about Movement. In the case of society more broadly, discourses linking *Movement* to neoliberal notions of freedom, independence and individualism were transmitted to participants through their interactions accessing and navigating the physical and built environments and their interactions and relationships with people. Transport, housing, education, workplace, and hospitality were all common places in the built environment where participants reported challenges with physical accessibility. Accessibility was also determined by access to adaptive equipment and technologies – such as power wheelchairs or automated software – which may be considered ‘add-ins’ to the physical environment but enable access and mobility within it. The problem of physical accessibility is not a ‘new issue’ within critical disability scholarship (Gibson, 2014) or disability rights in New Zealand (Ministry of Social Development, 2016) but the significance, in this case, is that when spaces and places are physically inaccessible, it communicates a pervasive acceptance and valorisation of functional independence within society that largely remains unquestioned, and suggests that full citizenship can only be gained through independence (Gibson, 2016b). This notion bears similarities to notions of ‘independence’ shared by disability activism of the 1970s and 80s and the “Independent Living” movement which constructed ‘living well’ with disability in terms of one’s ability to self-govern and self-determine one’s personal life, ability to participate in one’s community and fulfilling social roles(Martinez, 2003). Within this conceptualisation, success is defined when ‘disabled’ people can have the same choices, control and autonomy as ‘non-disabled’ people (Gibson, 2016b). However, there are tensions inherent in this rights-based conceptualisation because of the way it encourages interventions to approximate 'typical' bodies, and makes the assumption that goals of independence and independent function are desired for those living with functional impairment (Gibson, 2016b).

Notions of independence also feed into the political ideals of neoliberalism, which has been influential in shaping understandings of personal responsibility for one's health, wealth and happiness since the mid 1970s (Nicholls, 2018b). Alongside principles such as decentralisation, privatization, managerialism and competition, neoliberalist policies have also valorised principles such as freedom of choice, individualism and responsibility for one's own needs including self-care (Lovell & Cordeaux, 1999; Nicholls, 2018b). These values have influenced how people understand and think about health, including placing increased importance for the individual to strive for and obtain 'optimal health' within a broader social context of reduced government investment in public services and infrastructure able to provide this for all (Hogan, 2023; Nicholls, 2018b).

Broader social discourses were also transmitted to participants in this study through inter-personal interactions. Participants described that the degree to which they felt included or excluded differed depending on the social context, who they were with, and in the case of larger groups or organisations, the group culture dynamics towards accepting physical difference. One of the issues repeatedly brought up by participants was that of the social stigma attached to 'disability' and the need to conform to able-bodied norms across many contexts including educational institutions, the workplace and while out in the community (e.g. shopping mall, supermarkets, cafes etc).

How bodies and *Movement* are defined, categorised and understood determines patterns of marginalisation and who counts as 'disabled' within society (Gibson, 2016a). Gibson (2016a) argues that this distinction is made via the medical model through the establishment of an impairment or 'problem' that arises due to bodily dysfunction that impacts a person's mobility, social participation or occupation. In doing so, this distinction isolates the 'problem' of disability with the *person* rather than with broader contextual factors or the environment. The localisation of the problem to the individual was apparent in participants' reports of marginalisation when people heard about the cause of their impairment. For example, according to participants' reports, an impairment that was understood to be subsequent to a traumatic injury was judged less harshly than one caused by a longstanding genetic condition. The outcome of such categorisations is that the 'disabled' person is necessarily categorised in contrast to one who is 'able-bodied' or 'normal'. This categorisation implies that if one is to address the issues of being 'disabled', the solution is to address the body impairment of the disabled person – or, in the case of many participants in this study, to 'present' as normally in society as possible to avoid being interpreted and labelled as such.

Research Implications

Transmission of biomedical and broader social discourses about *Movement* to participants has broader implications. First, it highlights that there is weight to the social constructivist argument and the importance of addressing the 'Made Body' within the context of adult SMA. The social constructivist lens argues that it is *language* that shapes the way in which we understand and think about the world and what we hold to be 'true' (Burr & Dick, 2017). This study has demonstrated how the uptake of health and broader social discourses led certain properties of *Movement* to be considered more important by participants than others— even though their own unique experiences of their condition and what they knew supported them to 'live well' with SMA radically differed from dominant understandings.

Second, the study highlights and confirms the importance of power relations in shaping personal experience. This finding resonates to a large degree with the work of French social theorist Michel Foucault, who was interested in examining how processes such as classification and categorisation proliferated and the impact that this had on society (Burr & Dick, 2017). Social discourses – culturally significant 'broad meaning systems' (Speer, 2005) were considered to be important by Foucault not only as frameworks through which the world could be made sense of, but because of the way they shaped and generated the thoughts and actions of those using them (Burr & Dick, 2017; McHoul & Grace, 2015) Foucault argues that part of the 'productive power' of discourses comes from their 'disciplinary effects' or ability to encourage individuals to want to conform to the established 'norms' in society (Burr & Dick, 2017; McHoul & Grace, 2015). In the case of this research, this was reflected in how participants desired to conform with dominant discourses surrounding *Movement* in both health and society more broadly, valorising the achievement of normative movement that enables functional independence over alternatives.

Not every discourse produces strong disciplinary effects. However, Foucault argues that the more that those with power work to normalise one particular discourse or way of thinking or being, the more counter-discourses are generated and produced that resist it (Burr & Dick, 2017). It was interesting to observe this resistance actively and organically arising as participants instinctively moved towards activities, healthcare, social spaces and places that offered more inclusive, wholistic understandings of *Movement* – or demanded more of the existing social structures/institutions to meet their needs (e.g., through activism).

Third, social constructions of *Movement* and *Movement Loss* have profound impacts on the person. While not a primary investigation within this research, it was noted that when participants were confronted with dominant discourses of *Movement,* they felt a greater need to strive for and conform to able-bodied representations of *Movement.* This increased subjective feelings of stress, frustration and social anxiety related to the physical symptoms of their SMA, and, ultimately, led them to question their value and self-worth, and the extent to which they belonged and were accepted in society more broadly. These findings are suggestive of some of the underlying social contributors towards challenges in social participation experienced by adults living with SMA internationally (Wan et al., 2020).

Avenues for Change

This research highlights the potential for change by reconsidering and broadening the ways we understand, think about and communicate about *Movement* in health and society. The findings reported in response to research question one in this study, for example, draw attention to the fact that *Movement* represents so much *more* to the person living with SMA than functional independence. There are things that we can learn from the understandings of *Movement* shared that can support and grow understandings of *Movement* and *Movement Loss* that are more wholistic, dynamic and expansive and provide a base for human flourishing for those living with SMA rather than 'disablement'.

One example of this from research question one was the idea that while conventional notions of *Movement* in healthcare and society link it to functional independence, for participants in this study, when physical function became restricted or challenging, *Movement* transcended the body boundary and extended into the physical and social environment through the use of supportive technology and relationships. These findings bear resemblance to posthuman understandings of *Movement* (Gibson et al., 2021) and the connectivity model of disability (Nicholls et al., 2016) from critical rehabilitation scholarship. Within these models, people have relationships with technologies, people, animals etc., that are functional relationships. Drawing on models like this within health care and society has the potential to enable possibilities for agency to remain open for individuals living with conditions like SMA regardless of the physical changes associated with the condition. It also has the potential to mitigate social stigma associated with physical limitation– especially as we consider these types of functional relationships are used across the ability spectrum – including by people classified as having 'normal' functioning.

Within mainstream health and rehabilitation, there has been a growing commitment to placing the responsibility of the management of health conditions on the individual, for example, through behavioural interventions and preventative management (Nicholls, 2018b). This discourse is reflected in SMA care and research internationally in the creation of "best practice" guidelines for physical rehabilitation interventions for SMA (Trenkle et al., 2021) which place responsibility on the individual to engage in rehabilitation to improve their physical outcomes; or indeed, the current discourse about pharmaceutical interventions being the 'best' or most 'proactive' interventions for those with SMA alongside social/government policies which require individuals and their family/whanau to make significant sacrifices to travel to get access (Espiner, 2021; Forbes, 2023). This research provides the impetus for us to pause as healthcare practitioners and as a society and question the values, messages and discourses behind such interventions and to be critical of their true impact. This matters because, as one participant reflected in this study:

> “[we] don’t know what [we] don’t know”
> (Participant G).

For years, the international SMA community has been advocating for change: for pharmaceuticals, and treatments that reduce disease burden or symptom severity. There is an assumption that by gaining access to these interventions those living with SMA will achieve ‘better outcomes’ by emancipating them from the chains of ‘unrelenting progression’ and enabling them to ‘participate fully in society’ – contribute to the workplace, climb a mountain if that is what they choose to do. While the pursuit and investment in such interventions undoubtedly can address physical limitations, it is also important to be critical about what makes it ‘untenable’ to live in a body with physical limits. And, indeed, if we do not address or consider the discourses about *Movement* operating in health and society at large, can we *ever* expect members of this community to be released from the ‘chains’ of disability?

Implications for Healthcare

This research highlights the importance of addressing social constructions of *Movement* as just as important as efforts to improve ‘functional' impairments. From a healthcare perspective, this research encourages healthcare practitioners to take a critical stance towards the biomedical model and to acknowledge that ‘truths’ held within this model are socially constructed. While this model might be used by health professionals with the intention to ‘do good’, it is important to acknowledge this model can also have unintended consequences for patients.
It also means:

- Acknowledging the impact of language and assumptions when talking about notions like ‘disease progression’.
- Supporting individuals and their families to engage with the uncertainty related to their condition.
- In NZ, where pharmaceutical treatment is not available for adults at this time, support *can* be provided. Health professionals can lean into social interventions that can be provided for free.
- Support emotional responses to *Movement Loss* including grief, sadness, anxiety, and experiences of frustration.
- Encourage patients to understand *Movement* as more than ‘functional independence’. Support to find alternative ways of being and doing that enable movement to be found in more wholistic ways.

This research also has implications for staff training or professional development for health professionals. For example:

- Training to support person-centred therapeutic practices that support long-term partnerships and engagement with adults living with SMA.

- Training to support mental health of adults living with SMA, including addressing grief, anxiety, depression related to their condition and experiences of ‘disablement’ in health and society.
- Professional development opportunities that support clinicians to be critical and reflective on the efficacy of current practices, and consider alternatives where appropriate.

Implications for Society

From a social perspective, this means thinking creatively about how to address issues such as accessibility and the social stigma associated with disability. It means investing and building cultures of social inclusion in places like schools, universities, workplaces and the community. It also means that governments should provide adequate and appropriate investment in disability support services and equipment that enable those living with functional impairments to have agency to spend disability funding where it is needed. Investment in support services needs to be sufficient to enable disabled people to access and participate in their community in ways that are meaningful to them. This means providing infrastructure and equipment that supports meaningful community participation (such as maintenance, upkeep and accessibility of facilities like swimming pools; the provision of power wheelchairs with functions that support engagement in meaningful activities (e.g. high-low functions that enable the user to be upright/positioned at a height) or suitable to access the community (e.g., power wheelchairs that can be used outdoors).

As with health, this research calls society to consider the ways that language and discourse operate to perpetuate and valorise particular notions of *Movement* in society, while others are marginalised. From the feedback provided in this study, consideration could be paid to:

- The messaging around *Movement* that occurs during government health campaigns, such as the ‘Push Play’ campaign, which aimed to promote 30 mins of daily play for children, but which marginalises disabled people who cannot participate in high-intensity activity achieved by ‘typical’ bodies.
- Education of teachers at all stages of education to reduce stigma attached to physical limitations and to support inclusion of students with physical limitations in their classes.
- Schools and workplaces need to be supported to encourage inclusive cultures for those living with physical limitations.

Implications for The SMA Community and other Communities Living with Movement Loss

The identification of *Movement* and *Movement Loss* as social constructs, and the deconstruction and reconstruction of these constructs to identify social discourses has the potential to be very freeing for members of these communities. We have been taught to think and understand these concepts in particular ways (particularly through institutions such as healthcare, education and others) and apply value in particular ways. Openness to understand these notions in different ways, and create new language and discourse around them opens up the possibility to better serve those living with SMA and their families to live well with the condition. Powerful examples of this in society already exist, such as crip theory(Jenks, 2019; Thorneycroft, 2024), feminism, the pride movement of the LGBTQ+ community, and indigenous movements (such as Māori activism, te ao Māori and te reo Māori in Aotearoa).

Research Impact

At the outset of this research, I had hoped this research would contribute towards increasing local research of SMA, which had the potential to reflect the specific social, cultural and political pressures impacting the adult SMA community here in Aotearoa, NZ. I hoped that this knowledge base would be useful for both clinicians, individuals, families and whānau living with SMA and other chronic or progressive conditions. I had also hoped to provide an avenue for SMA voices to be represented and heard outside traditional news media.

Here I will discuss how those aims are likely to be achieved.

Broader Social Impact

Internationally, this study continues to be the only critical qualitative study investigating the views of adults living with SMA. It is the first qualitative study of SMA in New Zealand.

This research was completed with the assistance of Pūnaha Io – the Neuro-genetic Registry and Biobank of New Zealand, and the support of the New Zealand Muscular Dystrophy Association. My ongoing relationship with these organisations will mean that there are avenues by which the findings of this research can be fed back to clinicians and healthcare professionals who have a vested interest in supporting those living with SMA and members of the broader neuromuscular community. There will also be opportunities to share the findings of the study within the broader neurogenetic network, at conferences such as the Australasian Neuromuscular Network Annual Congress in 2025. Presenting findings within this forum has the potential to reach a large number of treating physicians and researchers in Australia and New Zealand, so there is the opportunity for the research to be considered within the broader context of care in these countries.

While this study focused particularly on the experience of NZ adults living with SMA, many of the findings of this research are broadly applicable to many ‘degenerative’ disorders where losing physical mobility over time is impactful on the person and their participation in society. Such populations range from other neuromuscular or neurological disorders (such as stroke, Parkinson’s disease, multiple sclerosis, amylotrophic lateral sclerosis, or cerebral palsy), developmental disorders, cancers or the mobility loss associated with the aging processes. Here, a critical understanding may be beneficial but lacking within the existing literature pertaining to these conditions or life stages.

Finally, this study has the potential to contribute towards critical scholarship looking to understand the concept of *Movement* in health and society. Gibson’s (2016d) book, *Rehabilitation:*

a post-critical approach, calls for what she describes as a "*Movement* movement" – a need to reconsider and redefine how we understand and think about *Movement* in rehabilitation contexts. This research contributes to this scholarship by highlighting how *this* community understands *Movement* and *Movement Loss* in the context of their condition and how these understandings are impacted by forces within society and health at large. By deepening our understanding of these factors and disseminating these findings to health professionals and within society, there is the possibility and opportunity to change current social practices so that they can be more flexible and inclusive in the long term.

Impact for the SMA Community

I hope that participating in this study has had a positive impact on those individuals who took part. At the end of their interviews, many participants expressed their gratitude for this work. One participant, Participant H, reflected on the struggle for representation of the SMA community in NZ, and that having the research completed by an insider to the community supported their feelings of safety and confidence that their voice would be heard. Several participants were already involved in driving social change about disability awareness in their own lives. Participating in this research appeared to be another meaningful outlet by which this desire for change could be actioned in a way that would benefit others with SMA and their whānau.

Strengths and Limitations of the study

Strengths

This study addresses the current gap in critical qualitative perspectives on *Movement* in international SMA research. It was noted in Wan et al. (2020), a scoping review of health and well-being in SMA adults that there is a need for a greater understanding of the impact of social participation aspects of SMA, and it is hoped that this study contributes in some small way towards this body of work internationally once published.

Secondly, this is the first NZ-based qualitative study completed on adults living with SMA. Many NZ individuals living with SMA and their families/ whānau have been forced to emigrate to receive treatment overseas (Espiner, 2021; Forbes, 2023). This study included members of this population to support a broad variety of views and experiences about *Movement* and *Movement Loss*. The 90–minute interviews were able to generate rich data where participants were able to speak freely to topics considered relevant to them.

The use of reflexive thematic analysis enabled a wide lens coming into the research. This lens was progressively narrowed down in response to what was deemed important in participant's accounts. This has enabled me to express the views of participants without being forced to view the data through a pre-existing framework as is the case with other methods and methodologies.

Reflexive thematic analysis has also enabled me to draw on my insider experience (as a physiotherapist and someone who lives with SMA type 3) to inform and enrich my research, while also using ‘reflexive scrutiny’ to examine my own biases and identity and how this guides my thought processes (Hamdan, 2009). This process has supported me in building my awareness of who I am, where I come from and what I bring to the research space during this work. It has also driven me to actively engage in considering the ethical implications of this research (Hill & Dao, 2021). In doing so, I hope that the final product of this thesis reads as both heartfelt and directed towards meaningful social change.

Limitations

This study had several limitations. First, there is an acknowledgement of the limits and scope of this study due to the time constraints of the AUT master’s thesis programme. This has meant the findings of this study have had to remain tightly bound to the confines of the research questions, rather than exploring aspects of care— such as interventions to support *Movement* which might have greater applicability in social or healthcare settings.

Secondly, the data collected in this study comes from one time point (September–December 2023). Since this time, there has been a change in government and additional cuts to health and disability support funding, alongside the implementation of tighter restrictions on how this money can be spent (Espiner, 2024). Despite increases in budget allocated to Pharmac, no changes in access to pharmaceuticals for the adult SMA community have been announced (Espiner, 2024; Pharmac, 2024b). One of the effects of democracy is that there are fluctuations in policy and dominant political discourse over time, and therefore, it may be that conceptualisations of *Movement* and *Movement Loss* also shift and change in response to this. Future research, such as Foucauldian discourse analysis may be better able to account for shifts response to factors like disease progression, political or social changes, or the degree of comfort or acceptance one has in their identity living with SMA.

Thirdly, despite consultation at the beginning of this project and efforts within the study design to encourage participation of Māori in this study, I was able to recruit only one Māori participant. This was significantly less than the 50:50 ratio that had been aimed for. One of the reasons behind the reduced response could be that SMA is of lower prevalence in Māori versus non-Māori, making the pool of potential Māori participants small within an already rare disease. However, the reduced response rate could also have been due to unaddressed cultural factors. In future research, it would be interesting to see whether the incorporation of Kaupapa Māori design principles may support the participation of Māori in similar research.

Personal Reflections

Before starting this research, I knew that I wanted my studies to contribute towards the gap in research and resourcing for members of the adult neuromuscular community in New Zealand that I saw in my clinical practice as a physiotherapist. My lived experience of SMA and the ethical issues around access to new treatments for the SMA community which were regularly publicised in the media led me to consider using my masters' research to support advocacy groups in their efforts to improve access to care and outcomes for the SMA population. I also noted that many of the issues that I saw impacting the SMA community also impacted the families of the children I worked with in special education settings, so there was a hope that my research might also contribute more broadly to the NZ disability community.

Reflecting on this project, the process of reflexive thematic analysis through the lens of social constructivism has taken my research in directions that I never would have considered before this research, and has led me to reconsider the things I feel are most important in living well with a long-term condition like spinal muscular atrophy.

For example, before this research, my training and work as a physiotherapist had led me to prioritise interventions involving personal behaviour change, such as exercise to change my patients' outcomes, and in my own personal management of my SMA. While these interventions could be applied relatively effectively within private practice in musculoskeletal settings, when I shifted to working in special education the notion of 'rehabilitation' and 'exercise' became problematic. The children I worked with had high complex needs and required the use of wheelchairs for community mobility. They would likely never have 'normal' bodies or 'normal' movement, and yet this was the standard we measured them against during objective tests, and therapy provided was aimed at addressing these deficits to improve *Movement*. While this work was always done in an effort to benefit the child and their family, I also often felt conflicted about the indirect impact that clinical interventions might have on children and their identity as they grew up. When we focus on correcting a 'deficit', that signals to the child that their body is a problem. I wondered what kind of long-term impact that might have on someone as they reached adulthood.

One of the interesting things I found when completing the interviews for this study was that many participants reflected upon the fact that they actually felt ok managing their current level of mobility but that it was the idea of progressive movement loss that was worrying to them. As a physiotherapist, it was not uncommon in my role to provide advice about lifestyle changes that could help mitigate disease progression, so I found it interesting that many participants felt that this was out of reach. Reflecting on my research now, I wonder whether this might have been due to the expectations they had been exposed to by health professionals which had led them to believe that based on their diagnosis 'nothing could be done'.

Another curious thing I reflected on was the way that the changing SMA body was viewed in a negative light. It is *normal* for bodies to change over time, and experience fluctuations day-to-day and over one's lifetime. Part of my learning from my own experience of living with SMA has related to being able to view change with a more neutral mindset: Not *all* change is irreversible degenerative change. I think it is important to be able to acknowledge that— particularly in a context where the 'chronic progressive' label attached to the condition creates very 'concrete' and set expectations about the trajectory of disease. While there will always be uncertainty about the future and what life might look like in years to come, with uncertainty also comes with possibility.

Change can open up new opportunities, new experiences, new ways of understanding the world and being in it which can be fulfilling, life-affirming and joyful.

The critical lens taken in this research led me to re-examine what is means to live a ‘good life’ while living with SMA. For myself, coming to understand that the very notion that “SMA” is a concept that has been socially constructed has been transformative and has in many ways ‘released’ me from the underlying feelings of shame, guilt, fear and powerlessness I have often felt in response to living with SMA. Yes, there are certain limits to what my body can do and the way it responds to stress, how it performs on particular objective tests. But I also have the power to choose how to respond to that and define what it means in *my* life. I can move in ways that feel good, and define success not by what an able-bodied person could achieve, but by *my own* achievements. I can learn how to adapt and change with my body and work my way through the challenges I face along the way. I can learn. I can try new things. I can engage in challenge. I can surround myself with people who love and support me, and know that *Movement* is so much more than what you can do with your body. It’s part of the fabric and interconnectedness of community and of life, and when we move together that is when strength and resilience to change can be found.

I will finish by sharing a poem that I wrote while reflecting on one of my own experience of *Movement* which I had previously viewed through a lens of pathology, and considering what it might mean if that *Movement* was redefined in a way that was more positive and open to the possibility of joy, fulfillment and transformation.

What if?

What if
‘falling’
Was falling in love
with the world so deeply
that one couldn’t help diving into it?

My world and the physical world colliding.
Spinning coloured fracturals everywhere
like a kaleidoscope.

Returning from flight,
Dazed, giddy, laughing.
Drunk with the world’s goodness

Eagerly awaiting
one’s next encounter
with the Earth
and God.

(Rachel Allan, 2024)

Conclusion

In this study, I have used reflexive thematic analysis informed by social constructivism, CDS and CRS to investigate how NZ adults living with SMA understand and think about *Movement* and *Movement Loss* and explore how these understandings might be shaped by society and the NZ health system.

My process of reflexive thematic analysis resulted in a framework that summarised conceptualisations of *Movement* and *Movement Loss* into three broad themes: '*Movement* Matters', '*Movement* is being and doing' and '*Movement* is Transformation'. Within these conceptualisations, it was found that participants understood and thought about *Movement* in ways that reflected biomedical discourses experienced in health contexts and broader social-political discourses (such as ableism, and neoliberalism) which were expressed more broadly in society. Conceptualisations were informed and shaped directly through the relationships and interactions participants had in health and society. They were also indirectly influenced through structural issues such as the accessibility of the physical environment and ease of navigating social services to get their needs met. These interactions – direct and indirect – significantly impacted participants' wellbeing, self-esteem, their sense of worth and resilience in the face of change.

It was found that participants and others close to them often acted in ways to resist dominant discourses about *Movement* and *Movement Loss*. In doing so, participants were able to intentionally reclaim *Movement,* and move towards understandings of *Movement* that supported wellbeing rather than worked against it.

The findings of this study highlight the importance of moving beyond dominant conceptualisations that view *Movement* and *Movement loss* purely in binary terms, and the importance of exploring alternative ways of understanding *Movement* to support those with progressive conditions like SMA to live good lives where physical limitation does not translate automatically to a process of disablement by society.

The findings of this study also add to the existing body of SMA research literature which at the present time lacks a clear critical voice. There is a strong need for further critical research in this area given the rapidly changing treatment environment and the ongoing need to ensure that changes support the community in the ways they are intended. It contributes to scholarship in CRS, which is concerned with building awareness about the influence of health discourses on *Movement*, and generating changes in health care service and delivery that support understandings of *Movement* that are more wholistic and person-centred. Similarly, this work contributes to scholarship in CDS, which looks to highlight social inequities impacting disabled people and generate social change that supports more equitable outcomes.

With regard to the specific context of the disability community in NZ, this research highlights that social and health discourses of *Movement* contribute towards the marginalisation of this population in ways that impact healthcare access, relationships, service quality, alongside physical accessibility and inclusion in society at large. How we construct *Movement* in society and healthcare is important in determining the way that individuals and their families and whānau understand their condition, what possibilities they perceive as being open to them, and how they think about change.

To move forward in both healthcare and society it is necessary to challenge existing notions of *Movement*: To be critical of the information and discourses taught in medical school or university, or taught by proxy in our interactions in society at large. By acknowledging and reflecting on our own constructions of *Movement,* we can begin to build awareness needed generate meaningful change for those living with SMA and other similar conditions.

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Appendix/Appendices

Appendix A: AUT Ethics Approval Letter Dated 14 September, 2023

Auckland University of Technology Ethics Committee
(AUTEC)

AUT
TE WĀNANGA ARONUI
O TĀMAKI MAKAU RAU

14 September 2023
Kate Waterworth
Faculty of Health and Environmental Sciences

Dear Kate

Re Ethics Application: **23/228 Conceptualisations of movement (and movement loss) in adults living with Spinal Muscular Atrophy in Aotearoa New Zealand: A critical analysis**

Thank you for your responses to AUTEC's conditions.

Your ethics application has been approved for three years until 14 September 2026.

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.
2. All public facing documents must have the AUTEC approval number and be of a high standard of spelling and grammar. Dates on the Information Sheet(s) and Consent Form(s) must be consistent.
3. Any amendments to the project must be approved by AUTEC prior to being implemented.
4. A progress report is due annually on the anniversary of the approval date.
5. A final report is due at the expiration of the approval period, or, upon completion of project.
6. Any serious or adverse events must be reported to AUTEC, this includes unforeseen issues that might affect continued ethical acceptability of the project.
7. AUTEC grants ethical approval only. You are responsible for obtaining management permission for access 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.

The application number and title need to be referenced on all correspondence related to this project.

All forms are available online http://www.aut.ac.nz/research/researchethics

For any enquiries, please contact ethics@aut.ac.nz
(This is a computer-generated letter for which no signature is required)

The AUTEC Secretariat
Auckland University of Technology Ethics Committee

Cc: rachel.allan2@gmail.com; jfadyl@aut.ac.nz

Auckland University of Technology, D-88, Private Bag 92006, Auckland 1142, New Zealand.
T: +64 9 921 9999 ext. 8316: E: ethics@aut.ac.nz: www.aut.ac.nz/researchethics

Appendix B: AUT Ethics Approval Letter Dated 17 October, 2023

Auckland University of Technology Ethics Committee
(AUTEC)

17 October 2023
Kate Waterworth
Faculty of Health and Environmental Sciences
Dear Kate

Re: Ethics Application: **23/228 Conceptualisations of movement (and movement loss) in adults living with Spinal Muscular Atrophy in Aotearoa New Zealand: A critical analysis**

Thank you for your responses to the conditions for the amendment to your ethics application.

The amendment to aim for 50:50 Māori: non-Māori split, analyse Māori data separately and consent to future interviews is approved.

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.
2. All public facing documents must have the AUTEC approval number and be of a high standard of spelling and grammar. Dates on the Information Sheet(s) and Consent Form(s) must be consistent.
3. Any amendments to the project must be approved by AUTEC prior to being implemented.
4. A progress report is due annually on the anniversary of the approval date.
5. A final report is due at the expiration of the approval period, or, upon completion of project.
6. Any serious or adverse events must be reported to AUTEC, this includes unforeseen issues that might affect continued ethical acceptability of the project.
7. AUTEC grants ethical approval only. You are responsible for obtaining management permission for access 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.

The application number and title need to be referenced on all correspondence related to this project.

All forms are available online http://www.aut.ac.nz/research/researchethics

For any enquiries, please contact ethics@aut.ac.nz

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

The AUTEC Secretariat
Auckland University of Technology Ethics Committee

Cc: rachel.allan2@gmail.com; jfadyl@aut.ac.nz

Auckland University of Technology, Private Bag 92006, Auckland 1142, New Zealand
T: +64 9 921 9999 ext. 8316: E: ethics@aut.ac.nz: www.aut.ac.nz/researchethics

Appendix C: Participant Information Sheet for Semi-Structured Interviews.

(Materials B. distributed by Pūnaha Io the Neuro-Genetic Register and Biobank to potential participants)

Auckland University of Technology
Private Bag 92006, Auckland 1142, NZ
T: +64 9 921 9999
www.aut.ac.nz

Moving with Spinal Muscular Atrophy.

05/10/2023

Tēnā koe, hello!
You are invited to take part in research aiming to understand the experiences of adults living with spinal muscular atrophy in New Zealand.

This study is being carried out by master's student and physiotherapist, Rachel Allan, with the support of researchers Kate Waterworth and Joanna Fadyl at the Centre for Person Centred Research at AUT. This project will contribute towards a Master of Health Science qualification.

This research will be completed with the support of the *Muscular Dystrophy Association of New Zealand* and *Pūnaha Io - The Neurogenetic Registry and Biobank.* This research is funded through AUT University post graduate budget.

What is the purpose of this study?

We aim to explore the ways that adults living with SMA (Spinal Muscular Atrophy) understand and think about *movement* and *movement loss,* and the way that these understandings are informed and shaped by one's interactions in the NZ health system and society. The purpose is to produce a collective understanding of these experiences (including diversity of experience) and make this available to people living with SMA and those they interact with in the wider community.

What are the benefits of this research?
To our knowledge, this is the first qualitative study investigating the experiences of those living with SMA in New Zealand. In doing this research, we hope to help clinicians to understand people's wellbeing journey after being diagnosed with SMA.

The knowledge shared through the research will help improve services and supports for people living with SMA in New Zealand.

How was I identified to take part in the study?
You are being invited to take part in this study because you are registered on the New Zealand Neurogenetic Registry. Alternatively, you may have been identified via personal or professional networks

What will I be expected to do?
If you consent to take part, you will be invited to take part in an **interview**.

This will be held **remotely (by video-call)** or **in-person at AUT Akoranga Campus** at a time that is suitable for you. If held remotely, we will use a remote platform of your choosing (e.g., via skype, zoom, Microsoft Teams). We will explore your experience living with SMA and the way this has impacted the way you understand and think about movement, and what it means to live well with SMA. The interview will be audio recorded and will be transcribed.

We expect the interview will last between 60-90 mins.

You are welcome to bring someone else (e.g. family/whānau) to support you.

The interview can be paused or stopped at any time if you feel uncomfortable or require rest breaks.

What are the costs of participating?
The only cost to you is your time, which we value highly and appreciate. If you travel for the interview, we will reimburse your costs. We will give you a voucher to thank you for being involved.

What are the discomforts of taking part?
We don’t expect that there are any risks to you from participating in this study.

If you would like to take part in the interview but are unable to do so because of the constraints of the interview, accommodations can be made to support your participation and ensure your voice can be heard.

We recommend discussing options with our research team, whose contact details are at the end of this document.

How will my privacy be protected?
Your information will be confidential to the research team. The interview will be audio recorded. The recording with be transcribed and any identifying material will be removed. All data is stored in secure password protected files. Your personal information will be kept separately from the audio recording. Data will be kept for 6 years and then destroyed.

How do I agree to participate in this research?
If you are willing to participate in the research after reading this information, we would like you to email Rachel (jck2637@aut.ac.nz)

Auckland University of Technology
Private Bag 92006, Auckland 1142, NZ
T: +64 9 921 9999
www.aut.ac.nz

Your participation in this research is voluntary (*it is your choice)* and whether you participate or not will neither advantage nor disadvantage you. You can withdraw from the study at any time. If you choose to withdraw from the study, you will be offered the choice between having any data that is identifiable as belonging to you to be removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

Will I receive feedback on the results of the research?
The findings will be written up as a report mid-2024.

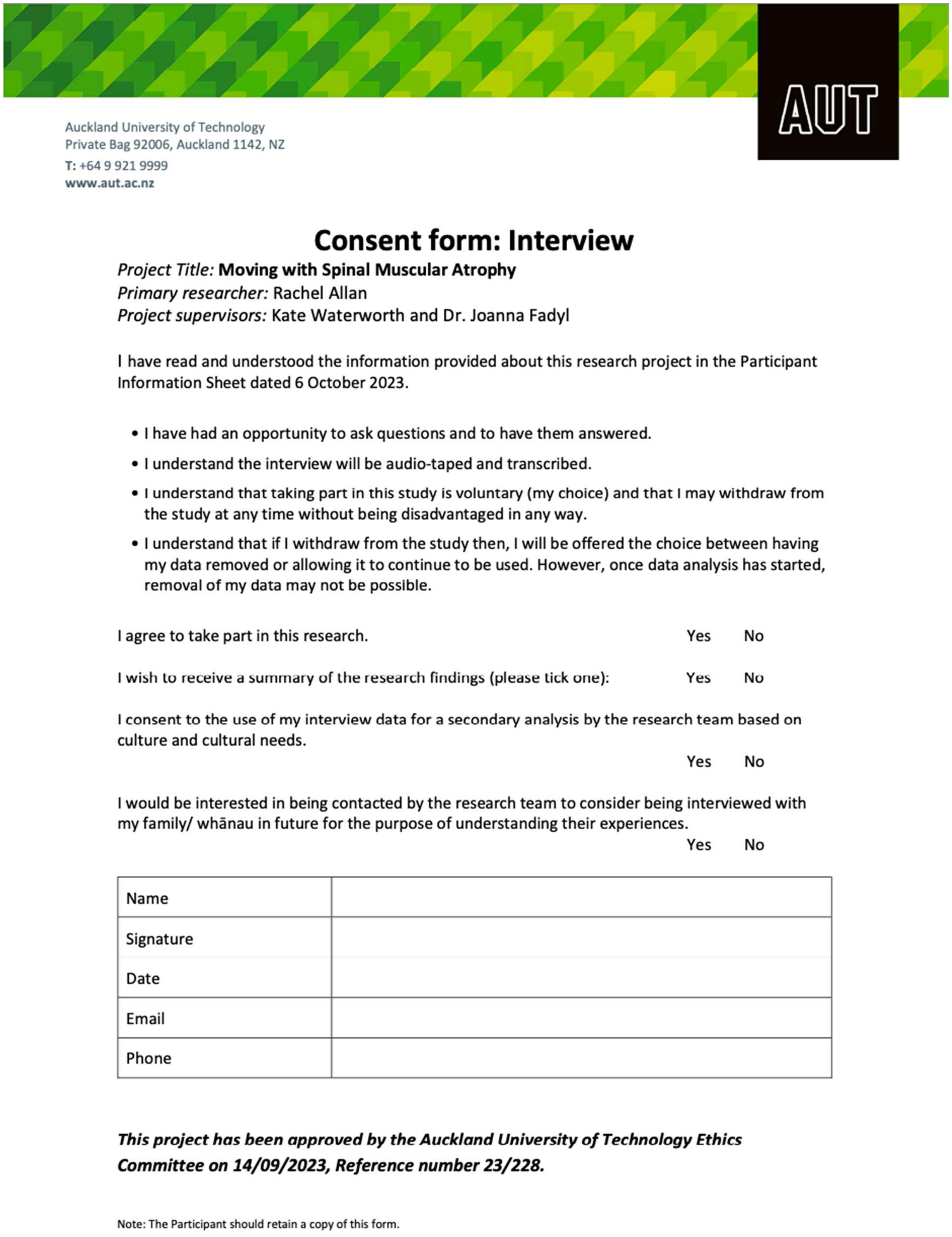
We will provide a summary of findings to our collaborating organisations to share with their staff and members via their communication channels. You can indicate on your consent form if you would like to receive this summary of findings direct from the research team.

Who do I contact for more information or if I have concerns about the research?
If you would like more information about this research, please contact one of the researchers.

- Primary researcher: Rachel Allan jck2637@aut.ac.nz
- Project supervisor: Kate Waterworth kate.waterworth@aut.ac.nz
- Project supervisor: Joanna Fadyl joanna.fadyl@aut.ac.nz

Approved by the Auckland University of Technology Ethics Committee on 14/09/2023
AUTEC Reference number 23/228.

Appendix D: Interview Consent form



Auckland University of Technology
Private Bag 92006, Auckland 1142, NZ
T: +64 9 921 9999
www.aut.ac.nz

Consent form: Interview

Project Title: **Moving with Spinal Muscular Atrophy**
Primary researcher: Rachel Allan
Project supervisors: Kate Waterworth and Dr. Joanna Fadyl

I have read and understood the information provided about this research project in the Participant Information Sheet dated 6 October 2023.

- I have had an opportunity to ask questions and to have them answered.
- I understand the interview will be audio-taped and transcribed.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.
- I understand that if I withdraw from the study then, I will be offered the choice between having my data removed or allowing it to continue to be used. However, once data analysis has started, removal of my data may not be possible.

I agree to take part in this research. Yes No

I wish to receive a summary of the research findings (please tick one): Yes No

I consent to the use of my interview data for a secondary analysis by the research team based on culture and cultural needs.
Yes No

I would be interested in being contacted by the research team to consider being interviewed with my family/ whānau in future for the purpose of understanding their experiences.
Yes No

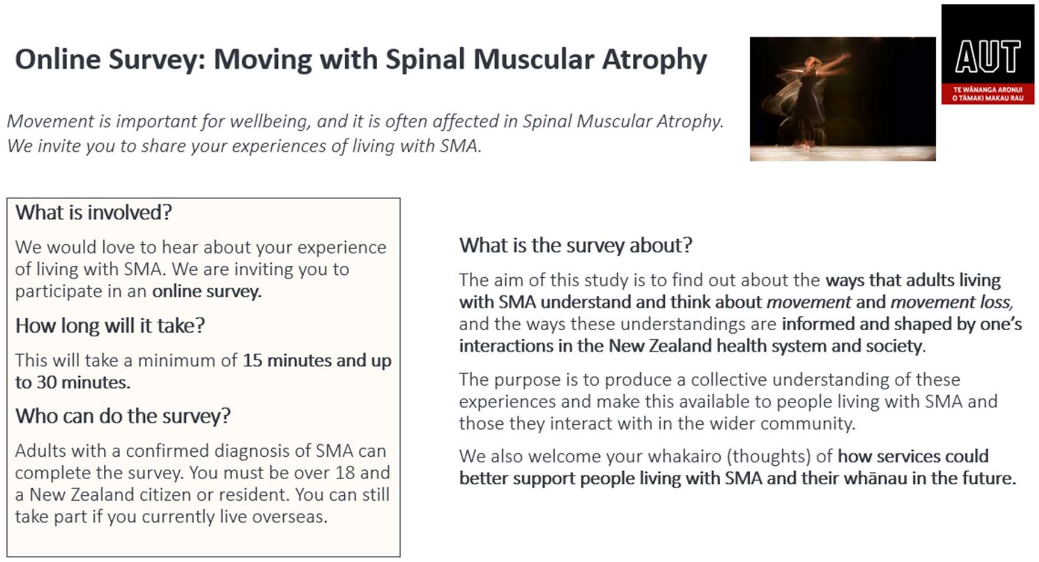
Name	
Signature	
Date	
Email	
Phone	

This project has been approved by the Auckland University of Technology Ethics Committee on 14/09/2023, Reference number 23/228.

Note: The Participant should retain a copy of this form.

Appendix E: Online Survey Information Flyer

These two images formed part of Materials A. distributed by Pūnaha Io the Neuro-Genetic Register and Biobank. The images were embedded in the email invitation sent by the Registry



Online Survey: Moving with Spinal Muscular Atrophy

Movement is important for wellbeing, and it is often affected in Spinal Muscular Atrophy. We invite you to share your experiences of living with SMA.

What is involved?

We would love to hear about your experience of living with SMA. We are inviting you to participate in an **online survey.**

How long will it take?

This will take a minimum of **15 minutes and up to 30 minutes.**

Who can do the survey?

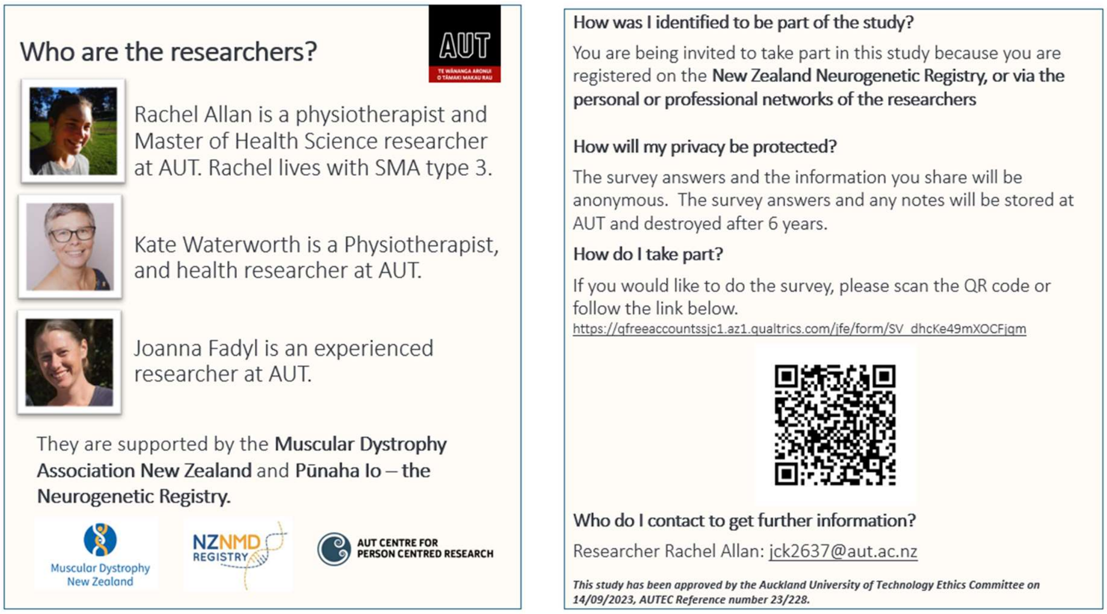
Adults with a confirmed diagnosis of SMA can complete the survey. You must be over 18 and a New Zealand citizen or resident. You can still take part if you currently live overseas.

What is the survey about?

The aim of this study is to find out about the **ways that adults living with SMA understand and think about *movement* and *movement loss*,** and the ways these understandings are **informed and shaped by one's interactions in the New Zealand health system and society.**

The purpose is to produce a collective understanding of these experiences and make this available to people living with SMA and those they interact with in the wider community.

We also welcome your whakairo (thoughts) of **how services could better support people living with SMA and their whānau in the future.**



Who are the researchers?

Rachel Allan is a physiotherapist and Master of Health Science researcher at AUT. Rachel lives with SMA type 3.

Kate Waterworth is a Physiotherapist, and health researcher at AUT.

Joanna Fadyl is an experienced researcher at AUT.

They are supported by the **Muscular Dystrophy Association New Zealand** and **Pūnaha Io – the Neurogenetic Registry.**

How was I identified to be part of the study?

You are being invited to take part in this study because you are registered on the **New Zealand Neurogenetic Registry, or via the personal or professional networks of the researchers**

How will my privacy be protected?

The survey answers and the information you share will be anonymous. The survey answers and any notes will be stored at AUT and destroyed after 6 years.

How do I take part?

If you would like to do the survey, please scan the QR code or follow the link below.
https://qfreeaccountssjc1.az1.qualtrics.com/jfe/form/SV_dhcKe49mXOCFjqm

Who do I contact to get further information?

Researcher Rachel Allan: jck2637@aut.ac.nz

This study has been approved by the Auckland University of Technology Ethics Committee on 14/09/2023, AUTEC Reference number 23/228.

Appendix F: Information Page and Consent form for Online Survey

(this is the first page of the online survey)

Moving with Spinal Muscular Atrophy

Thank you for clicking the link!

This page has important information about the survey and how you can take part. Take a moment to read through this and if you need to talk with one of the team, our details are further down the page.

If you decide you would like to take part, click 'take this survey' at the bottom of the page.

Information on this survey

You are invited to take part in a survey about your experience living with Spinal Muscular Atrophy. This survey is being run by researchers at the Centre for Person-Centred Research, at Auckland University of Technology (AUT), in collaboration with the Muscular Dystrophy Association of New Zealand and Pūnaha Io the Neurogenetic Registry and Biobank.

Participation is completely voluntary – it is your choice whether you take part.

- If you choose not to take part, this will not affect you in any way.
- If you choose to take part, read the statements at the bottom of this page and tick to indicate you wish to proceed.

If you then wish to withdraw from the survey, you can only do so at any time before you submit your responses. Once you submit your responses, we won't be able to remove your data given the survey is electronic and anonymous.

What is the purpose of this survey?

The purpose of this survey is to find out about your experiences living with spinal muscular atrophy and the way that this has impacted the way that you experience and think about movement.

The findings will be written into a report and provided to the Muscular Dystrophy Association NZ and Pūnaha Io Neurogenetic Registry and Biobank and published in an academic journal.

Why am I being invited to participate in this survey?

We have distributed survey links to New Zealand adults living with Spinal Muscular Atrophy whose names are on the Neurogenetic Registry. You are being invited as someone who is part of the neurogenetic registry who lives with SMA.

What will happen in this survey?

If you decide to take part, you will move to the next screen and will be invited to answer a few questions about you and your experiences of living with Spinal Muscular Atrophy.

What are the benefits of being involved?

We will write a report with the data collected from this survey and give it to our collaborating organisations. We hope this will contribute to their work with government and health care professionals to improve future experiences for all New Zealanders living with Spinal Muscular Atrophy or other long-term neuromuscular disorders.

How will my privacy be protected?

The survey answers and all the information you share will be anonymous.
The survey answers and any notes will be stored securely at AUT and be destroyed after 6 years.

What are the costs of participating in this research?

The only cost to you is your time. We estimate the survey will take between 10–30 minutes, but please take as long as you need.

What opportunity do I have to consider this invitation?

The survey is available to take any point from:
Start: 9am DD MM 2023
Finish: 5pm DD MM 2023
You can use the link in the email you may have received or continue here to proceed to the survey at any time during this period.

How do I agree to take part in this survey?

To take part in this survey, please:

1. Read the statements below and tick the box at the end to show you have read and understood this information and consent to take part, then:
2. Click the button ‘take the survey’.

Will I receive feedback on the findings of this survey?

We will provide a summary of findings to our collaborating organisations so they can share the findings with their members.

Who do I contact for further information about this survey?

Researcher, Rachel Allan: jck2637@aut.ac.nz
Project supervisor, Kate Waterworth: kate.waterworth@aut.ac.nz
Project supervisor, Dr Joanna Fadyl: joanna.fadyl@aut.ac.nz

What do I do if I have concerns about this research?

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC, ethics@aut.ac.nz, (09) 921, 9999 ext 6038

This project has been approved by the Auckland University of Technology Ethics Committee on 14/09/23 Reference number 23/228.

Would you like to take part in this survey?

If yes, then please read the following statements and check the boxes to confirm you consent.

○ I have read and understood the information provided above.

○ I understand that completing this survey is voluntary (my choice), and that once I submit my responses, I won’t be able to withdraw them from the survey.

○ I confirm that I am 18 years or older

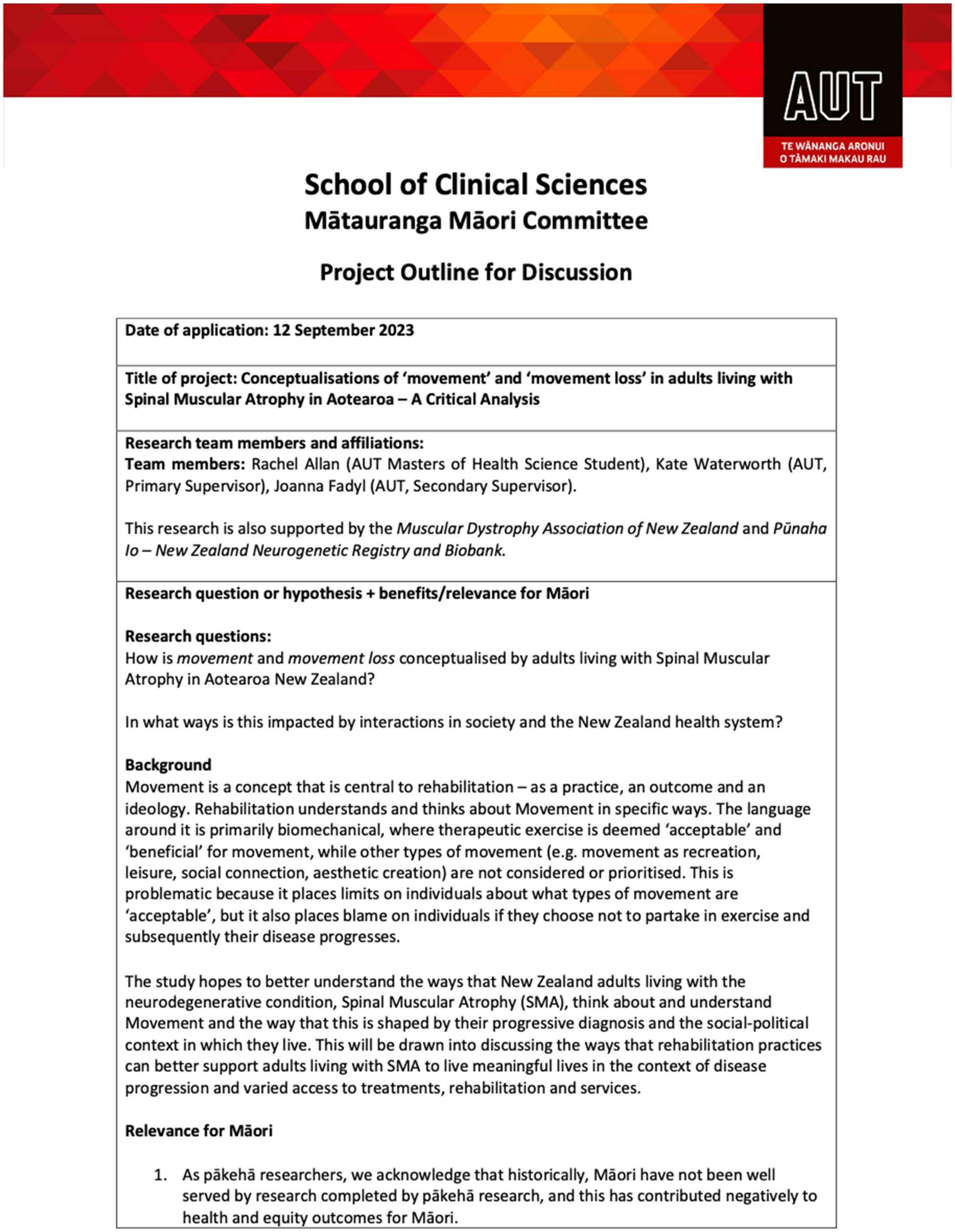
○ I confirm that I have a diagnosis of Spinal Muscular Atrophy

○ I confirm that I am a New Zealand citizen or resident.

○ I agree to take part.

Take this Survey

Appendix G: Letter of application to AUT School of Clinical Sciences Komiti Mātauranga Māori



AUT
TE WĀNANGA ARONUI
O TĀMAKI MAKAU RAU

School of Clinical Sciences
Mātauranga Māori Committee

Project Outline for Discussion

Date of application: 12 September 2023

Title of project: Conceptualisations of 'movement' and 'movement loss' in adults living with Spinal Muscular Atrophy in Aotearoa – A Critical Analysis

Research team members and affiliations:
Team members: Rachel Allan (AUT Masters of Health Science Student), Kate Waterworth (AUT, Primary Supervisor), Joanna Fadyl (AUT, Secondary Supervisor).

This research is also supported by the *Muscular Dystrophy Association of New Zealand* and *Pūnaha Io – New Zealand Neurogenetic Registry and Biobank.*

Research question or hypothesis + benefits/relevance for Māori

Research questions:
How is *movement* and *movement loss* conceptualised by adults living with Spinal Muscular Atrophy in Aotearoa New Zealand?

In what ways is this impacted by interactions in society and the New Zealand health system?

Background
Movement is a concept that is central to rehabilitation – as a practice, an outcome and an ideology. Rehabilitation understands and thinks about Movement in specific ways. The language around it is primarily biomechanical, where therapeutic exercise is deemed 'acceptable' and 'beneficial' for movement, while other types of movement (e.g. movement as recreation, leisure, social connection, aesthetic creation) are not considered or prioritised. This is problematic because it places limits on individuals about what types of movement are 'acceptable', but it also places blame on individuals if they choose not to partake in exercise and subsequently their disease progresses.

The study hopes to better understand the ways that New Zealand adults living with the neurodegenerative condition, Spinal Muscular Atrophy (SMA), think about and understand Movement and the way that this is shaped by their progressive diagnosis and the social-political context in which they live. This will be drawn into discussing the ways that rehabilitation practices can better support adults living with SMA to live meaningful lives in the context of disease progression and varied access to treatments, rehabilitation and services.

Relevance for Māori

1. As pākehā researchers, we acknowledge that historically, Māori have not been well served by research completed by pākehā research, and this has contributed negatively to health and equity outcomes for Māori.

We also acknowledge that researchers are legally required to consider the ethical positioning of their research for Māori under Te Tiriti o Waitangi.

2. To our knowledge, this would be the first qualitative study on SMA completed in context of Aotearoa New Zealand. While our research does not look to specifically target Māori as the sample population, we do wish to support Māori participation and engagement in the study, and ultimately ensure Māori are well served by the research that we produce.

3. SMA is an inherited neurogenetic disorder. While unpublished demographic research has indicated that Māori may have lower prevalence of SMA than non-Māori, the genetic nature of this condition holds relevance to Māori due to its ties to whanau and whakapapa.

4. This work utilizes a critical relativist paradigm and looks to question the narrow understandings of *movement* held by the western biomedical model and rehabilitation at large.

   Indigenous perspectives provide valuable insight into alternative ways of understanding concepts such as *movement* and *disability*, and we believe tāngata whaikaha Māori have valuable knowledge base from which 1) the status quo in the New Zealand health system may be questioned; and 2) generate insight into how we might be able to facilitate change that is meaningful for tāngata whaikaha Māori and whanau hauā.

   Including and accounting for these perspectives in a meaningful way has the potential to provide foundational evidence to help address current health inequities for Māori, and also provide knowledge that could be used to further Kaupapa Māori Research in this area.

Research participants
8-10 participants

What stage is the research project at? (e.g. proposed or implemented)
Proposed.

PGR1 application has been approved, ethics application has been sent to AUT ethics committee and first round of feedback has been received.

We hope to begin data collection in September 2023.

Consultation with Māori to date
We have consulted with Ronelle Baker (Board member and commissioner at Mana Mokopuna/ Children and Young people's Commission, principal advisor in accessibility at Stats NZ, and tāngata whaikaha Māori living with muscular dystrophy), to discuss her perspectives on the research and how the research may be completed in a way that supports Māori values and engagement.

This is the first formal consultation with Māori through AUT network.

Methodology
Qualitative (critical relativism, constructionism) drawing upon critical social theory and critical disability theory for methodology.

We will be conducting an online survey, semi-structured interviews and using reflexive thematic analysis to analyse the results.

Recruitment processes

Potential participants will be recruited through advertisement through *Pūnaha Io – the Neurogenetic registry and Biobank*, and the *Muscular Dystrophy Association of New Zealand* networks.

Online Survey:

The Neurogenetic Registry will send an email invite to adults >18yo whose details are on the registry to participate in the *Moving with SMA* online survey. The Muscular Dystrophy Association will support this by also sending an email advertisement about the survey to their members with SMA who are >18yo.

Semi-structured interviews:

The Neurogenetic Registry will identify 8-10 potential participants for from the registry who meet certain demographic criteria set by the research team (age, ethnicity, SMA, region) to invite to participate in the semi-structured interviews.

Individual emails are sent to potential participants to invite them to participate in the interview process. A time limit of 2 weeks will be put in place for potential participants to choose to respond to the email. At this point, another potential participant may be invited to participate instead. If participants consent to take part, they will be invited to contact Rachel Allan from the research team.

Data collection

An online survey of open-ended questions via *Qualtrics* will be completed.

If participants consent to be interviewed, this will be arranged either in person (at AUT North Campus) or by videocall on a platform of the participant's choice (including the option of zoom). The interview will be recorded on a digital audio recorder. Recordings will be transcribed by Rachel.

Data analysis

Data will be analysed using reflexive thematic analysis. Patterns of shared meaning will be constructed from across the dataset, informed by theory.

Dissemination of results

This research will result in a Masters of Health Science Thesis, which will be held in the AUT library data base. The findings will also be submitted for presentation at a NZ and an international conference, and for publication in a relevant journal.

A report of the findings will also be provided to supporting organisations (Muscular Dystrophy Association New Zealand and Pūnaha Io- Neurogenetic Registry and Biobank) for further distribution to the SMA and neuromuscular community.

Any specific areas for discussion?

The broader research team recognise that the contemporary and historical context have contributed to experiences of racism and burden for Māori researchers. Our awareness of this has meant we are looking to support the participation of tāngata whaikaha Māori in this study, and ensure that perspectives shared are appropriately interpreted and shared with the community.

We would like to hear your feedback and suggestions around this, as well as any other aspects you wish to discuss.

Would you like your project to remain confidential? ~~Yes~~ No

Do you intend to bring any support people to the meeting? ~~Yes~~ No

Have you read the *Te Ara Tika guidelines for Māori Research Ethics*? Yes ~~No~~

Note: Observers may be present at the meeting (except where the project is confidential)

Appendix H: Letter of Feedback with Recommendations for Study Design from AUT School of Clinical Sciences Komiti Mātauranga Māori 09.11.2023

AUT
TE WĀNANGA ARONUI
O TĀMAKI MAKAU RAU

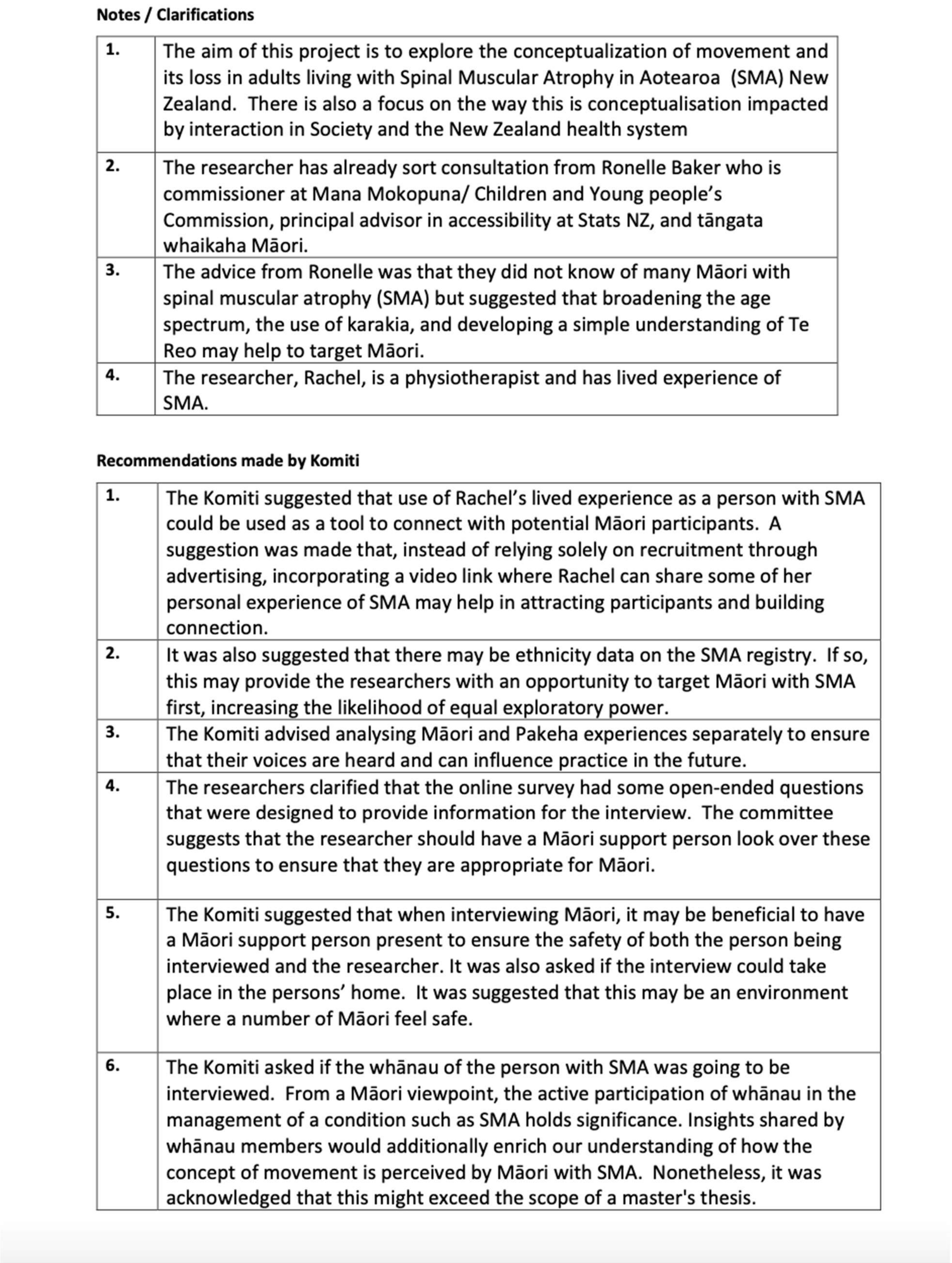
School of Clinical Sciences

Komiti Mātauranga Māori

Verification of Māori Consultation

This document provides verification that the research project named below was discussed with the School of Clinical Sciences Komiti Mātauranga Māori, Auckland University of Technology. Specific comments and recommendations are indicated following the table.

Title of project Conceptualisations of ‘movement’ and ‘movement loss’ in adults living with Spinal Muscular Atrophy in Aotearoa – A Critical Analysis		
Research Team members and affiliations: Rachel Allan (AUT Masters of Health Science Student), Kate Waterworth (AUT, Primary Supervisor), Joanna Fadyl (AUT, Secondary Supervisor).		**Meeting Date:** 1st October 2023
Discussion Areas		**Discussed**
Whakapapa: Relationships		
Researcher experience in field		X
Consultation with local stakeholders		X
Consenting process		
Clarity of data usage		
Dissemination of findings		X
Benefits to participants		
Protecting the rights & interest of Māori		
Clear purpose of project		
Relevance to Māori		
Likely outcome for participants, communities, other stakeholders		
Participant recruitment methods		X
Māori involvement in project (participants, researchers, etc.)		X
Cultural & Social Responsibility		
Participants’ access to appropriate advice		
Participants treated with dignity and respect		
Privacy and confidentiality		
Whānau support		
Transparency of research process		
Mana tangata – Power & Authority		
Reciprocity (acknowledgements, compensation, gifts)		
Risks of participation identified		
Ownership of outcomes		
Informed consent process		



Notes / Clarifications

1.	The aim of this project is to explore the conceptualization of movement and its loss in adults living with Spinal Muscular Atrophy in Aotearoa (SMA) New Zealand. There is also a focus on the way this is conceptualisation impacted by interaction in Society and the New Zealand health system
2.	The researcher has already sort consultation from Ronelle Baker who is commissioner at Mana Mokopuna/ Children and Young people's Commission, principal advisor in accessibility at Stats NZ, and tāngata whaikaha Māori.
3.	The advice from Ronelle was that they did not know of many Māori with spinal muscular atrophy (SMA) but suggested that broadening the age spectrum, the use of karakia, and developing a simple understanding of Te Reo may help to target Māori.
4.	The researcher, Rachel, is a physiotherapist and has lived experience of SMA.

Recommendations made by Komiti

1.	The Komiti suggested that use of Rachel's lived experience as a person with SMA could be used as a tool to connect with potential Māori participants. A suggestion was made that, instead of relying solely on recruitment through advertising, incorporating a video link where Rachel can share some of her personal experience of SMA may help in attracting participants and building connection.
2.	It was also suggested that there may be ethnicity data on the SMA registry. If so, this may provide the researchers with an opportunity to target Māori with SMA first, increasing the likelihood of equal exploratory power.
3.	The Komiti advised analysing Māori and Pakeha experiences separately to ensure that their voices are heard and can influence practice in the future.
4.	The researchers clarified that the online survey had some open-ended questions that were designed to provide information for the interview. The committee suggests that the researcher should have a Māori support person look over these questions to ensure that they are appropriate for Māori.
5.	The Komiti suggested that when interviewing Māori, it may be beneficial to have a Māori support person present to ensure the safety of both the person being interviewed and the researcher. It was also asked if the interview could take place in the persons' home. It was suggested that this may be an environment where a number of Māori feel safe.
6.	The Komiti asked if the whānau of the person with SMA was going to be interviewed. From a Māori viewpoint, the active participation of whānau in the management of a condition such as SMA holds significance. Insights shared by whānau members would additionally enrich our understanding of how the concept of movement is perceived by Māori with SMA. Nonetheless, it was acknowledged that this might exceed the scope of a master's thesis.

7.	The Komiti advised allowing participants and whanau the opportunity to decide what format interviews might take – eg together or separately.
8.	The Komiti noted the risks of assumptions of meaning during the interview process, both from a Māori and lived experience perspective, and would encouraged the researcher to delve deeper to explore what participants are really saying, and checking in that you are hearing what participants are telling you.
9.	It was strongly recommended that the researcher represent their analysis of interviews to those Māori being interviewed early in the analysis to ensure that the researchers interpretation of information given is correct, and demonstrating respect in the way their korero is being honoured.

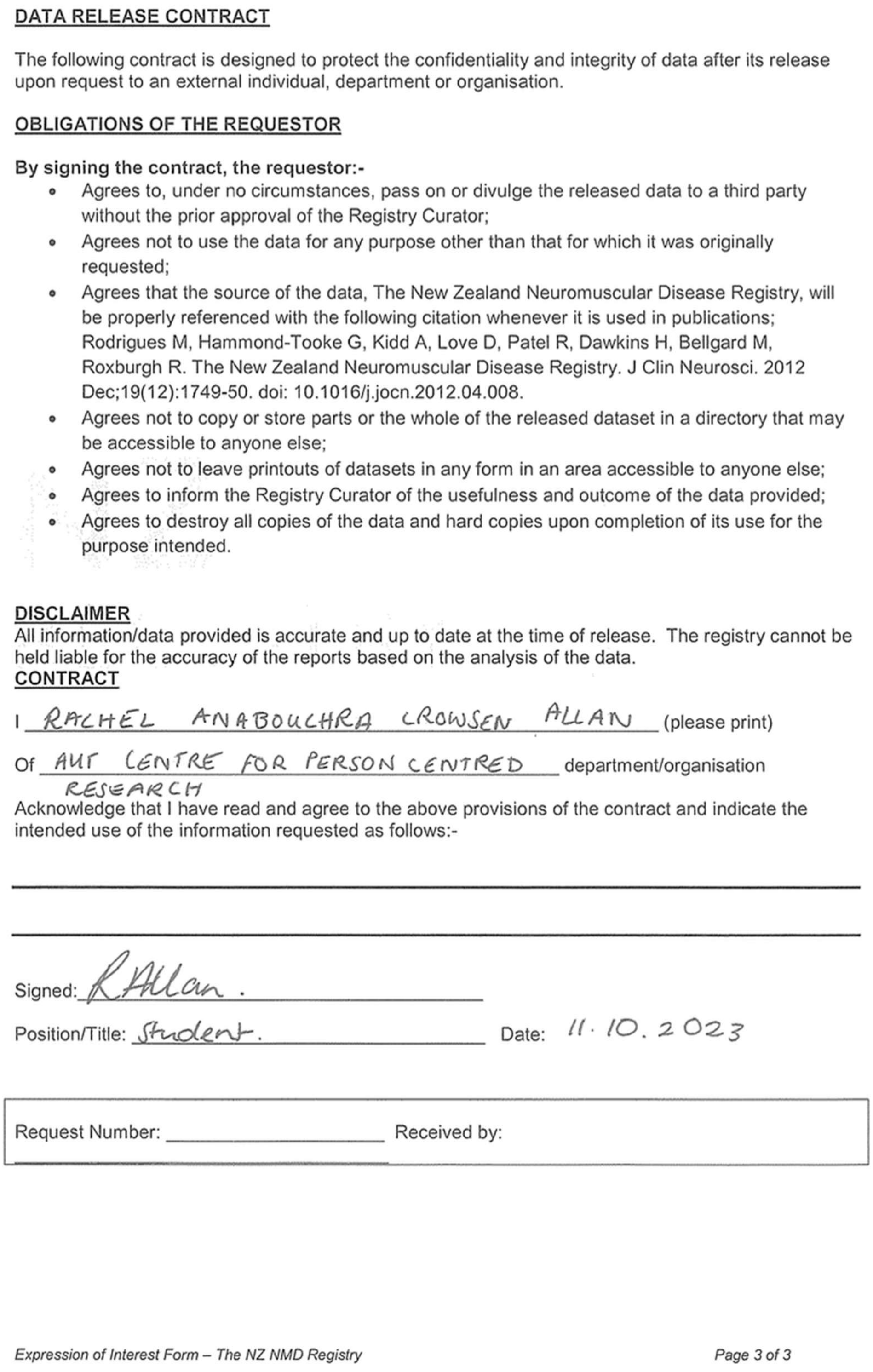
Please contact the Committee's Administrator Greta Smith at socs-mmc@aut.ac.nz if you have any questions about this feedback.

You may be contacted in 12 months' time for feedback about the process and the usefulness of these comments and recommendations to your project.

Signature: Date: 09/11/2023

Grant Mawston
Mātauranga Māori Consultation Committee

Appendix I: Application for Access to the Pūnaha Io Neuro-Genetic Register and Biobank of NZ



DATA RELEASE CONTRACT

The following contract is designed to protect the confidentiality and integrity of data after its release upon request to an external individual, department or organisation.

OBLIGATIONS OF THE REQUESTOR

By signing the contract, the requestor:-

- Agrees to, under no circumstances, pass on or divulge the released data to a third party without the prior approval of the Registry Curator;
- Agrees not to use the data for any purpose other than that for which it was originally requested;
- Agrees that the source of the data, The New Zealand Neuromuscular Disease Registry, will be properly referenced with the following citation whenever it is used in publications; Rodrigues M, Hammond-Tooke G, Kidd A, Love D, Patel R, Dawkins H, Bellgard M, Roxburgh R. The New Zealand Neuromuscular Disease Registry. J Clin Neurosci. 2012 Dec;19(12):1749-50. doi: 10.1016/j.jocn.2012.04.008.
- Agrees not to copy or store parts or the whole of the released dataset in a directory that may be accessible to anyone else;
- Agrees not to leave printouts of datasets in any form in an area accessible to anyone else;
- Agrees to inform the Registry Curator of the usefulness and outcome of the data provided;
- Agrees to destroy all copies of the data and hard copies upon completion of its use for the purpose intended.

DISCLAIMER
All information/data provided is accurate and up to date at the time of release. The registry cannot be held liable for the accuracy of the reports based on the analysis of the data.

CONTRACT

I RACHEL ANABOUCHRA CROWSEN ALLAN (please print)

Of AUT CENTRE FOR PERSON CENTRED RESEARCH department/organisation

Acknowledge that I have read and agree to the above provisions of the contract and indicate the intended use of the information requested as follows:-

Signed: R Allan .

Position/Title: Student.

Date: 11. 10. 2023

Request Number: ____________ Received by:

Expression of Interest Form – The NZ NMD Registry *Page 3 of 3*

Appendix J: Link to video advertisement for Online Survey and Semi-Structured Interviews.

Video Advert Link: https://youtu.be/zsI1w7H2vt4

This link was distributed as part of Materials A. and Materials B. distributed by Pūnaha Io the Neuro-Genetic Register and Biobank to potential participants.

Appendix K: Online Survey Questions

Demographics.

Let’s get started with some questions. Remember your answers are anonymous.

In order for us to learn about the range of participants taking part in this research, we would be grateful if you could answer the following questions. Please either type your answer in the space provided or tick the answer that best applies.

My age is:

How would you describe your gender?

○ Male
○ Female
○ Another Gender
○ Prefer not to say

What ethnic group do you belong to? Select all that apply to you.

○ Māori
○ Samoan
○ Cook Islands Maori
○ Tongan
○ Niuean
○ Chinese
○ Indian
○ Other e.g. Dutch, Japanese, Tokelauan
○ New Zealand European

If Māori, what are your iwi affiliations?

Where do you currently live?

○ Northern
○ Te Manawa Taki
○ Central
○ Te Waipounamu
○ I currently live overseas

What is/are your current occupation/s? (examples: primary caregiver, student, artist, entrepreneur, business woman…)

What type of Spinal Muscular Atrophy (SMA) are you diagnosed with?

- ○ Type 1
- ○ Type 2
- ○ Type 3
- ○ Type 4

PART 2:

This survey will continue with a small number of open-ended questions. You can answer them with as much or as little detail as you like. The boxes are expandable so don't feel limited in your responses.

Thinking about your experience living with SMA, and the ways that it has impacted your experience of movement, please answer the following questions.

Can you describe how you came to be diagnosed with SMA?

We are interested in hearing how the experience of living and moving with SMA might change over time. Drawing on your experience, what is it like to live and move in a body with SMA?

What was your experience of living and moving as a child?

Was there a time during your youth where you experienced a big change to living and moving? If so, can you describe this.

Describe some aspects of your experience of living and moving at the current time.

What do you believe your experience of living and moving might be like 10 years from now?

Tell us about how living with SMA impacted you and your whanau generally.

Tell us about your experience of accessing and navigating health care services while living with SMA. We are interested in hearing about when things have gone well or it has been challenging.

Tell us about your experience of accessing and navigating other social institutions (e.g. school, the work place, sports and leisure activities, libraries, public transport) while living with SMA. We are interested in hearing about when things have gone well or it has been challenging.

Do you have any comments about how well your needs are met overall in the current systems?

Tell us about some activities that bring you joy and fulfillment.

Tell us about an experience where you had to change your approach to one of these activities because of your SMA. We are interested in hearing about when things have gone well or it has been challenging.

In your opinion, what does it mean to live a healthy, active life with SMA?

In your opinion, how might individuals living with SMA be supported to live healthy, active lives?

Please share anything else you feel is important for us to know relating to your experience of living with SMA.

Appendix L: Semi-Structured Interview Guide

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Private Bag 92006, Auckland 1142, NZ
T: +64 9 921 9999
www.aut.ac.nz

Semi-structured Interview Guide

Project Title: **Moving with Spinal Muscular Atrophy**

Note that these are prompts to guide the interviewer regarding topics of interest. Not every participant will be asked every question. The interviewer will also follow the lead of the participant and will explore topics they raise in more depth as they go. Further, questioning was refined as the interviews progressed to help really explore notions of Movement and Movement Loss.

☐ **Can you tell me a bit about yourself?**

☐ **In what ways has living with SMA impacted you and your whānau generally?**

☐ **What is it like to live in your body with SMA?**
This might include physical aspects such as your daily routine. You might also choose to discuss any mental, spiritual, emotional or social aspects of your experience.

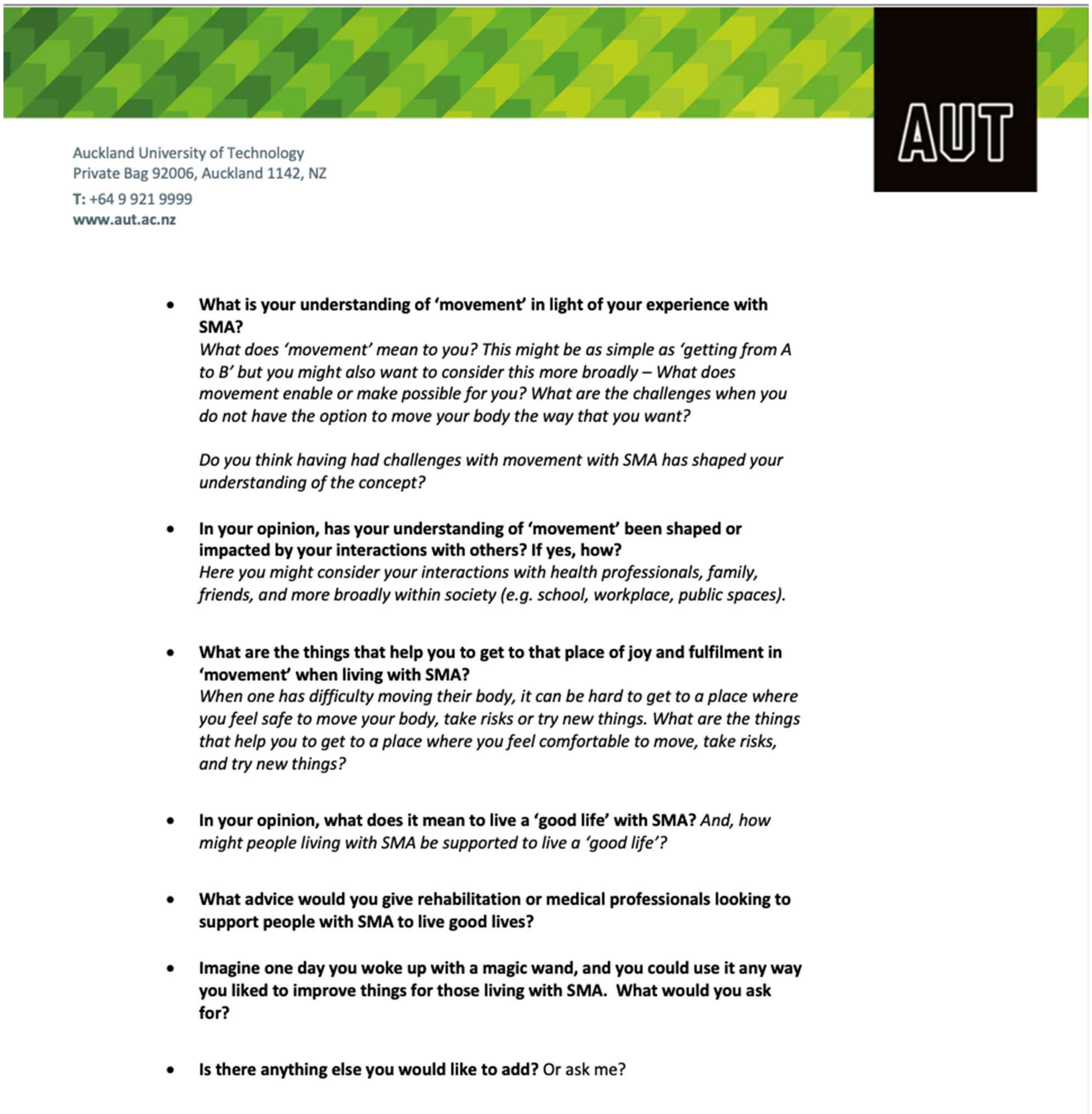
☐ **What has your experience been of accessing and navigating health care services?**
You can consider where have things have gone well or where there have been challenges. You can also include any experiences relating to whānau supporting you here as well.

☐ **What has your experience been of accessing and navigating other spaces and places?**
This might include places like schools, the workplace, sports, leisure activities, libraries, public transport. You can consider where have things have gone well or where there have been challenges. You can also include any experiences relating to whānau supporting you here as well.

☐ **Do you have any comments on how well your needs are met overall in the current systems?**

☐ **Can you tell me about some of the activities that bring you joy and fulfilment while living with SMA?**
You could consider things such as hobbies, social interactions, physical activities. These activities can be supported by others.

☐ **Was there a time that you had to change your approach to one of these activities because of your SMA? If so, can you share your experience with us?**



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- **What is your understanding of 'movement' in light of your experience with SMA?**
  What does 'movement' mean to you? This might be as simple as 'getting from A to B' but you might also want to consider this more broadly – What does movement enable or make possible for you? What are the challenges when you do not have the option to move your body the way that you want?

  Do you think having had challenges with movement with SMA has shaped your understanding of the concept?

- **In your opinion, has your understanding of 'movement' been shaped or impacted by your interactions with others? If yes, how?**
  Here you might consider your interactions with health professionals, family, friends, and more broadly within society (e.g. school, workplace, public spaces).

- **What are the things that help you to get to that place of joy and fulfilment in 'movement' when living with SMA?**
  When one has difficulty moving their body, it can be hard to get to a place where you feel safe to move your body, take risks or try new things. What are the things that help you to get to a place where you feel comfortable to move, take risks, and try new things?

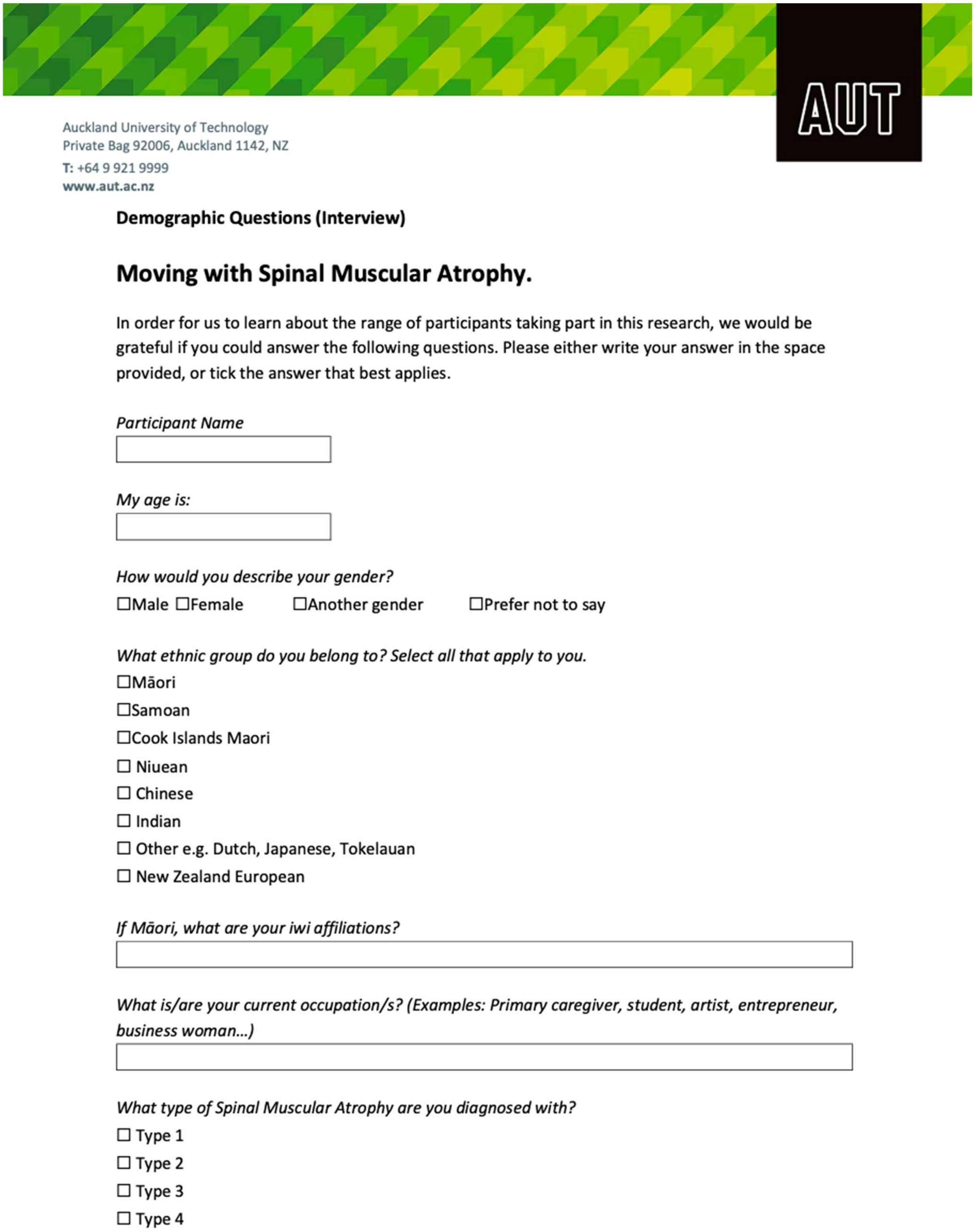
- **In your opinion, what does it mean to live a 'good life' with SMA?** *And, how might people living with SMA be supported to live a 'good life'?*

- **What advice would you give rehabilitation or medical professionals looking to support people with SMA to live good lives?**

- **Imagine one day you woke up with a magic wand, and you could use it any way you liked to improve things for those living with SMA. What would you ask for?**

- **Is there anything else you would like to add?** Or ask me?

Appendix M: Interview Demographic form



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Demographic Questions (Interview)

Moving with Spinal Muscular Atrophy.

In order for us to learn about the range of participants taking part in this research, we would be grateful if you could answer the following questions. Please either write your answer in the space provided, or tick the answer that best applies.

Participant Name

My age is:

How would you describe your gender?

☐Male ☐Female ☐Another gender ☐Prefer not to say

What ethnic group do you belong to? Select all that apply to you.

☐Māori
☐Samoan
☐Cook Islands Maori
☐ Niuean
☐ Chinese
☐ Indian
☐ Other e.g. Dutch, Japanese, Tokelauan
☐ New Zealand European

If Māori, what are your iwi affiliations?

What is/are your current occupation/s? (Examples: Primary caregiver, student, artist, entrepreneur, business woman…)

What type of Spinal Muscular Atrophy are you diagnosed with?

☐ Type 1
☐ Type 2
☐ Type 3
☐ Type 4

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Where do you currently live?

☐ Northern
☐ Te Manawa Taki
☐ Central
☐ Te Waipounamu
☐ I currently live overseas

This project has been approved by the Auckland University of Technology Ethics Committee on 14/09/2023, Reference number 23/228.

Appendix N: List of Preliminary Codes Used in Phase 2 (Coding) of Reflexive Thematic Analysis

This table represents early attempts to consolidate codes so that participant data could be grouped across interviews according to common topics.

CODE	*DESCRIPTION*
#Descriptions of SMA	Refers to how the participant locates themselves in comparison to others of SMA. Often the participant will utilise biomedical descriptors in order to be able to do this.
#The SMA body	Refers to the **embodied lived experiences** such as **sensations** (such as pain, or the experience of heavy, weighted limbs), **experiences** like fatigue, or fluctuations in function and the need to adapt. **Strategies** like planning and management skills to navigate one's body in space, to ensure that one's needs are met, to 'look normal' It might also involve **one's relationship to one's body** – is the body an *ally*? Or a *foe*?
#Whanau and Family impact	Anything discussing the impact of SMA on a participant's family.
#Accessing and navigating health care	**Relationships** (e.g. what happens in the clinical interaction? Is this person an ally? Or someone who is a danger to me (e.g. by physically putting me at risk, threat to personhood e.g. by denying my experience, denying access to care?) **Pathways** e.g. systemic pathways to get access to things like equipment or services (like physiotherapy or respiratory care)
#Accessing and navigating places and spaces	**Relationships** – e.g. with teachers, disability support providers, inclusion **Pathways** – getting to/ from places, getting around the community, accessibility of the physical environment, equipment that makes the environment accessible
#Progressive label	Refers to discussions regarding the impact of the progressive label associated with an SMA diagnosis, their feelings about this, the perceived impact this diagnosis has had on them
#Adapting to change	Ways in which participants have adapted their lives in response to their SMA. E.g. adaptive equipment, communication strategies, adapting their mindset. It also includes examples where the participant may have needed to withdraw from an activity because of their physical limitation or because the activity became too emotionally triggering for them to continue.
#Movement is…	Participants definition of Movement as a concept, drawing on their lived experience of SMA. This may also include the types of movement they consider to be most important and relevant to them, or their reflections on participating in organised movement (such as physiotherapy).
#Movement shaped by SMA	Refers to the extent to which the participant locates their understanding of movement as influenced directly by the physical impairments caused by SMA

#Movement shaped by Others	Refers to the extent to which the participant locates their understanding of movement as influenced by the way they are treated by others in society.
#Joyful, fulfilling and meaningful movement	Refers to the activities reported by participants to give them joy or fulfilment. Also includes activities that participants referred informally that they had a preference to (for example, describing a preference for swimming to stretch their muscles out when managing their condition)
#Being brave and trying new things	Participant's perceived enablers/drivers for them to continue to push the boundaries of what is possible for them. These might be **external** to the person: E.g. Whanau, Family, big events or opportunities, Or **internal**: e.g. accessing the part of their personality/ personhood that gives them the grit and determination to get things done.
#Spinraza and Risdiplam and the meaning of access	Refers to the opinions of individuals around the relative importance of pharmaceuticals like *Spinraza* and *Risdiplam* to them.
#Big Pharma and SMA	Discussion of pharmaceutical treatments and the ethical the dilemma of distribution for society more broadly.
#Truth to power	Power distributions within society impact the person living with SMA. Engagement in activities such as advocacy, stepping up to institutions to make a difference
#Towards change	The advice given by participants to support change.
#Places you go	The emotions felt by the participant in response to their social interaction. For example, Grief, frustration, humiliation, sadness, depression, shock, anxiety, triumph, joy, fulfilment, hope.

Appendix O: List of Meaningful Activities

The list below is a summary of activities listed by participants as providing them with experience of joy and fulfillment despite the physical limitations imposed on them by their SMA.

Giving	Looking after house plants (watering them, repotting them) Activities with children or grand children Activities with companion animals Cooking for one’s family
Connecting with Nature	Gardening Being out in the garden or in nature Beach combing or Swimming at the beach Leisure walking in nature Walking or going out in wheelchair with a companion animals.
Learning and Intellectual pursuits	Upskilling and doing courses Reading Jigsaws Playing games like scrabble, up-words, word games, card games
Connecting with others	Connecting with people Connecting with organisations (e.g., community groups, charities, NGOs) Going to music festivals or concerts Taking children to sports, being involved with their school things. Going out with friends (e.g., for coffee or food, to concerts, parties, the movies, quiz nights, or events) Organised Sport (e.g., wheelchair soccer)
Being Active	Exploring and going new places (e.g. day trips or weekend trips that don’t involve flying). Swimming at the beach or at a pool Walking or going out in one’s wheelchair Dance Sports – wheelchair soccer, air rifle shooting Hunting – shooting to catch food Moving with companion animals
Creative Pursuits	Writing and Journaling Crafts: Scrapbooking, Card-making, Cross stitch Art: Painting, Photography, Digital art, Pottery, going to art galleries. Music: Playing music, attending concerts. Interior design Fashion
Sensory	Feeling of weightlessness while in the pool Skincare Getting hair and nails done.
Mind body	Meditation
Technology	Playing videogames with friends. Watching Netflix, TV series or movies
Education and Work	Professional development activities. Being in paid employment.