Shoulder Pain Intervention delivered over the interNet (SPIN) after Spinal Cord Impairment (SCI): development of a self-guided digital exercise intervention

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Abstract

For people living with spinal cord impairment (SCI), chronic shoulder pain is common and frequently limits community mobility. This leads to loss of independence and reduced quality of life. Evidence has shown that specific exercises, supervised by a physiotherapist, can significantly reduce shoulder pain. However, cost, need for expertise, and transport barriers can limit access to treatment services. Technology is increasingly being used to help bridge this gap and deliver health care services directly to people in their communities. Despite this, there remains a lack of well-designed and evidence-based digital interventions, delivered remotely, that support self-guided exercises to help manage shoulder pain in this population. My doctoral work aimed to develop an evidence-informed and self-guided digital intervention: SPIN (Shoulder Pain Intervention over the interNet) to help people living with SCI (pwSCI) manage their shoulder pain.

The Person-Based Approach (PBA) was used to guide the development of SPIN. This approach involved iterative phases that were informed by a deep understanding of the needs and context of those who would use the intervention (pwSCI who have shoulder pain).

A systematic review and meta-analysis of other digital self-guided physical activity and exercise interventions was conducted early in the research. It found that interventions that were underpinned by a theoretical framework and that incorporated self-regulatory behavioural strategies had a positive effect on physical activity and other health outcomes in people living with chronic health conditions. These findings lent support to the notion of a self-guided intervention and helped inform what features SPIN should incorporate.

Primary evidence was then collected through an Interpretive Descriptive qualitative study, undertaken with pwSCI who have shoulder pain. The purpose was to better understand the factors that would influence engagement, when contemplating and using a self-guided digital intervention. Themes were drawn from the data that represented decision-making steps for pwSCI that occurred at key points. A schematic

model was developed: *Should I use it? Can I use it? Will I use it?*. This work informed the subsequent PBA phase which involved the design and development of SPIN.

Guiding principles were formulated during the design phase, using data from the earlier phase. These shaped the design objectives and intervention features of SPIN, ensuring they continued to meet the identified needs of those who would use the intervention. Initial wireframes were then created. Wireframes are basic screen layouts that demonstrate intervention features, focusing on content, space allocation and flow, without getting distracted by aesthetics. These were refined over the development phase through focus groups with academic and clinical informants and individual 'think aloud' sessions with pwSCI. A final SPIN wireframe prototype was produced, ready for the post-doctoral phase of software design and coding.

My doctoral work has developed a digital intervention that is evidence-informed, self-guided and responsive to users' needs, addressing many of the problems with existing apps. It has been explicit in its development during each phase and has continued to keep users' identified needs central throughout. The findings from this work have applicability to current clinical practice while addressing many limitations.

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Attestation of authorship

"I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor 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."

Co-authored works

Chapter and publication	Author and nature of contribution
Chapter 3 Stavric, V., Saywell, N., & Kayes, N. M. (2019). Development of a self-guided web-based exercise intervention (SPIN) to treat shoulder pain in people living with spinal cord injury: Protocol of a mixed methods study. *BMJ Open*, 9(9), Article e031012. https://doi.org/10.1136/bmjopen-2019-031012	**Stavric (80%)**, conceptualisation of research aims and study, development of method, preparation and creation of original manuscript draft, responses to journal reviewer feedback, revision and editing of manuscript, and funding acquisition for the project. **Saywell (10%)**, conceptualisation of research aims and study, development of method, provision of supervision of the study (oversight and leadership responsibility), provision of feedback on manuscript drafts and reviewer feedback. **Kayes (10%)**, conceptualisation of research aims and study, development of method, provision of supervision of the study (oversight and leadership responsibility), provision of feedback on manuscript drafts and reviewer feedback.
Chapter 4 Stavric, V., Kayes, N. M., Rashid, U., & Saywell, N. L. (2022). The effectiveness of self-guided digital interventions to improve physical activity and exercise outcomes for people with chronic conditions: a systematic review and meta-analysis. *Frontiers in Rehabilitation Sciences*. 3:925620. https://doi.org/10.3389/fresc.2022.925620	**Stavric (80%)**, conceptualisation of research aims and study, development of method, registration of the study, formal data synthesis, collaboration with Rashid on statistical analyses, preparation, creation of original manuscript draft, responses to journal reviewer feedback, and revision and editing of manuscript. **Kayes (8%)**, conceptualisation of research aims and study, development of method, provision of supervision of the study (oversight and leadership responsibility), provision of feedback on manuscript drafts and reviewer feedback. **Rashid (4%)**, provision of statistical analysis of data, collaboration on interpretation of data, provision of

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Doctor Nicola Saywell

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Publications, presentations, and awards

Published peer-reviewed scientific journal manuscripts in this thesis

Stavric, V., Saywell, N., & Kayes, N. M. (2019). Development of a self-guided web-based exercise intervention (SPIN) to treat shoulder pain in people living with spinal cord injury: Protocol of a mixed methods study. *BMJ Open*, 9(9), Article e031012. 10.1136/bmjopen-2019-031012

Stavric, V., Kayes, N. M., Rashid, U., & Saywell, N. L. (2022). The effectiveness of self-guided digital interventions to improve physical activity and exercise outcomes for people with chronic conditions: a systematic review and meta-analysis. *Frontiers in Rehabilitation Sciences*. 3, Article 925620. https://doi.org/10.3389/fresc.2022.925620

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Conference presentations

Stavric, V., Saywell, N., & Kayes, N. (2018). *Shoulder Pain Intervention delivered over the interNet (SPIN): lost in translation.* Physiotherapy and Occupational Therapy Seminar. The International Spinal Cord Society Annual Scientific Meeting, Sydney.

Stavric, V., Saywell, N. L., & Kayes, N. M. (2019). *A web-based intervention to treat shoulder pain: can we design it to keep them coming back?* 2019 Australian & New Zealand Spinal Cord Society (ANZSCoS) Annual Scientific Meeting, Melbourne.

Stavric, V., Kayes, N., Rashid, U., & Saywell, N. (2022). *Giving patients agency over their rehabilitation: The effectiveness of self-guided web-based interventions to improve physical activity for people with chronic health conditions: A systematic review and meta-analysis*. Physiotherapy Conference 2022, Rotorua.

Conference posters

Stavric, V., Saywell, N., & Kayes, N. (2017). *Protocol to translate a shoulder pain intervention into clinical practice using the internet.* American College of Rehabilitation Medicine Conference Atlanta.

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Physiotherapy branch presentation

Stavric, V. (2018). *Shoulder Pain delivered over the interNet (SPIN) after spinal cord impairment*. Auckland Branch PNZ.

Other publications

Stavric, V. (2021). SPIN: Shoulder Pain Intervention delivered over the interNet. Why Research Matters: A collection of spinal cord research from around the world. The Spinal Research Institute. https://www.flipsnack.com/thesri/why-research-matters-2021-edition/full-view.html

Awards during candidature

2021 International Spinal Research Trust Writing prize

Award and publication of a report of my work related to the development of a self-guided digital exercise intervention for shoulder pain in people living with spinal cord injury. This writing was an easy-to-understand and compelling written piece for a non-scientific-readership in 800 words or less.

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Glossary of terms

Behaviour change technique (BCT)	An observable and replicable component of an active ingredient of a given intervention designed to change behaviour (Michie et al., 2013). Can be used alone or in combination with other BCTs
Behavioural intervention feature	An intervention feature that operationalises one or more BCTs
Engagement	The action of being actively involved and invested
Exercise	Planned, structured, and repetitive bodily movement done to improve or maintain one or more components of physical fitness (Caspersen et al., 1985)
Frontend and backend	App development terms. *Frontend* is the part the user interacts with directly-usually referred to as 'client side'. *Backend* is the 'server side' that organises and stores data.
Guiding principles	Statements that succinctly reflect what is distinctive about the intervention and inform the intervention objectives and intervention features (Yardley, Morrison, et al., 2015)
Minimal human contact	Human contact for the intervention comprises no more than initial contact for set up or orientation AND any ongoing interaction with the intervention is generated automatically
Physical activity	Any bodily movement produced by skeletal muscles that results in energy expenditure (Caspersen et al., 1985)
TheraBand™	Elastic resistance band used for resistance exercises
'Think aloud'	Method used in usability testing to gather data when testing a product during design and development phases. Participants are asked to continuously think out loud and verbalise their thoughts as they move through and interact with the tested item. (Nielsen, 2012)
Wireframe	Basic app or website screen layouts that demonstrate intervention features to allow focus on content, space allocation and flow without getting distracted by aesthetics

Translations of te reo Māori (Māori language)

In 1840, Te Tiriti o Waitangi (the Treaty of Waitangi) was signed between Britain and the indigenous Māori chiefs of Aotearoa New Zealand. It is considered the founding document of Aotearoa New Zealand.

Over time, as more English speakers arrived, English became the dominant language and use of te reo Māori declined dramatically. In 1985, it was asserted that te reo Māori was a taonga (treasure) that the Crown (government) was obliged to protect under Te Tiriti o Waitangi. Te reo Māori was made an official language of Aotearoa New Zealand in 1987 (Ministry for Culture and Heritage, 2022).

In honouring Te Tiriti o Waitangi, people from Aotearoa New Zealand have been provided with opportunities to recognise and learn from and about te ao Māori (Māori customs and protocols). One of these has been to embrace te reo Māori, appreciating that the language is intertwined with its culture. Pihama et al. (2015), in Te Matataua o te reo, suggests that te reo Māori needs to be "an embedded, natural feature of everyday life in Aotearoa" (p. 33). This could consist of te reo Māori being seen, heard, and spoken in homes, workplaces, schools, businesses and throughout the public sector (Harr et al., 2019). As such, te reo Māori language is now increasingly being incorporated in everyday use and many organisations and reports now use language and phrases that have been gifted to them through a process of consultation and collaboration.

Te reo Māori is contextually and culturally rich. As such strict translations are imperfect, however, these are approximations to assist in understanding.

The following te reo Māori terms have been used in this thesis:	
Pae Ora	Te reo Māori title gifted to represent "Healthy Futures" Health Plan
Te Pae Tata	Te reo Māori title gifted to represent "Our Vision" Interim New Zealand Health Plan
Te Whatu Ora	Te reo Māori title gifted to represent weaving of wellness and culture: Health New Zealand
Whānau	Te reo Māori term for family, extended family, community, support

The following te reo Māori terms have been used in the SPIN app:	
Aku hoa	Friend, companion, mate, ally
Haere mai	Expression of welcome
Kei te pehea koe?	How are you? (when speaking to one person)
Kei te moemoeā?	How is your dream (presently)?
Kia ora	Hello, have life, be healthy
Kia tūpato	Be cautious, careful
Ka pai	Good work, this work is good
Mahi	Work, perform
Nau mai, haere mai	Welcome
O ratou hoa	Group of friends
Paraihe	Prize, award, trophy
Whāinga	Goal, achievement aim, purpose, objective
Whānau	Family, extended family, community, support
Whakamihi	To praise, congratulate, acknowledge

List of appendices

List of abbreviations

ACC	Accident Compensation Corporation
AUT	Auckland University of Technology
AUTEC	Auckland University of Technology Ethics Committee
BCT	behaviour change technique
CI	confidence interval
ES	effect size
g	Hedge's value
I^2	heterogeneity
MoH	Ministry of Health
NGO	non-governmental organisation
NR	not reported
OA	osteoarthritis
PA	physical activity
PA&E	physical activity & exercise
PAR	Participatory action research
PBA	Person-based approach
PICO	Population, Intervention, Comparison, Outcome
PRISMA	preferred reporting items for systematic review and meta-analyses
PwSCI	person living with spinal cord injury
QoL	quality of life
R	statistical software package that allows for quantitative data analysis
RoB 2	Cochrane Risk of Bias 2 tool
SAG	stakeholder advisory group
SCI	spinal cord injury or spinal cord impairment
SD	standard deviation
SMD	standardised mean difference
SPIN	Shoulder Pain Intervention over the interNet
UCD	user-centred design
WUSPI	Wheelchair users shoulder pain index

Chapter 1 Introduction

For people living with spinal cord impairment (pwSCI), chronic shoulder pain is common and frequently limits community mobility (Dalyan et al., 1999; Sie et al., 1992). This can lead to loss of independence and reduced quality of life (Gutierrez et al., 2007). Evidence suggests that a specific programme of exercises, supervised by a physiotherapist, can significantly reduce shoulder pain (Cratsenberg et al., 2015; Mulroy et al., 2011; Wellisch et al., 2021). However, barriers associated with dependency for transport, physical inaccessibility, and limited specialised care restrict access to treatment services for pwSCI (Burkell et al., 2006; Cowan et al., 2013; Vang et al., 2020). Digital technologies are increasingly being used to help overcome many of these barriers by offering an alternative method of intervention delivery. Despite an increase in the evidence base for exercise-based interventions delivered via telehealth platforms (Lee et al., 2021; Touchett et al., 2022), these remain clinician-led. Because of limited clinician availability, access remains restricted. Self-guided digital interventions could address this problem. However, there is a lack of well-designed and evidence-based digital interventions that support self-guided exercise to manage shoulder pain in this population. My doctoral work aimed to translate an evidence-based exercise programme into a self-guided digital intervention to help manage shoulder pain in pwSCI, hereafter referred to as SPIN (Shoulder Pain Intervention delivered over the interNet).

1.1 Aims and objectives

The aim of my doctoral research was to translate an evidence-based exercise programme into a self-guided digital intervention to help manage shoulder pain in pwSCI. The specific objectives were to:

1. determine the effectiveness of existing self-guided digital exercise interventions in people living with chronic health conditions;
2. identify factors perceived to encourage or facilitate engagement in self-guided, digital exercise interventions;

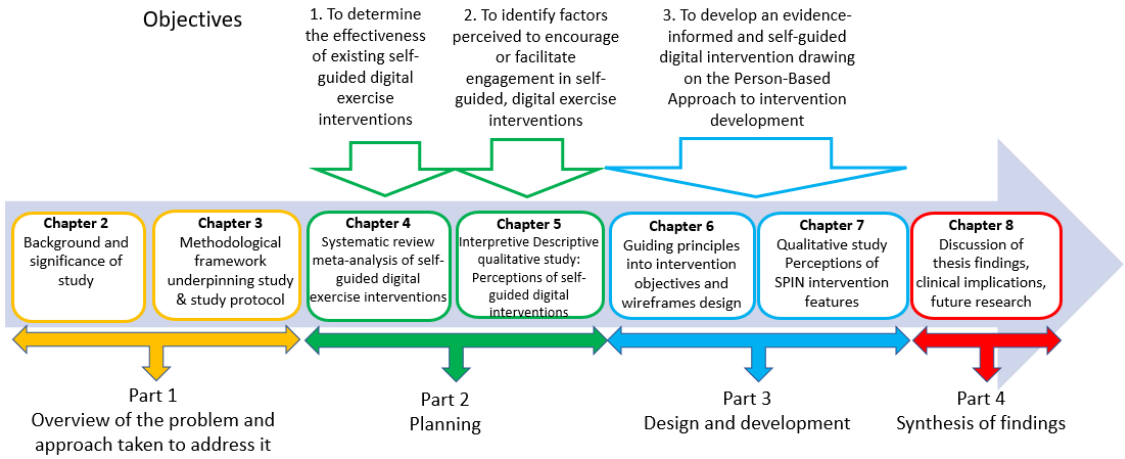
3. develop an evidence-informed and self-guided digital intervention drawing on the Person-Based Approach to intervention development (Yardley, Morrison, et al., 2015).

1.2 Thesis structure

This thesis is organised into four parts. Figure 1 displays an outline of the research phases and related chapters.

Figure 1

Thesis structure



Green chapters represent Person-Based Approach planning phase that addresses the first objectives. **Blue chapters** represent design and development phases addressing the final objective.

Part 1 provides an overview of the problem and the approach taken to address it.

- Chapter 2 situates the problem in the context of the population it affects, the significance of the study and how it can address the problem. It also introduces key terminology and delimitations of the study.
- Chapter 3 presents the rationale for the methodological framework underpinning this work. The Person-Based Approach (PBA) to digital intervention development (Yardley, Morrison, et al., 2015) which informed the approach to development of the self-guided digital intervention is described. This chapter also includes a published study protocol outlining the planning, design, and development phases of SPIN (found in Appendix B).

Parts 2 and 3 represent the planning (green in Figure 1) and design and development (blue in Figure 1) phases of the PBA.

Part 2 - planning. The information gathered in this phase was used to inform the later design and development of SPIN.

- Chapter 4 includes a published systematic review and meta-analysis that investigated the effectiveness of existing self-guided digital physical activity and exercise interventions in people living with chronic conditions (published format found in Appendix D). This addressed objective one of my doctoral work.
- Chapter 5 includes a published Interpretive Descriptive qualitative study (published format found in Appendix I) addressing objective two of my doctoral work. The aim of this study was to identify factors that may encourage engagement, by exploring the experiences and perspectives of pwSCI who have experienced shoulder pain regarding the possibility of a self-guided digital exercise intervention to address shoulder pain.

Part 3 – design and development. This phase addresses the third objective of my doctoral work. The chapters in this part outline the design and development of SPIN, drawing on insights from Part 2.

- Chapter 6 describes the creation of guiding principles that drew on the data gathered from the planning phase and how these led to design objections and intervention features. The wireframe development process that shaped SPIN's initial wireframes (V.1) is also described.
- Chapter 7 reports on the qualitative person-based usability wireframe study that helped refine the SPIN wireframes. People living with SCI, who had shoulder pain, and who had previously provided input to the Interpretive Descriptive qualitative study, were involved, as were clinical and academic informants. This chapter details all the stages of this study, from the recruitment through to findings and wireframe modifications. The final SPIN wireframe prototype (V.4) is presented at the end of this chapter.

Part 4 presents a synthesis of the findings from my doctoral work.

- Chapter 8 integrates the outcomes and contributions from my doctoral work and demonstrates how they advance existing knowledge and practice. Strengths

and limitations of this research are also discussed. Implications for clinical settings are subsequently proposed. Finally, recommendations for the next steps in SPIN's development and future post-doctoral research completes this chapter.

The published manuscripts that are presented in the chapters have been integrated within the body of the thesis, consistent with AUT formatting requirements. Figures and tables have therefore been numbered consecutively as they appear in the thesis, rather than as they appear in published format.

Chapter 2 Background

2.1 Chapter overview

In this chapter I provide background information about shoulder pain for pwSCI and its impact on them. I include the evidence for the management of shoulder pain and related opportunities and barriers. I follow with an argument on the importance of this as an area of research. I will first position myself and discuss how my clinical experience has influenced my research journey and interest in the research topic. Key gaps in evidence will then be identified and the importance of research being undertaken to address these gaps articulated.

2.2 The researcher's positionality

From my days as a physiotherapy student in Canada, I have always been interested in the area of spinal cord injury (SCI) care and rehabilitation, and invested in people affected by SCI. My European heritage and middleclass upbringing allowed me opportunities and my early clinical career enabled me to gain a varied experience. Moving to Aotearoa New Zealand allowed me take up a role exclusively in SCI rehabilitation at a spinal rehabilitation unit. In this role, I provided outpatient physiotherapy to pwSCI and guidance to clinicians in local communities for pwSCI once they had been discharged from the inpatient ward of the Auckland regional spinal rehabilitation unit. While working in this role, what struck me was the need for ongoing information and care for pwSCI living in the community, particularly as their needs changed over time. Shoulder pain is an example of a problem that often develops after years of living with SCI. While in this position, I undertook post-graduate study, and I could see how evidence-based treatment could make a difference to people.

This role also included an outreach component, taking us to clinics to see pwSCI who lived throughout the North Island. I noted the population spread when holding these outreach clinics; a large percentage of pwSCI chose to return to their communities after their SCI. This included many which were remote or a distance away from urban centres and the regional SCI facilities (there are only two in Aotearoa New Zealand).

This led to the challenge of being able to offer in-person evidence-based SCI interventions to pwSCI once they had been discharged. One method was to offer therapy in bursts (over one to two weeks). The need to find engaging ways for patients to continue with their programme independently was a continuous challenge.

Another hugely formative aspect of my clinical experience was the person-centred way of working. People living with SCI were part of the team, especially once they were discharged and living in the community. Our outpatient and outreach clinics were conducted in a transdisciplinary manner, with all disciplines together with the person with SCI, reviewing their needs. It was often up to them to identify problems and they frequently drove the solution, having control of their care**.**

When I started my academic role, I remained involved with the SCI community but noted how different things were now that I was on the 'outside'. I had a better appreciation for how difficult it was for those outside of the spinal unit to access this specialised level of care. This inspired me to think of ways to bridge the gap between community and access to clinical care. Our research team was exploring digital rehabilitation tools. This prompted me, given my clinical experiences, to question whether there may be a digital intervention solution for pwSCI who have shoulder pain.

2.3 Spinal cord impairment as a condition

Spinal cord impairment results from traumatic insult, vascular disruption or a disease process that compromises the spinal cord. Such injuries and impairments will usually lead to some degree of neurological deficit related to the level and severity of cord impairment (National Health Service, 2010; Sapru, 2011). The resultant damage may be permanent, temporary, or delayed (National Health Service, 2010).

In Aotearoa New Zealand, the estimated annual incidence rate of SCI is 30 to 40 cases per million (New Zealand Spinal Cord Injury Registry, 2022; van den Heuvel et al., 2017), which is higher than Australia but on par with other developed countries (Jazayeri et al., 2015). Worldwide SCI prevalence (20.6 million) is less than other neurological conditions like stroke (101 million) or traumatic brain injury (69 million) (Dewan et al., 2019; Ding et al., 2022; Feigin et al., 2022). However, the economic

consequences are significant with estimated lifetime costs per pwSCI ranging from 1.5 to 3.0 million dollars in a Canadian study (Krueger et al., 2013). Given this study is now ten years old, these costs will have increased. The authors presented direct care costs associated with SCI, as well as indirect costs, by calculating life years lost through quality-adjusted life years in living with the condition. In contrast to other neurological conditions, SCI often affects people earlier in life. As such, loss or reduction in voluntary motor function, sensory deprivation and disruption of autonomic function is compounded by the loss of productivity and economic contribution over a lifespan. The worldwide mean age of sustaining a traumatic SCI is 33 years, very similar to that of Aotearoa New Zealand at 34 years (van den Heuvel et al., 2017; Wyndaele & Wyndaele, 2006). This is almost half the age of onset of other neurological conditions such as stroke and Parkinson's disease (Boehme et al., 2017; Jacobs et al., 2020) and highlights the potential for long term impact of injury on the economic and social structures of peoples' lives.

Given the potential for long-term consequences, SCI health and support services focus on reducing the impact and optimising independence through provision of care that incorporates components of acute management, rehabilitation, community re-integration, and long-term follow-up by providing comprehensive clinical services. A fundamental rehabilitation goal for this population is restoration of functional independence. One well-used strategy employed to support this is to capitalise on any remaining intact muscle function to increase a person's community independence and quality of life (Harvey et al., 2009). For example, if muscles show evidence of residual innervation, they may be able to be strengthened enough to be able to assist with functional tasks such as mobility and transfers.

2.4 Shoulder pain in people living with SCI

One consequence of a lesion to the spinal cord, especially lesions above the neurological level of L3, is the loss of innervation to muscles of the trunk and lower limbs. Consequently, many pwSCI rely on their upper extremities for performance of daily activities and locomotion. Each transition to an alternate chair, surface, or toilet requires the shoulder to be the main weight-bearing joint. The anatomy and supporting musculature of the gleno-humeral joint means it is poorly suited to this

type and frequency of loading. The shoulder is designed for mobility over stability (Consortium for Spinal Cord Medicine, 2005; Requejo et al., 2008) with a shallow glenoid fossa and narrow labrum (Requejo et al., 2008). It has less supporting musculature than weight-bearing joints resulting in limited stability (Mohammed & Dunn, 2014). Over years (especially if the SCI occurs at a young age), this repetitive loading may lead to an increased risk of injury and persistent or recurrent shoulder pain. Many pwSCI report shoulder pain, with prevalence rates ranging from 30% to 70% (Bossuyt et al., 2018; Curtis, Drysdale, et al., 1999; Jain et al., 2010; Sie et al., 1992). This is also true locally with 48% of pwSCI living in Aotearoa New Zealand reporting they have experienced shoulder pain (Derrett et al., 2012). The effect of shoulder pain on the ability to carry out activities is more significant for pwSCI than in an ambulatory population. This is due to reliance on their upper extremities for mobility and locomotion, transfers, and needing to navigate and reach for things from a lower (seated) position. There are a variety of determinants and aetiologies of shoulder pain in pwSCI (Bossuyt et al., 2018; Dyson-Hudson & Kirshblum, 2003; Jain et al., 2010). However, irrespective of the underlying cause, the consequence of the pain is consistently reported to include activity limitation and reduced community mobility (McCasland et al., 2006; Pentland & Twomey, 1994b), which can lead to reduced quality of life (Gutierrez et al., 2007).

2.4.1 Exercise intervention for shoulder pain

Exercise intervention can help reduce shoulder pain in people who have sustained a SCI. Results from non-controlled studies (Curtis, Tyner, et al., 1999; Nash et al., 2007; Nawoczenski et al., 2006; Van Straaten et al., 2014), a randomised controlled trial (Mulroy et al., 2011), and systematic reviews (Cratsenberg et al., 2015; Wellisch et al., 2021) have demonstrated that specific protocols of stretches and strengthening exercises are effective in reducing shoulder pain in this population. This is supported by a recent systematic review and meta-analysis in people with musculoskeletal pain (Leemans et al., 2022). These authors concluded that there is moderate certainty evidence that exercise therapy is effective in reducing movement-evoked pain in this population. Mulroy et al. (2011) found that a therapist-led programme of stretching and strengthening of key shoulder muscles three times a week over 12 weeks, combined with movement modification, was more effective at reducing self-reports of

shoulder pain (as measured by the Wheelchair Users Shoulder Pain Index-WUSPI) compared to controls (effect size of d=-1.2). The effectiveness of exercise to reduce shoulder pain in wheelchair users was further supported by Cratsenberg and colleagues' (2015) narrative systematic review and a more recent systematic review and meta-analysis by Wellisch et al. (2021). These authors reported that significant and clinically meaningful improvements in shoulder pain measured by WUSPI (mean difference 19.06, 95% CI [5.72-32.40]) and physical function, measured by a mixture of outcome measures, (standardised mean difference 0.61, 95% CI [0.27-0.94]) were found for active physiotherapy interventions that included combinations of stretches and strengthening exercises. These results are worth noting since the effects of reducing shoulder pain extend beyond body function and impairment, as decreased shoulder pain is also associated with increases in social participation and improved quality of life in pwSCI (Kemp et al., 2011).

2.4.2 Problems with access to exercise intervention

Despite the potential benefits, exercise programmes are not always accessible to pwSCI. People living with SCI experience intrinsic and extrinsic barriers that hinder access to appropriate health services (Burkell et al., 2006; Letts et al., 2011; Umeasiegbu, 2013). For example, pwSCI, often do not know where to go for specialised advice and express concern about a lack of condition-specific exercise expertise in care providers (Cowan et al., 2013). Discrepancies have also been noted in funding for services, equipment provision, and health outcomes among different ethnicities (Umeasiegbu, 2013). For example, in Aotearoa New Zealand, there are discrepancies between compensation for accident-related SCIs and those that are illness-related. Accident-related SCIs fall under the Aotearoa New Zealand Accident Compensation Corporation (ACC) funding scheme and illness-related SCIs are covered under the general Ministry of Health (MoH) and regional divisions of Health New Zealand. As Howard-Brown and Esplin note in their joint ACC and MoH SCI initiative and implementation plan situation analysis report in 2014, "Despite various strategies aiming to eliminate barriers for people with disabilities and promote better public services, there are differences for people with the same disability or medical outcome and level of impairment as an [accident-related] ACC client." (Accident Compensation Corporation & Ministry of Health, p. 82). Residential location, specifically rural settings,

can also limit health care or rehabilitation services due to issues with transportation, accessibility of facilities and availability of specialist professionals (Umeasiegbu, 2013). Glennie and colleagues (2017) reported similar findings when comparing environmental barriers, health status, and quality-of-life outcomes between pwSCI living in rural and urban settings. Even when pwSCI do attend a health care provider, up to 90% of them experience some sort of accessibility barrier affecting their examination or treatment (Munce et al., 2014; Stillman et al., 2014).

2.4.3 Adherence versus engagement

Access to appropriate facilities and skilled providers are not the only hurdles to the implementation of effective strategies to manage shoulder pain for pwSCI. Even when an exercise intervention has proven efficacy, evidence highlights that uptake of, and sustained engagement in, exercise programmes is poor. Adherence, defined as "the extent to which a person's behaviour – taking medication, following a diet and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider" (Sabate, 2003, p. 3), has been the metric by which performance of exercise programmes has often been measured. Non-adherence in exercise-based interventions for the general population has been estimated to be as high as 70% (Bassett, 2003; Reilly et al., 1989; Sluijs et al., 1993) for interventions that are unsupervised, with those that are home-based at particular risk of non-completion (Reilly et al., 1989). This was also found to be true in pwSCI by Ditor and colleagues (2003). They found that despite experiencing benefits in pain, stress, and quality of life from taking part in a supervised nine-month exercise intervention trial and being given unlimited gym access after the trial ended, participants' attendance dropped once supervision stopped. McLean et al.'s (2010) systematic review of evidence to improve adherence in adults with musculoskeletal dysfunction concluded that strategies promoting both short- and long-term adherence to physiotherapy treatment need to be broad in spectrum.

Despite an extensive body of literature exploring adherence in a range of contexts and populations, there is some debate about the concept. For example, adherence has also been defined as "the fact of someone behaving exactly according to rules, beliefs, etc." (Cambridge Dictionary, n.d.). Applied in a health or rehabilitation context, this

definition implies a hierarchical patient-therapist relationship with the expert therapist bestowing information on the non-expert patient. It also invites a judgement on a patient's behaviour and their compliance with expert advice, such as labelling a 'non-compliant' patient as 'difficult' and making it the patient's problem (Bright et al., 2015; Graffigna et al., 2015; Kayes et al., 2015).

The concept of engagement, a "co-constructed process and state…of gradually connecting with each other and/or a therapeutic program, which enables the individual to become an active, committed and invested collaborator in healthcare." (Bright et al., 2015, p. 9), shifts the focus from adherence, which often situates the problem with the individual, to a joint problem solving, collaborative model. If the engagement process is viewed as a shared goal, intervention goals are more likely to be embraced, to have resonance, be perceived as achievable, and exercises deemed appropriate to a person's context and environment. Interventions that better support both the planning process and active phase of exercise, and that include reassessment of expectations and experiences, help ensure the intervention remains relevant and appealing to the user.

Broadening this notion to include exercise interventions that are digitally based would be a natural evolution of the definition. Perski and colleagues (2017) have proposed a conceptual definition of engagement with digital behaviour change interventions that is compatible with that previously presented: "(1) the extent (e.g. amount, frequency, duration, depth) of usage and (2) a subjective experience characterised by attention, interest, and affect" (p. 258). This extended definition considers engagement in behavioural terms (usage) but suggests a broader concept. Working conceptually from the perspective of engagement would allow the exploration of factors that identify and foster elements of engagement. As Kelders et al. (2020) noted in their review, it is clear that factors such as digital design and technology alone can impact on engagement with digital health interventions and need to be considered.

2.4.4 Digital technology as a vehicle for people living with SCI

Connectivity in Aotearoa New Zealand

Using digital technology for pwSCI in Aotearoa New Zealand has potential. Data from the Internet World Stats indicate that over 90% of people in Aotearoa New Zealand

use the internet (93.4%) (Internet World Stats, 2022). This is higher than Australia (90.0%), lower than the United Kingdom (95.0%) and comparable to North America (93.4%). This high degree of internet use indicates that it is a viable mode of information sharing. Interestingly, Aotearoa New Zealand's mobile connectivity is even higher (135.6%) reflecting the high degree of smartphone ownership (96.8%) (Kemp, 2021). This can also be seen by the rise in mobile connections and decrease in home broadband connections (Stats NZ, 2017). The World Internet Project International Report asks about how people engage with the internet. In 2016, it asked about how people, in all reporting countries, used it in relation to health information; at least 70% went online to search for health information (Cole et al., 2016). In Aotearoa New Zealand, half of all internet users accessed health services via internet options (Stats NZ, 2014), demonstrating the viability of the internet and digital connectivity for this type of service.

Connectivity after SCI

For people who sustain a SCI, there is a reduction in the performance of many activities. However, internet and digital usage increases, with authors estimating routine usage rising by 33% after sustaining a SCI (Rodrigues & Araujo, 2012). A survey of pwSCI found that 98% accessed the internet daily or weekly for purposes other than work or study (Post et al., 2019). People living with SCI turn to the internet for health information and services, in a similar pattern to the general population (Houlihan et al., 2003). It seems reasonable to assume that with the level of internet and smartphone penetration in Aotearoa New Zealand, those living with SCI would also be high consumers of health-related matters via these platforms. In exploring health information experiences and preferences for people with traumatic brain injuries, SCI and burns, Coffey et al. (2016) found that those living with SCI reported the internet and digital platforms removed many access barriers to health information. Given the choice, their participants preferred information to be made available to them through digital means. The latest iteration of the World Internet Project to run in Aotearoa New Zealand found that approximately half (49%) of disabled respondents felt that using the internet had improved their quality of life and/or social interactions (Diaz Andrade et al., 2021). Mattar and colleagues (2015), in their qualitative research, found that information technology played a positive role in health and well-being for

people living with SCI. They reported that the convenience, access to information and influence on wellbeing, outweighed the technical challenges that may come along with it. These findings suggest that a self-guided exercise programme in a digital format, for pwSCI, has potential utility.

These findings have led to researchers exploring how digital technology, the internet and health apps can be used to help deliver health care services and rehabilitation for many health conditions, including SCI (Mortenson et al., 2019; Pancer et al., 2019; Ramey et al., 2019). Using digital technology to deliver therapy to people who have sustained a SCI is a natural extension of this technology. It can reduce the difficulty often experienced by this population in accessing treatment and receiving specialised physiotherapy. The challenge, however, is to develop an intervention that makes use of evidence and technology in a way that minimises resources but is engaging and supportive, ensuring accessible and sustained use. People living with SCI who have shoulder pain would particularly benefit from such a tool.

2.5 Significance of the study

The proliferation of the internet and digital technologies has provided increasing opportunities to deliver health services and care to people and to improve access in a resource-constrained climate (Free et al., 2013; van den Berg et al., 2007). For example, web-based physical activity interventions have been shown to be effective in the short-term in a number of community dwelling adults who have access to the internet (Boudreau et al., 2020; Foster et al., 2013; Jahangiry et al., 2017; Storm et al., 2016).

However, this effect may differ in other populations. Additionally, web-based interventions that provide *physical activity* interventions will vary from those that provide web-based *exercise* interventions both in content and outcome. Reviews by Cratsenberg et al. (2015) and Wellisch et al. (2021) support exercise as a viable therapeutic intervention to decrease shoulder pain for pwSCI. Encouragingly, using web-based interventions for exercise delivery shows promise in populations with a variety of health conditions, including SCI (Brooks et al., 2014; Coulter et al., 2016; Dahlberg et al., 2017; Frederix et al., 2015; Tallner et al., 2016). However, while these

interventions can be defined as web-based, many do not fall under the category of having *minimal support*, as most require clinician-generated weekly emails, phone calls or monitoring. This approach is based on replacing face-to-face clinician support or paper-based resources with remote or electronic resources. Although this has advanced the notion of web-based exercise, it is still practitioner driven, not self-guided. While other self-guided web-based resources (elearnSCI.org; FacingDisability.com; SCIRE Professional) exist for people living with and working with SCI, none are designed to help someone living with SCI, who is experiencing shoulder pain, to engage in an exercise programme independently. Designing interventions with an understanding of users' needs and challenges, that enable them to be actively involved in and in charge of their care will increase engagement opportunities in the short- and long-term (Kuijpers et al., 2013).

On a broader level, evidence-based digital interventions can contribute to the reduction of health disparities locally and globally by reaching a greater number of people (Munoz, 2010). Automated, self-guided digital interventions would have low ongoing costs, and consequently, would likely be the greatest contributors to this reduction as there is no limit on the number of people who could use them (Munoz, 2010). Therefore, it is important to explore how these types of interventions are best developed and implemented.

Having access to health care and guidance may also lower the threshold for seeking treatment. Ginn et al. (1997) found that in able bodied participants with shoulder pain, a delay of one month in treatment resulted in worse functional ability scores and pain-free range of motion. For pwSCI, reducing the delay in seeking help for shoulder pain could potentially lead to less deterioration and improved functional outcomes.

This approach aligns with many of the five themes from Aotearoa New Zealand's Ministry of Health Strategy: 1) people-powered, enabling people to make choices about the care they receive and having consumer involvement at all levels; 2) closer to home, providing care closer to where people live, work, and study, and play, especially for managing long-term conditions; and 3) smart system, taking advantage of opportunities offered by new and emerging technologies (Ministry of Health, 2016). The recent Health and Disability System Review put forth a series of system-wide

recommendations to guide Aotearoa New Zealand's health reforms and Pae Ora (Healthy Futures) legislation. My doctoral work supports a number of these: ensuring consumers, whānau, and communities are at the heart of the system; changing the driver of the system; ensuring the system is focused and engages communities; improving the wellbeing of disabled people; and use of digital and data technologies (Ministry of Health, 2020).

However, it is still unknown if digital technologies that provide exercise interventions are relevant to pwSCI. People living with chronic conditions often face additional barriers and competing factors influencing the decision to exercise or be physically active (Kayes et al., 2011; Mudge et al., 2013). Having the ability to access health care, services, and rehabilitation remotely may have an even greater impact. Bossen and colleagues (2014) conducted a systematic review on the effectiveness of self-guided web-based PA interventions for people living with chronic conditions. They found conflicting evidence, suggesting that the question remains unresolved, especially for pwSCI.

The use of digital technologies, that require minimal to no ongoing clinical contact, to successfully deliver and support physical activity and exercise interventions for pwSCI has many potential benefits. They could overcome many of the barriers associated with access and cost, and also provide pwSCI a means to address their activity limitation, while instilling in them a sense of agency for their own health and wellbeing.

2.6 Delimitations of the study

My doctoral work has focused on a component of telerehabilitation. Cooper et al. (2001) broadly defines telerehabilitation as "the application of telecommunication, remote sensing and operation technologies, and computing technologies to assist with the provision of medical rehabilitation services at a distance" (p. 1174). The aim of this research was to investigate computing technologies that could provide exercise rehabilitation services at a distance with minimal to no clinical input. Applications of telerehabilitation that included telecommunication and remote sensing were not included or considered as part of this work.

2.7 Changes in terminology over the course of my doctoral work

Over the course of my doctoral work, there have been shifts in my thinking with regards to SPIN's delivery format, and the breadth of the research aim. As a consequence, there are small changes in terminology used between earlier published works and later sections of this thesis. For transparency, these shifts are explained in more detail in the relevant sections. For example, Chapter 6 (page 116) will detail that while I had originally envisaged SPIN to be a web-based intervention, it became clear in my interaction with stakeholders that an app-based intervention would be a better option. Consequently, in early published work, I refer more specifically to 'web-based', but elsewhere have used the more general phrase, 'digital intervention'. Similarly, Chapter 7 (page 137) will provide context for how the original research aim of translating an evidence-based exercise programme to *treat* shoulder pain, shifted to translating an evidence- based exercise programme to *help manage* shoulder pain. As such, earlier published work uses *treat* terminology but the final research aim and final SPIN prototype was to support pwSCI to *help manage* shoulder pain.

2.8 Chapter summary

Shoulder pain is a common problem for pwSCI and its impact can have widespread effects on activity and participation. There is good evidence that exercise-based interventions are an effective strategy for managing shoulder pain in pwSCI, but access to exercise interventions and uptake of these interventions is poor due to a range of extrinsic and intrinsic factors. One approach that would allow better access to an effective treatment for pwSCI is the development of a self-guided digital intervention. This has the potential to overcome many of the identified barriers. Therefore, the aim of my project was to translate an evidence-based exercise programme into a self-guided digital intervention to help manage shoulder pain in pwSCI that is both effective and engaging. The following chapter explores the methodological approaches I considered to achieve this aim as well as the subsequent published study protocol.

Chapter 3 Methodological framework to support my doctoral work and published protocol

3.1 Chapter overview

In this chapter I will present the range of research approaches I explored in relation to the research question and the rationale for why the Person-Based Approach (PBA) was identified as suitable for addressing the aims and objectives of this research. The chapter will finish with the inclusion of the published manuscript of the study protocol.

3.2 Need for a usable, engaging, and practical digital product

The overall aim of my work was to develop a self-guided digital exercise intervention to help manage shoulder pain in people living with SCI. As part of this, exercise-based interventions that have been shown to be effective (Cratsenberg et al., 2015; Mulroy et al., 2011; Wellisch et al., 2021) were identified for translation into a digital format. This digital format is a mode of delivery that aims to address access barriers discussed in Chapter 2. Taking note of the mode of delivery and digital design are just as important as the content (exercises), given they can influence effectiveness beyond the theory and evidence-based principles of the original intervention (Dombrowski et al., 2016; Kelders et al., 2020). As such, ensuring the digital delivery method is usable, practical, and engaging was an essential area of focus for the translation of the exercise intervention and drove the search for a methodological framework that would support it. Before selecting PBA, other methodological approaches were explored and evaluated in the context of the aims of my doctoral work. These included user-centred design (UCD) approaches and participatory approaches. These will be discussed in more depth below.

3.2.1 User-centred design approaches

Iterative development cycles involving prototype development and refinement, through user testing, are characteristic of several methodological approaches that explore the human-computer interface and include usability testing, human factors and ergonomics, and UCD (Norman & Draper, 1986; Sanders, 2006). These approaches

have evolved from expert-led design and testing of the human-computer interface and now seek to understand users' knowledge, skills, and behaviour while using the product. The content of the consultations typically focuses on ease of use, aesthetics, functionality, learnability, efficiency of the product and user satisfaction (Abras et al., 2004). While these factors are important to the successful use of SPIN, following a UCD approach would only address one component of SPIN development. The UCD approach emphasises "figuring out" users' needs at the time of testing, rather than considering the potential longer-term use and need in the context of users' lives (Massanari, 2010, p. 405). The goal of SPIN is for longer term support and behaviour change. These are considerations that UCD, in its early application, does not incorporate into its approach. As one author notes, "Users...typically speak to you in terms of desired features and solutions, not of needs and problems." (Tidwell, 2006, p. 4).

3.2.2 Participatory approaches

The second, and perhaps more central, part of my project's overall research aim was to support pwSCI who experience shoulder pain to complete the exercises, without the need for clinician support. The effectiveness of the exercise intervention for pwSCI and shoulder pain is dependent on their participation and performance of exercises, so continual active engagement is key. However, continued engagement with exercise programmes and digital interventions is difficult to maintain (Davies, Corry, et al., 2012; Ditor et al., 2003; Eysenbach, 2005; Kohl et al., 2013). Given that the intervention will be used with minimal contact or support, understanding the perceptions, behavioural needs, and challenges of the user was crucial. This was necessary to ensure that the initial planning and later intervention development was relevant and meaningful.

For people living with chronic health conditions, active and ongoing engagement with health services or products, with or without a digital component, may be further influenced by additional confounding factors (Mudge et al., 2013; van Gemert-Pijnen et al., 2011). Developing an understanding of the actual needs of the people who the intervention is for is best achieved by actively involving them. Actively involving people who will be served by the intervention at all stages of planning and implementation

can be traced to the origins of Participatory Action Research (PAR) (Nelson et al., 1998) and more recently to participatory design or co-design (Massanari, 2010; Sanders, 2006).

By its nature, PAR promotes pluralism and engaging participants as co-researchers to make the world a better place, often in service of improving conditions for participants (Chevalier & Buckles, 2019). Participatory approaches use findings from one phase of the research to inform the next and have been suggested to lead to mutual learning for both researchers and participants, because of shared understanding of the problem. The wider scope of participant exploration and involvement provides deeper and richer, and at times, unexpected insights. For example, shared understanding can lead to the participants being involved in problem solving (Bodker et al., 2004). It may also contribute to increased engagement over time (von Hippel, 2005).

My doctoral work already had a pre-determined aim of developing a self-guided digital exercise intervention. This differs to PAR whose approach accepts that the path and outcome are often undetermined. As well, while PAR may strive for shared understanding of a problem, it has not traditionally been used for the purpose of intervention development to address the problem.

3.2.3 The Person-based approach (PBA)

The PBA contains elements of both UCD and PAR and is an approach that has evolved specifically for the development of digital health interventions. It seeks a deeper understanding of the perspectives and psychosocial context of potential users, prior to development. It also assumes people will use the intervention with minimal contact or support. Successful development, therefore, requires an understanding of how people will use these interventions in daily life, beyond initial use. While it still employs usability testing like those of UCD, PBA is rooted in health psychology. The approach seeks to understand and address the required health-related behavioural needs first. It then adds the online component or feature to support the identified need (Muller et al., 2019; Yardley, Morrison, et al., 2015).

While the PBA may not have an emancipatory interest such as those in PAR projects (Ozanne & Saatcioglu, 2008), the “person-centred” approach is about encouraging

autonomy, collaboration, understanding and empowering the person the intervention is designed for (Yardley, Morrison, et al., 2015). This can bring out broader community support during dissemination and implementation (Sanoff, 2008).

As such, PBA does not only seek to answer the question, “Can they use it?” which speaks to usability, but also the question, “Do they want to use it?” enhancing the chances of enjoyment, engagement and ultimately, benefit (Michie et al., 2017; Yardley, Ainsworth, et al., 2015; Yardley et al., 2016).

3.3 Study design

The PBA, and the research aim itself, lent itself to mixed methods. This approach broadens understanding by incorporating both qualitative and quantitative approaches to build on the results of one approach or to better understand results from the other (Creswell, 2009; Johnson & Onwuegbuzie, 2004). It is underpinned by a pragmatist philosophy (Dewey, 1938; Kaushik & Walsh, 2019). Shaw et al. (2010) argued that mixed methods and pragmatism are entirely applicable to physiotherapy practice for the way in which they reflect the multifaceted approach taken in clinical reasoning and how they support research on clinical best practice.

The PBA and the pragmatist paradigm share several assumptions. First, they recognise that realities and experiences are not fixed, rather they evolve and are subjective and context dependent, and will be unique based on each person’s individual experiences and needs (Kaushik & Walsh, 2019; Yardley, 2000). Therefore, these approaches seek to understand people’s subjective experiences, to activate respondents’ ‘stock of knowledge’ (Ritchie & Rigano, 2001, p. 744). Second, they embrace knowledge from multiple theories and practices. As such, they are broad, incorporating and recognising several methods of research. They endorse methodological pluralism, using whatever philosophical and/or methodological approach that works best for a particular research question (Allemang et al., 2021; Kaushik & Walsh, 2019; Onwuegbuzie & Leech, 2005; Tashakkori & Teddlie, 1998). Third, knowledge is not discovered by a logico-deductive scientific method but is produced or constructed with participants through a collaborative process more suited to a multidimensional problem (Johnson & Onwuegbuzie, 2004). PBA’s active involvement of pwSCI and the value that

pragmatism places on experiential knowledge demonstrates further congruence between these two approaches (Allemang et al., 2021; Yardley, Morrison, et al., 2015). This is supported epistemologically by drawing on a range of data sources, as the PBA is rooted in understanding users' experiences, and in the overall intent of the intervention, and how it will be used and tested in the future using both qualitative and quantitative methods (Yardley, Morrison, et al., 2015). Finally, both are suited to clinical contexts as they are oriented towards solving real world problems (Feilzer, 2010; Johnson & Onwuegbuzie, 2004; Kaushik & Walsh, 2019; Yardley, Morrison, et al., 2015).

In my doctoral work, the mixed method design is seen with a combination of quantitative and qualitative approaches. A quantitative approach was used in the systematic review and meta-analysis to evaluate and compare data across multiple randomised controlled trials (Higgins et al., 2011). The qualitative components of this research followed and drew on Interpretive Descriptive methodology (Thorne, 2008). Interpretive Description originated in recognition that existing methodologies originating in social science, such as grounded theory, phenomenology, or ethnography were not always fit for purpose in applied health science research (Thorne et al., 1997). Researchers in health fields, having to use social sciences methodologies, were also not able to draw from their disciplinary experience and learnings and epistemological roots. This restricted their capacity to extend clinical and practice knowledge. Since the goal of health science research is often to inform clinical practice, Interpretive Descriptive methodology developed as a way to address clinical questions that are relevant to health disciplines. Interpretive Description explicitly aims to inform clinical practice through a non-categorical methodology and is coherent with many of the assumptions of pragmatism outlined above. For example, like pragmatism, it promotes the construction of knowledge and a pluralistic use of methods, where formal and disciplinary knowledge combine with other mid-range theories, so that an analytic framework is constructed to support the research to solve the real-world problem (Thorne et al., 1997). These both also align with the PBA. Interpretive Description assumes that the inquiry will draw from existing disciplinary knowledge so that the findings can be related back to previous work and to clinical significance (Thorne et al., 1997). This qualitative approach to clinical description, using

interpretation and exploration (Thorne et al., 2004) is congruent to and supports the aim of my doctoral work.

3.3.1 Reflexivity

In view of my positionality (outlined in Chapter 2), I participated in a pre-assumption interview to make visible any of my assumptions that could influence the planning phase. Being aware of my previously held assumptions was important to support my ongoing reflexivity as the research progressed. For instance, in the interviews with pwSCI, I was more aware this meant being open to any ideas of what may help them with their shoulder pain, to find out what mattered most to them when it comes to managing their shoulder pain, and not just seek out what they thought about the idea of SPIN. It also helped me with my interpretation of data and how comments were perceived and coded. My assumptions about the value exercise plays in improving shoulder pain may have been unique to me and not shared by pwSCI. Through this process I also became aware of how much I valued the therapeutic relationship and had ideas about what SPIN could look like. This could also have influenced whether comments were adequately explored during the interview sessions and how they were coded. I was also aware of how my demographic positionality could have impacted on recruitment, how people responded in the sessions and my engagement with the data. Striving to be curious and reflexively acknowledging people's stock of knowledge, while being aware of my identity as a 'physiotherapist', allowed me to overcome some pre-existing assumptions, to recognise participants' diverse perspectives (McNair et al., 2008) no matter what the possible outcome. This reflexivity was continuously applied as the doctoral work evolved, as understanding was formed and operationalised into SPIN. The transcript of the full pre-assumption interview is included in Appendix A.

A manuscript describing the detailed protocol was published in *BMJ Open* (Stavric et al., 2019). The full citation for the article is:

Stavric, V., Saywell, N., & Kayes, N. M. (2019). Development of a self-guided web-based exercise intervention (SPIN) to treat shoulder pain in people living with spinal cord injury: Protocol of a mixed methods study. *BMJ Open*, 9(9), Article e031012. https://doi.org/10.1136/bmjopen-2019-031012

The manuscript is included here as published; however, the citations, figures and tables have been formatted to be consistent with the thesis. A copy of the published article is found in Appendix B.

3.4 Beginning of published manuscript: Study protocol

3.4.1 Abstract

Introduction: Chronic shoulder pain is common after spinal cord injury (SCI) and limits community mobility. This leads to loss of independence and reduced quality of life. Evidence suggests that exercises can help reduce shoulder pain. However, cost, expertise and transport barriers frequently limit access to treatment services. The objective of this study is to develop an evidence-based, acceptable, usable, and persuasive self-guided web-based exercise intervention to treat shoulder pain in people living with SCI.

Methods and analysis: An iterative and phased person-based approach (PBA) will capture users' perspectives on usability and acceptability to develop guiding principles that will shape the design of the intervention. The intervention will be based on key elements identified through participant input and from evidence identified through systematic and narrative reviews, to ensure the intervention addresses participants' needs and increase the likelihood of uptake. The prototype will be iteratively refined through focus groups and 'think aloud' sessions. Review data will be synthesised drawing on systematic and narrative review conventions. Qualitative data will be analysed using conventional content analysis (planning phase) and directed content analysis (development phase) to inform intervention design and refinement.

Ethics and dissemination: Ethical approval has been granted by the Auckland University of Technology Ethics Committee (AUTEC) in Auckland, Aotearoa New Zealand. The results of the study will be published in a peer-reviewed journal and presented at relevant national and international conferences. A summary of findings will be presented to key stakeholder groups. We will progress to a definitive trial should the findings from this intervention development study indicate the intervention is acceptable and usable.

3.4.2 Introduction

People with spinal cord injury or spinal cord impairment (from non-traumatic causes) (SCI) rely on their upper extremities for locomotion as well as performance of daily activities. Consequently, up to 70% of people living with SCI experience shoulder pain which can have a significant impact on activity which reduces community mobility, independence and quality of life (QoL) (Curtis, Drysdale, et al., 1999; Dalyan et al., 1999; Gutierrez et al., 2007; McCasland et al., 2006; Pentland & Twomey, 1994a; Sie et al., 1992).

Exercise-based rehabilitation is often included in the management of shoulder pain. Protocols including stretches and strengthening exercises have been shown to significantly reduce shoulder pain in people with SCI in a series of non-controlled studies (Curtis, Tyner, et al., 1999; Nash et al., 2007; Nawoczenski et al., 2006; Van Straaten et al., 2014), a randomised controlled study (Mulroy et al., 2011) and a systematic review (Cratsenberg et al., 2015). Despite the known benefits of exercise to reduce shoulder pain, many people living with SCI who experience shoulder pain often do not engage in these exercises (Ditor et al., 2003). They cite barriers to accessing exercise and rehabilitation opportunities that include limited access to knowledgeable health professionals, poor physical accessibility and transportation difficulties (Burkell et al., 2006; Cowan et al., 2013). Digital health interventions offer a potential opportunity to overcome many of these barriers in a cost-effective way (Griffiths et al., 2006). They can provide automated and remote personalised feedback and support for self-guided exercise, in a person's own time and environment.

Although web-based exercise resources are currently available for people living with SCI (Coulter et al., 2016; Shepherd Centre, 2017), they have some limitations. For example, they require the ongoing support of a clinician, are not specific to treating shoulder pain or do not have the capability to automate exercise progression. Shoulder Pain Intervention delivered over the interNet (SPIN) is being developed to address these limitations. To our knowledge, this will be the first web-based, self-guided intervention that will prescribe, monitor, and progress evidence-based exercises for people living with SCI who experience shoulder pain. The intervention will

be an interactive tool using responses from users on their pain or degree of exercise difficulty to tailor the programme.

Translation of an existing evidence-based intervention in to a web-based format presents a number of challenges (Michie et al., 2017). For example, attracting users and encouraging engagement with the intervention can be further complicated by how usable the technology is and how quickly it continues to evolve. Therefore, the development of SPIN will be theory-driven, evidence-based and underpinned by the Person Based Approach (PBA) to intervention development (Yardley, Morrison, et al., 2015). The PBA seeks a deep understanding of the perspectives and psychosocial context of potential users through iterative qualitative research (Yardley, Morrison, et al., 2015). The PBA draws on evidence from primary and secondary sources to identify barriers and facilitators to uptake. As Yardley and colleagues (2015) suggest, it makes use of behavioural evidence and theory (Michie et al., 2011), while keeping the user's needs and context in focus, increasing the likely engagement in and effectiveness of the intervention (Band et al., 2017; Morrison et al., 2012; Webb et al., 2010). SPIN is planned to be self-guided and so will be used with minimal health professional contact. As such, ensuring the design is underpinned by a clear understanding of the perceptions, assumptions, behavioural needs, and challenges of the user will increase its relevance and usability. The aim of this project is to develop an evidence-based, acceptable, usable, and persuasive self-guided web-based exercise intervention to treat shoulder pain in people living with SCI.

3.4.3 Methods and analysis

Patient and public involvement

The research question was developed from clinical experiences and then further refined through consultation with the Burwood Academy of Independent Living End-User Consultation Committee, a consumer group with the expertise of living with SCI who advises on research projects (Burwood Academy of Independent Living, n.d.) (Appendix C).

A stakeholder advisory group (more details are provided below) will also be formed to help support the study at key points. Key findings will be presented by researchers and participants at community and academic meetings.

Study design

The PBA proposes four phases of intervention development that include planning; design; development; and trialling. The current study is focused primarily on the first three phases. Figure 2 provides a definition of each phase according to the PBA and an overview of how they map onto the current study. The iterative nature of intervention development implies that phases are not discreet, and movement will occur between them.

Figure 2

Phases of intervention development

PBA Description	Phase	Current Study	
		Purpose	Planned Outcome
Use of primary and secondary **qualitative evidence** to understand users' behavioural and psychosocial needs and challenges in using the intervention.	Planning	To determine **factors that need to be included** to **encourage or facilitate engagement** with this self-guided web-based exercise intervention.	A rich description of key **needs, challenges and facilitators** of engagement in web-based tools and exercise for people living with SCI who experience shoulder pain to **underpin the design phase's guiding principles and features**.
Formulation of **key guiding principles** that capture the main intervention objectives as identified in the planning phase and that are continuously referred to throughout the development of the intervention.	Design	To design an **evidence-based, self-guided, web-based** intervention. Exercise, behavioural support and self-guided components will be included within the intervention features.	Key intervention objectives. Key intervention features. 1st iteration of SPIN prototype (wireframe version).
Intervention components are evaluated and optimised based on user feedback.	Development	To develop an **evidence-based, self-guided, web-based** intervention. Iterative feedback and prototyping to **refine the intervention** through **wireframe focus group testing** and then further refined with **think-aloud testing.**	Final SPIN prototype (digital version). Ready for trialling.
Intervention is evaluated in **real-life context** and modified to improve future implementation.	Trialling	To carry out a mixed methods pilot trial. This phase will be dependent on the preceding phases.	A brief outline entitled '**future work'** is included in this paper.

PBA person-based approach, **SCI** spinal cord injury, **SPIN** Shoulder Pain Intervention delivered over the interNet.

Participants

Eligibility

Participants will be eligible if they reside in New Zealand; are living with SCI, have completed active rehabilitation; are over 16 years of age; have capacity to give informed consent; are predominantly wheelchair users; and are experiencing or have recently (within 2 years) experienced shoulder pain. Participants will be excluded if they are unable to communicate with the researcher for the purposes of meaningful engagement in data collection.

Recruitment

Posters will be distributed within SCI community networks and SCI services and rehabilitation providers. Information will also be circulated through social media sites and professional and personal networks. People who express interest in the study will be invited to contact the researcher or give permission for the researcher to contact them. The sampling approach specific to each phase is provided in more detail below.

Stakeholder Advisory Group

A stakeholder advisory group (SAG) will be formed to support this project. The composition of the group will include a person living with SCI; a clinician with experience in SCI rehabilitation; a representative of a relevant non-governmental organisation (NGO) and a computer engineer with knowledge in web design and decision tree development. They will meet at least four times during the study including at the outset and following each phase. Their primary role will be to gauge how findings resonate with personal insights and experience, to make recommendations for the subsequent phases and to inform refinements to the intervention. For example, in the planning phase, they will be able to make recommendation for recruitment. See Appendix D for the SAG role description.

Planning Phase: collecting and synthesising evidence

Purpose:

- To determine the effectiveness of existing self-guided web-based exercise interventions
- To determine factors that need to be included to facilitate engagement with the current self-guided web-based exercise intervention

This phase will include collecting and synthesising primary and secondary evidence to inform the design of the intervention. Secondary evidence will include both a systematic and narrative review of the literature. Primary evidence will be collected through an Interpretive Descriptive study.

Systematic review of effectiveness of self-guided web-based exercise interventions

Yardley and colleagues (2015) recommend drawing on an existing evidence base. However, there are no reviews currently available which synthesise evidence regarding the effectiveness of self-guided, web-based exercise interventions. Consequently, the first stage in this work is to conduct a systematic review to a) determine effectiveness of this method of delivery in improving health outcomes for those with chronic health conditions and b) extract data on key characteristics of those interventions identified as effective. The results will be used to inform intervention development by identifying elements common to effective self-guided web-based interventions.

The systematic review will follow the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Moher et al., 2009).

Eligibility criteria

Studies will be included if they meet the inclusion and exclusion criteria presented in Table 1. Initial scoping revealed no interventions involving pwSCI. Therefore, the search was expanded to include those living with a chronic health condition.

Table 1

Inclusion/exclusion criteria for systematic review

Elements	Inclusion criteria	Exclusion criteria
Study design and reporting	Randomised controlled trial or pilot that contains data addressing effectiveness Full text available	Not in English Publication not peer-reviewed Conference proceeding
Population	Adults with an existing chronic health condition	
Intervention	Designed for the use of people living with a chronic health condition	
	Explicitly supports self-guided physical activity or exercise in a self-guided programme	
	Web-based or app-based	
	Intervention has minimal human contact comprising no more than initial contact for set up or orientation. Has ongoing contact that is generated automatically.	
Outcome	Health related	

Databases

Literature searches will be conducted in the following databases: Cumulated Index to Nursing and Allied Health Literature (CINAHL), MEDLINE, SPORTSDiscus through EBSCO Health Database, Allied and Complementary Medicine (AMED), Evidence Based Medicine (EBM) Reviews - Cochrane Methodology Register 3rd Quarter 2012, EBM Reviews - Health Technology Assessment 4th Quarter 2016 PsycINFO 1806 to July Week 2 2017, MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to present through OVID, in Scopus and in Web of Science. The Physiotherapy Evidence Database (PEDro) database will be searched (using simplified broad key terms) as a checking exercise. Reference lists of relevant reviews and studies will be hand searched.

A search strategy has been devised drawing on the Population, Intervention, Comparison, Outcome (PICO) framework with a focus on key terms relevant to *intervention* (web-based exercise) and *study design* (randomised control trial). The search will not be limited by *population* and *outcome* to keep the reach as broad as

possible and ensure studies are not missed. Search strategies will also include Boolean, wildcard, truncation, and proximity searching, tailored by database. Table 2 provides an example of a search to be conducted using an OVID database.

Table 2

Database search concepts and terms

	Search concept	Likely terms
#1	Web-based exercise	(web* ADJ6 Exercis*) OR (web* ADJ6 Rehabilitation) OR (web* ADJ6 Physiotherap*) OR (web* ADJ6 "Physical therap*") OR (web* ADJ6 therap*) OR (web* ADJ6 "fitness training") OR (web* ADJ6 physical activit*) OR (internet* ADJ6 Exercis*) OR (internet* ADJ6 Rehabilitation) OR (internet* ADJ6 Physiotherap*) OR (internet* ADJ6 "Physical therap*") OR (internet* ADJ6 therap*) OR (internet* ADJ6 "fitness training") OR (internet* ADJ6 physical activit*) OR (online ADJ6 Exercis*) OR (online ADJ6 Rehabilitation) OR (online ADJ6 Physiotherap*) OR (online* ADJ6 "Physical therap*") OR (online ADJ6 therap*) OR (online* ADJ6 "fitness training") OR (online ADJ6 physical activit*)
#2	E-health or physiotherapy	(Ehealth OR e-health) AND (exercise* OR rehabilitation OR physiotherap* OR "physical therap*")
#3	#1 OR #2	
#4	Study design RCT	"Random* control*" OR RCT OR "control* trial*"
#5	#3 AND #4	

Selection of studies

All citations returned in the search will be downloaded and saved into Endnote X8. Duplicates will be removed and then titles screened by VS, according to the pre-defined inclusion criteria. Initially, a selection of titles will be independently screened by a second assessor (NS). Any disagreements will be reviewed and discussed to ensure consensus is reached. Should agreement not be reached, a third assessor (NK) will serve as arbitrator. The abstracts and then full texts of all those studies potentially meeting the inclusion criteria will be reviewed by VS before settling on a final set of included studies in consultation with NS.

Data extraction and management

Key details from each of the included studies will be recorded in data extraction tables. Details will include: author and country; study design; participant numbers

and characteristics; treatment intervention (including features and components used); and health outcomes.

Quality assessment

Risk of bias for each of the included studies will be assessed as low, high or unclear drawing on guidelines by The Cochrane Collaboration's tool for assessing risk of bias in randomised trials (Higgins et al., 2011). Appraisal of the quality of included studies will follow the criteria outlined in the Critical Appraisal Skills Programme Randomised Controlled Trial Checklist (Critical Appraisal Skills Programme, n.d.).

Narrative review of relevant literature

The planning phase includes using qualitative evidence to inform intervention development. This second review of literature will explore what helps or hinders engagement with a) exercise and physical activity; and b) web-based interventions for people living with SCI. The findings will be used to generate discussion topics for the Interpretive Descriptive study (described further below). Findings will also inform the guiding principles for intervention design.

Eligibility criteria

Studies will be included if they meet the inclusion and exclusion criteria outlined in Table 3.

Table 3

Inclusion/exclusion criteria for narrative review

Elements	**Inclusion criteria**	**Exclusion criteria**
Study design and formatting	Qualitative study Full text available	Not in English Publication not peer-reviewed Conference proceeding
Phenomena of interest	Exploring experiences and perspectives of physical activity interventions Exploring experiences and perspectives of web-based interventions	
Participants	Adults living with SCI who experience mobility limitation	

Search strategy

Literature searches will be conducted in the following databases: Cumulated Index to Nursing and Allied Health Literature (CINAHL), MEDLINE, SPORTSDiscus through EBSCO Health Database, Allied and Complementary Medicine (AMED), Evidence Based Medicine (EBM) Reviews - Cochrane Methodology Register 3rd Quarter 2012, EBM Reviews - Health Technology Assessment 4th Quarter 2016, PsycINFO 1806 to July Week 2 2017, MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to present through OVID, in Scopus and in Web of Science. Reference lists of relevant reviews and studies will also be searched.

A search strategy will be devised by breaking the review question down into component parts including key words relevant to patient perspective, the substantive topics (web-based intervention, exercise, and physical activity) and study design. Table 4 provides an example of a strategy that combines these components and possible search terms. Searches will be run for each component and then combined to reflect the relevant question (see Table 4 searches #6 and #7).

Table 4

Narrative review search concepts and terms

	Search concept	**Likely terms**
#1	Experiences	barrier* OR facilitator* OR help* OR hinder* OR perspective* OR experience* OR acceptability OR satisfaction OR view* OR experiences OR perception*
#2	Study design	qualitative OR hermeneutics OR "thematic analysis" OR interview* OR "focus group*" OR "grounded theory" OR "content analysis"
#3	Physical activity or exercise	exercise* OR rehabilitation OR physiotherapy OR physical therapy OR therapy OR "fitness training" OR training" OR "physical activity"
#4	Web-based interventions	web OR internet OR online OR e-health OR ehealth
#5	Spinal cord injury	Spinal cord injur* OR "SCI" OR paraplegi* OR quadriplegi* OR tetraplegi* OR
#6	#1 AND #2 AND #3 AND #5	
#7	#1 AND #2 AND #4 AND #5	

Selection of studies

This review will follow a similar approach to the data selection as the systematic review described earlier.

Data selection and management

Key details from each of the included studies will be recorded in data extraction tables. Details will include: author details and country; study design; participant numbers and characteristics; experience explored (e.g., exercise or web-based interventions); barriers to engagement and facilitators to engagement.

Quality assessment

Appraisal of the quality of included studies will follow the criteria as outlined in the Critical Appraisal Skills Programme Qualitative Checklist (Critical Appraisal Skills Programme, n.d).

Data analysis

A narrative synthesis of data will be performed. Findings from the included studies will be reviewed and key concepts relevant to the review questions identified. These will be grouped into categories and then mapped to the original findings of included

papers to check for resonance and identify aspects that either confirm or conflict with the synthesised findings. From this, a more refined set of categories will be generated.

Interpretive Descriptive study

Primary qualitative evidence will be collected in this phase. An Interpretive Descriptive (Thorne et al., 1997) study will be carried out to explore the perceptions of people who live with SCI regarding a self-guided, web-based, exercise intervention to treat shoulder pain. The results will inform the guiding principles to underpin intervention design.

Participants

Participants (up to n=20) will be recruited using the eligibility criteria and recruitment process described earlier. We will draw on Malterud's concept of information power (Malterud et al., 2016) to guide sample size. Participants will be purposively selected to ensure diversity in social circumstances, age, ethnicity, gender, and impairment to ensure breadth of perspectives and experiences.

Data collection

Individual or focus group interviews will be conducted at a venue convenient to the participant(s), such as their residence, place of employment or another agreed location. Individual interviews may be carried out via other means (i.e., Skype, FaceTime) if preferred by the participant. A semi-structured interview guide will be used to focus on the phenomenon of interest while allowing enough flexibility for the interviewer to be responsive to participant responses (Turner, 2010). Topic areas will include participants' perceptions and suggestions of various web-based exercise scenarios, exploring concepts uncovered by the review findings. This will be followed by questions relating to how features of a web-based intervention could support people, e.g., how it would need to look, what would encourage participants to use it and to what extent it may overcome barriers identified in the review. Opportunities for problem solving and contribution to the intervention design process will also be integrated into these sessions (Caplan, 1990). For example, participants will be invited to comment on currently available website and app features that could be included in a future web-based intervention. Interviews will be audio recorded and transcribed verbatim.

Data analysis

Data will be analysed using conventional content analysis (Hsieh & Shannon, 2005). The transcripts will be read and reread to allow familiarity with the data and to identify items of potential interest. They will be read in conjunction with researcher notes taken at the time of the interviews so that the data and its context are considered when reading. Next, data from several transcripts will be inductively coded, using exact words from the text, where possible, to capture key concepts. Memos will be used to capture the researchers' initial impressions throughout this initial coding process. The codes and relevant data will then be collated in an iterative process of returning to the original data for recoding and refinement. Initial codes and memos will subsequently be examined to identify meaningful clusters. Following this, a coding framework with associated definitions will be developed. All transcripts, memos and codes will be entered into NVivo 12 (QSR International Pty Ltd, 2018). The remaining transcripts will then be analysed by searching for statements that specifically support or challenge the proposed codes to refine the cluster and categorisation. Strategies to ensure robust and rigorous interpretation will be used, drawing on Thorne's notions of epistemological integrity, representative credibility, analytic logic and interpretive authority (Thorne, 1997).

Design Phase

Purpose:

- To develop an evidence-based web-based prototype intervention

The design phase will synthesise information from the planning phase, in keeping with the PBA, to formulate guiding principles. These are statements that succinctly reflect what is distinctive about the intervention that meets user needs as identified in the planning phase (Yardley, Morrison, et al., 2015). They ensure intervention development remains constant and true in its direction towards meeting the earlier identified goals. The guiding principles can be broken down into *intervention objectives* and the *intervention features* needed to achieve them. Data will be drawn and integrated from several sources to underpin intervention objectives and features including: a) existing evidence-based exercise interventions that address shoulder pain; b) systematic review findings regarding features of effective self-guided and web-based interventions; c) narrative review and Interpretive Descriptive qualitative study

findings regarding aspects that support acceptability and engagement; and d) relevant behavioural theory. For example, if synthesis reveals that valuing independence is important, then an objective of the intervention would be that it can be used autonomously. This will then inform a set of related intervention features such as customisable elements for goal setting, self-monitoring, and choice.

The first iteration of the SPIN prototype will be produced during this phase as a set of wireframes. Wireframes are a paper-based visual schematic of the prototype that help participants experience working through the intervention's proposed sequence without live data or graphic design. It therefore, allows researchers and participants to discuss the features of the intervention separate to the aesthetics (Baier et al., 2015).

Development Phase

Purpose:

- To develop an evidence-based web-based intervention

During the development phase, people with SCI will take part in usability testing, providing feedback on the wireframes produced in the design phase. Data will guide the iterative development and refinement of SPIN into a digital working prototype of SPIN, ready for implementation and trialling. There will be a large amount of collaborative work between the participants, computer engineer, web-developer, stakeholder advisory group and the researcher during this phase.

Participants

Up to ten participants who originally participated in the planning phase will be purposefully sampled to take part in the focus groups. Up to five of those participants will then be further purposefully sampled to be involved in individual 'think aloud' sessions (Jaspers et al., 2004). Sampling will aim for a range of abilities and levels of comfort when interacting with the prototype. Sample size is based on previous usability work by Nielsen (2000) and Vizri (1992).

Data Collection

Focus groups will use wireframes as a prompt for discussion. The facilitator will lead exploration of the wireframes and will use exercises to elicit feedback on the intervention features, layout, order and content (Caplan, 1990). For example, initial discussion will be generated around broad topics including initial impressions,

including positive and negative feedback. More specific exercises will ask participants to sort prototype features in order of preference and importance. Sessions will be audio and video recorded with notes taken during the process.

Focus group findings will lead to development of a working digital prototype. Following that, individual 'think aloud' sessions will be used to gain a more in-depth, real-time understanding of how easy the working prototype is to use and follow, and how participants interact with the intervention and progress through the stages. In these sessions, we will invite participants to work through a 'live' component of the prototype (e.g., one exercise). They will be encouraged to speak their thoughts out loud while performing the representative task, commenting on what they are looking at, thinking, doing and feeling at each moment, in as close to their natural environment as possible (Georgsson & Staggers, 2016). These sessions will be audio and video recorded. Open-ended interviews and post-experience questionnaires may also be used (Georgsson & Staggers, 2016).

Data Analysis

Audio recordings from focus groups and 'think aloud' sessions will be transcribed verbatim. Data will be analysed using a directed content approach (Hsieh & Shannon, 2005), drawing on usability frameworks (Nielsen, 1994). Transcripts will be read and key concepts relevant to pre-identified usability elements. Consistent with directed content analysis, text that does not fit an existing code will be given a new code (Hsieh & Shannon, 2005). Data from this phase will be used to refine the SPIN prototype in preparation for implementation and trialling (outside of the scope of the current proposed research).

Future work

Should findings from the intervention's design and development phases indicate the website is acceptable and usable, we will progress to a mixed methods pilot trial of a twelve-week SPIN intervention. The aim of this pilot trial will be to explore the feasibility, acceptability, safety, and engagement of the intervention. The full protocol will be informed by the framework proposed by Proudfoot and colleagues (Proudfoot et al., 2011) outlining facets, elements and guidelines of best practice in evaluating and reporting internet interventions (Eysenbach, 2011). The full scope of this pilot trial will

depend on findings from earlier phases. It is anticipated that up to ten people with SCI who have not been involved with any of the intervention development phases will be invited to take part. Data such as pain and adverse events will be collected concurrently. Data such as shoulder pain and function will be collected pre and post intervention. Post-trial interviews will explore user experiences on the acceptability and the perceived benefits of the SPIN intervention.

3.4.4 Conclusion

This paper has described how we plan to develop a self-guided, web-based, exercise intervention (SPIN) to treat shoulder pain in people living with SCI. Using the PBA involves people living with SCI at each phase, increasing the likely engagement and effectiveness of the planned intervention.

End of published manuscript

3.5 Chapter summary

In Chapter 3, I presented the methodological framework underpinning this work and included the published protocol. The following chapter represents the beginning of the planning phase: A systematic review and meta-analysis on the effectiveness of existing self-guided digital interventions for improving physical activity and exercise outcomes was undertaken.

Chapter 4 The effectiveness of self-guided digital interventions to improve physical activity and exercise outcomes for people with chronic conditions: a systematic review and meta-analysis

4.1 Chapter overview

In this chapter, I present a published systematic review and meta-analysis I undertook to gather data in the planning phase. At the time of undertaking this review, there was no known existing literature that had investigated the use of self-guided digital interventions in the SCI population and only one review conducted almost a decade ago in people living with chronic conditions. Because of the similar impairments, activity limitations, and barriers to participation that pwSCI experience to those living with other chronic conditions, the objective of this review was to explore and analyse the effectiveness of self-guided digital interventions for improving physical activity and exercise outcomes in people living with chronic conditions.

This chapter addresses objective 1: to determine the effectiveness of existing self-guided digital exercise interventions in people living with chronic health conditions.

In the intervening time from the publication of the protocol in Chapter 3 (Stavric et al., 2019), amendments were made to the methods of this systematic review. Most notably was the decision to not use the Critical Appraisal Skills Programme Randomised Controlled Trial Checklist (Critical Appraisal Skills Programme) and exclusively use the Cochrane risk of bias tool for randomized trials (Sterne et al., 2019). The Cochrane risk of bias tool is the most used tool to assess risk of bias of RCTs in systematic reviews in the last decade (Higgins et al., 2011). It provides a thorough assessment of key aspects of the design that could impact on the robustness of the findings being presented. By comparison, the Critical Appraisal Skills Programme provides a relatively high-level quality assessment. The revised Cochrane risk of bias tool (RoB 2) was released just before this systematic review was started and was selected as a current and appropriate tool to include in this review.

The systematic review and meta-analysis were published in *Frontiers of Rehabilitation Science* (Stavric et al., 2022). The full citation for the manuscript is:

Stavric, V., Kayes, N. M., Rashid, U., & Saywell, N. L. (2022). The effectiveness of self-guided digital interventions to improve physical activity and exercise outcomes for people with chronic conditions: a systematic review and meta-analysis. *Frontiers in Rehabilitation Sciences*. 3:925620. https://doi.org/10.3389/fresc.2022.925620

The manuscript is included here as published; however, the citations, figures and tables have been formatted to be consistent with the thesis. A copy of the published article is found in Appendix E.

4.2 Beginning of published manuscript: Systematic review and meta-analysis

4.2.1 Abstract

Objective: The aim of this systematic review was to determine the effectiveness of self-guided digital physical activity (PA) and exercise interventions to improve physical activity and exercise (PA&E) outcomes for people living with chronic health conditions. Digital health interventions, especially those with minimal human contact, may offer a sustainable solution to accessing ongoing services and support for this population.

Methods: A comprehensive and systematic search was conducted up to December 2021, through seven databases, for randomized trials that evaluated the effect of self-guided web- or internet-based PA interventions on physical activity or exercise outcomes. Included studies had to have interventions with minimal human contact, and interaction with participants needed to be automatically generated. All studies were screened for eligibility and relevant data were extracted. Two independent reviewers assessed the risk of bias using the Cochrane risk of bias tool. Standardized mean differences and 95% confidence intervals (CI) were calculated. PA data were pooled, and forest plots were generated.

Results: Sixteen studies met the eligibility criteria and included a total of 2,439 participants. There was wide variation in health conditions and intervention

characteristics in mode and parameters of delivery, and in the application of theory and behavioural strategies. Self-reported PA in the intervention group was greater than controls at the end of the intervention standardized mean difference (SMD) 0.2, 95% CI [0.1, 0.3] and at follow up (SMD 0.3, 95% CI [0.2, 0.5]). The difference in objectively measured PA was small and non-significant (SMD 0.3, 95% CI [−0.2, 0.9]). All interventions included behavioural strategies and ten of the sixteen were underpinned by theory.

Conclusions: Self-guided digital PA&E interventions provided a positive effect on PA immediately after the intervention. An unexpected and positive finding was a sustained increase in PA at follow-up, particularly for interventions where the behavioural strategies were underpinned by a theoretical framework. Interventions with minimal contact have the potential to support sustained PA engagement at least as well as interventions with supervision.

Systematic Review Registration: https://www.crd.york.ac.uk/prospero/, identifier: CRD42019132464. (Appendix F)

4.2.2 Introduction

There is extensive evidence for the benefits of physical activity (PA) in managing chronic conditions given their impact on fitness, mobility, and general health (Fransen et al., 2015; Furmaniak et al., 2016). Interventions aiming to address physical inactivity do not appear to have been implemented in any meaningful way (Lee & Ory, 2013). This may in part be due to the limited availability of clinic-based, face-to-face interventions (Reuben & Cassel, 2011; Walsh, 2004) to address the unique needs of this population. Alternative methods of delivering PA and exercise (PA&E) interventions need to be explored.

Digital technologies and the internet offer a medium to deliver and support PA&E interventions. These can be defined as interventions that are delivered via a digital platform to support or encourage a person to perform PA or exercise, usually with the aims of improved health outcomes. They provide a mode of health care delivery for people who find standard care inaccessible due to physical, economic, or social barriers (Davies, Spence, et al., 2012; Hoaas et al., 2016). Advancements in technology

and digital content have allowed the development of digital therapeutic interventions that encourage people to use them with minimal support. These interventions have minimal to no ongoing human involvement in their set up and can be delivered automatically. Applications, incorporating behaviour change elements and persuasive features (Bennell et al., 2020; Direito et al., 2017; Matthews et al., 2016; Win et al., 2019), can be incorporated into devices to offer interactive and personalized approaches (van Gemert-Pijnen et al., 2018).

Previous reviews have investigated the effectiveness of digital PA interventions in the general adult population and meta-analyses have demonstrated positive effects on PA (Davies, Spence, et al., 2012; Jahangiry et al., 2017). However, people living with chronic health conditions face unique challenges accessing and undertaking PA and exercise. They express a desire for specialist knowledge; concern that exercising may exacerbate symptoms; and transport issues (Cowan et al., 2013; de Hollander & Proper, 2018; Hoaas et al., 2016; Jaarsma et al., 2014; Jetha et al., 2011). A previous review by Bossen and colleagues (2014) investigated the use of web-based interventions with minimal human contact, designed to increase PA in people living with chronic health conditions. They reported mixed results with no clear conclusion.

Several factors mean that an updated review is warranted. First, all studies in the review by Bossen et al. (2014) were published between 2005 and 2010. Innovations in technology and increasing acceptance of its use in therapeutic interactions have led to a change in the definition of minimal human contact. Second, the review did not include exercise-based interventions. Exercise is a subcategory of PA (Caspersen et al., 1985) and has proven benefits in many chronic health populations (Lee et al., 2012; Warburton & Bredin, 2017). Therefore, in this review, our reporting of PA interventions will include exercise interventions. There has been no review to date investigating digital PA&E interventions that include behavioural intervention features, for people living with chronic health conditions, delivered with minimal human contact.

The aim of this systematic review was to determine the effectiveness of self-guided digital PA&E interventions to improve PA&E related outcomes for people living with

chronic health conditions. A secondary aim was to determine key behavioural intervention features that were used in the selected studies.

4.2.3 Method

The protocol was registered with PROSPERO; CRD 42019132464. The review has been conducted and is reported following the guidelines of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement by Moher et al. (2009).

Eligibility criteria

Papers were included if they met the criteria as outlined in Table 5.

Table 5

Eligibility criteria of papers

Elements	Inclusion criteria	Exclusion criteria
Study design and reporting	Randomized controlled trial (RCT) or pilot that contains data addressing effectiveness	Not in English Publication not peer-reviewed Conference proceeding
	Full text available	
	Published up to end of December 2021	
Population	Adults with a chronic condition	Those at risk of developing a chronic condition Those caring for a person living with a chronic condition
Intervention	Designed for use by people living with a health condition	
	Explicitly supports physical activity or exercise in a self-guided program	
	Web-based or app-based	
	Intervention has minimal human contact comprising no more than initial contact for set up or orientation AND Any ongoing interaction with the program is generated automatically	
Outcome	Any physical activity or exercise related outcome that measures a body function, an activity or a participatory limitation as per the International Classification of Functioning, Disability and Health Framework (ICF) (World Health Organization, 2002)	

The key elements in Table 6 were used to devise the search strategy. Specifically, key terms were derived for “intervention” (digital exercise) and “study design” (randomized controlled trial). The search strategy did not include search terms for “population” and “outcome” to keep the reach as broad as possible. The criteria for population and outcome were applied during the screening process. Search terms were combined using Boolean, wildcard, truncation, and proximity searching.

The search strategy was tailored to specific databases. Table 6 shows the search conducted using an OVID database.

Table 6

Search concepts and terms using OVID

	Search concept	Terms used as keyword OR title
#1	Digital physical activity or exercise	("world wide web" OR "web based" OR "web-based" OR website* OR "web site*" OR "web app*" OR internet OR online OR Ehealth OR "e-health" OR telemedicine OR telecare OR telehealth OR "tele-health" OR telerehab* OR "tele-rehab*" OR "digital health" OR mHealth OR "m-Health" OR "mobile health" OR "mobile app*" OR "smartphone app*" OR "digital intervention*") ADJ8 (exercis* OR rehab* OR physiotherapy* OR "physical therap*" OR "physical activ*" OR "fitness train*")
#2	Study design RCT	"Random* control*" OR RCT OR "control* trial*"
#3	#1 AND #2	

Databases

Literature searches were conducted in the following databases up until the end of December 2019. This was updated to include any new publications to the end of December 2021: Cumulated Index to Nursing and Allied Health Literature (CINAHL), MEDLINE, SPORTSDiscus through EBSCO Health Database, Allied and Complementary Medicine (AMED), Evidence Based Medicine (EBM) Reviews—Cochrane Methodology, EBM Reviews— Health Technology Assessment, PsycINFO, Ovid MEDLINE(R) through OVID, Scopus, clinicaltrials.gov, Cochrane Central Register of Controlled Trial (CENTRAL), and in Web of Science. The PEDro database was searched (using simplified broad key terms). Reference lists of relevant reviews and articles were also hand searched.

Data extraction

All citations returned in the search were downloaded and saved into EndNote X8. Duplicates were removed and then titles screened by VS, according to the pre-defined inclusion criteria. A selection of titles (the first 100) was independently screened by a second assessor (NLS). Any disagreements were reviewed and discussed to ensure consensus was reached. A third assessor (NMK) acted as arbitrator. Thereafter, VS and NS would meet after every 200 titles. There was high agreement as to which titles warranted further review. This process refined selection criteria. The abstracts and then full texts of studies identified as probably meeting the inclusion criteria were reviewed by VS in consultation with NLS to confirm the final set of included studies.

Key details from each of the included studies were recorded in a data extraction table in Excel. These included: author and country; participant numbers and characteristics; study design; treatment intervention parameters including duration, frequency, and follow up. The synthesis of findings from key papers in the area (Eysenbach, 2011; Kelders et al., 2012; Michie et al., 2013; Morrison et al., 2012; Webb et al., 2010) were used to create a framework to guide data extraction and included: theoretical underpinning for the intervention; instruction on how to perform the PA or exercise; recording and tracking of PA or exercise; the use of goal setting; the use of action and coping planning; the type, use, and delivery of feedback and monitoring; the use and delivery of prompts; the use of any additional online PA or exercise resources; the use of PA or exercise testimonials; and the use of gamification (Appendix Q). PA&E related outcome measures and results at the end of the intervention, and at follow up, if reported, were also recorded. If multiple impairment level outcomes were measured, only outcomes that have previously been shown to be correlated with the construct being measured (e.g., plantar flexion strength with walking) were extracted. For studies that were comparing more than two arms, data from arms comparing self-guided interventions to a control were included in the analysis.

Risk of bias

Risk of bias for each of the included studies was categorized as low, having some concerns or high, drawing on the revised Cochrane risk-of-bias tool for randomized trials (RoB 2) (Sterne et al., 2019). Initially, two studies were scored independently by two authors (VS, NMK). Scores were compared and key points of disagreement were discussed, to improve interrater agreement on interpretation of the RoB 2 criteria. Following that, all included studies were independently assessed by both authors. Rates of agreement were calculated and are reported below. Disagreements were discussed to achieve consensus, with NLS acting as arbitrator.

Data synthesis

Data were narratively synthesized focusing on the characteristics of the studies and outcomes. Meta-analysis was conducted on all studies that used PA as an outcome. The PA outcome measures were categorized as self-report or instrumented, and the data from each were pooled separately for meta-analysis.

A summary of intervention effects for each study was obtained by calculating Hedge's g standardized mean differences (SMD)s, 95% confidence intervals (CI)s, standard deviations (SD)s and effect sizes (ES). The Hedge's g values were calculated from the post-intervention time points while accounting for the pre-intervention differences. A positive ES indicates a result in favor of the intervention and a negative in favor of the control. When insufficient data were available for analysis, study authors were contacted. If the data were not received or could not be computated from published material, it was not included in any further analysis and was noted as not reported (NR). If standard errors or confidence intervals were presented instead of standard deviations (SD), SDs were calculated using recommended formulae (Borenstein, 2009). When required, means and SD were approximated from figures using WebPlotDigitizer (Drevon et al., 2017; Rohatgi, 2020).

Given the clinical heterogeneity of the included studies, both fixed effects and random-effects models were considered for pooling PA data. The extent of heterogeneity was determined using a hypothesis test based on generalized Cochran's Q-statistic (Bowden et al., 2011). High heterogeneity was assumed when the Q-test coincided with a significant value ($p<0.05$) (Viechtbauer, 2010) in which case, a random effects model was used. I^2 statistic was presented if the random effects model was chosen (Huedo-Medina et al., 2006). Meta-analysis results were reported as pooled Hedge's g and 95% CIs. Hedge's ≤ 0.2, ≥ 0.5, and ≥ 0.8 were interpreted as small, medium, or large, respectively (Cohen, 2013). A CI which did not overlap zero was considered statistically significant. An intervention was interpreted as effective at improving a construct when the estimated effect size was positive and had a 95% CI which did not cross zero. A category of interventions was considered effective at improving a construct when the meta-analysis effect size was positive and had a 95% CI which did not cross zero. Forest plots were also generated for pooled data. Unpooled data were presented in table format, allowing comparisons between each outcome. Analyses were performed in R (Bunn et al., 2018) using the metafor package (Viechtbauer, 2010). UR and VS contributed to and confirmed the synthesis of the extracted data. Discrepancies in data synthesis were discussed amongst the authors until consensus were reached, with NMK and NLS serving as arbitrators.

With respect to the secondary aim, given the diversity of intervention features, context, and population, it was not possible to make a direct link between intervention features and outcome. Therefore, key behavioural intervention features of included studies were recorded and tabulated.

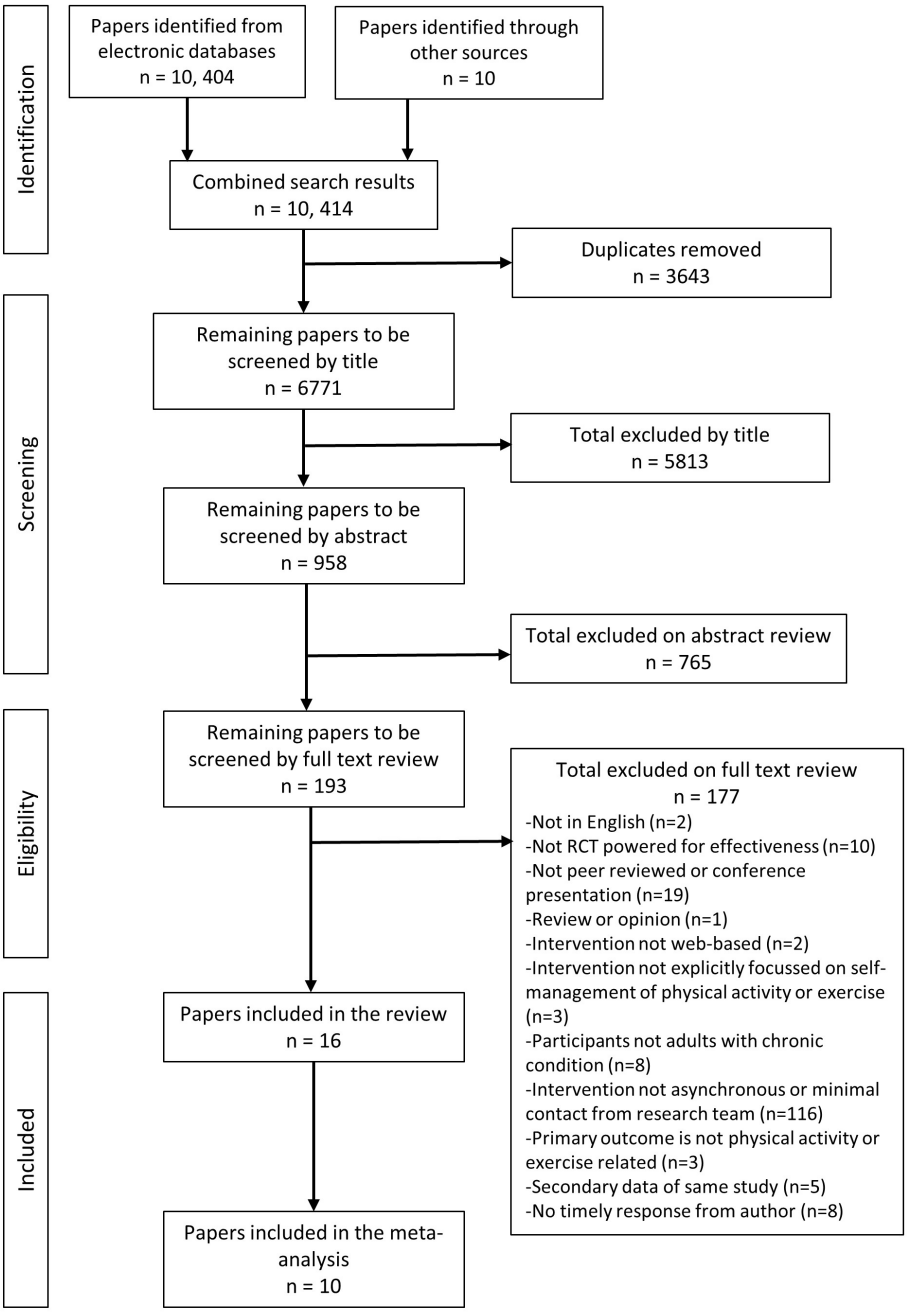
4.2.4 Results

Selection of studies

A flow diagram of the identification, screening and selection of papers is presented in Figure 3. There was 98% agreement with the co-author (NLS) during the screening phase, discrepancies were resolved by discussion. Following the full text review, 177 papers were excluded because they did not meet the a priori criteria (see Appendix G for a table of excluded papers). Three papers required discussion with arbitrator (NMK). Sixteen papers met the criteria and were included in the review with ten included in the meta-analysis.

Figure 3

Flow chart summarising the study selection process



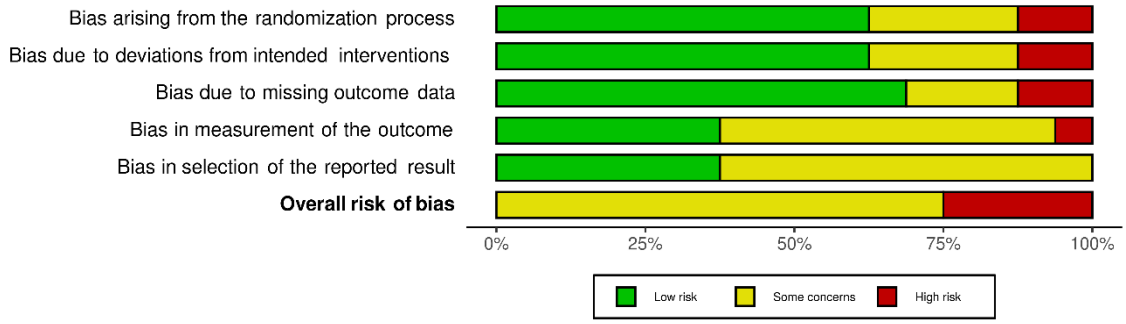
Risk of bias

The risk of bias assessment for included studies is available in Appendix H. Agreement between reviewers was high (92%). Consensus was reached where there was discrepancy. Overall, no studies were assessed as having a low risk of bias. The majority were assessed as having some risk of bias (Bossen, Veenhof, et al., 2013; Chapman et al., 2018; Holtdirk et al., 2021; Lee et al., 2014; Maddison et al., 2015; Nasseri et al., 2020; van Vugt et al., 2019; Wong et al., 2020; Wong et al., 2021; Yuan

et al., 2021), with the remaining five judged to be at high risk of bias in at least one domain (Crooks et al., 2020; Haglo et al., 2021; Kelechi et al., 2020; Kwon et al., 2018; Liu et al., 2018). As shown in the weighted summary plot (Figure 4), this could be attributed to having potential bias in the selection of reported results. Many studies did not have a published protocol, making it difficult to determine if analyses were carried out according to a pre-specified plan. Studies were also at risk of bias due to outcomes of interest being self-reported by participants who were unblinded to intervention status. Missing outcome data (for example, participants lost to follow up) also contributed to the bias.

Figure 4

Weighted summary plot of the overall type of bias encountered in the included studies



Characteristics of included studies

Included papers were published between 2013 and December 2021 (end of collection period). Publications in this research area have been increasing recently with half published in the last two years (Chapman et al., 2018; Geraghty et al., 2017; Kelechi et al., 2020; Kwon et al., 2018; Liu et al., 2018; Nasseri et al., 2020; van Vugt et al., 2019; Wong et al., 2020). Studies were conducted in Germany (Holtdirk et al., 2021; Nasseri et al., 2020), the Netherlands (Bossen, Veenhof, et al., 2013; van Vugt et al., 2019), the United Kingdom (Crooks et al., 2020; Geraghty et al., 2017), Korea (Kwon et al., 2018; Lee et al., 2014), Australia (Chapman et al., 2018), Brazil (Yuan et al., 2021), Canada (Liu et al., 2018), China (Wong et al., 2021), Hong Kong (Wong et al., 2020), New Zealand (Maddison et al., 2015), Norway (Haglo et al., 2021), and the United States (Kelechi et al., 2020).

Interventions were compared to usual care or wait list groups in six studies (Bossen, Veenhof, et al., 2013; Crooks et al., 2020; Geraghty et al., 2017; Holtdirk et al., 2021;

Maddison et al., 2015; Wong et al., 2020), to paper based interventions in four studies (Lee et al., 2014; Nasseri et al., 2020; Wong et al., 2021; Yuan et al., 2021), to another form of online intervention in three studies (Chapman et al., 2018; Kwon et al., 2018; Liu et al., 2018) and to a supervised intervention (Haglo et al., 2021). One study used the intervention of interest (minimal contact self-guided intervention) as the comparison group when testing versions of online and blended interventions (Kelechi et al., 2020). Table 7 displays characteristics of the included studies.

Characteristics of participants

Participants were recruited from primary health care, community settings and online databases. The number of participants within studies ranged from 24 to 438, with a combined total of 2,439 participants across studies (median n=93). The average age of participants across studies was 57.1 years with the mean age range from 43 to 67 years. Participants presented with the following chronic conditions: breast cancer (Chapman et al., 2018; Haglo et al., 2021; Lee et al., 2014), dizziness and vestibular syndrome (Geraghty et al., 2017; van Vugt et al., 2017), heart disease (Maddison et al., 2015; Wong et al., 2020), chronic obstructive pulmonary disease (Crooks et al., 2020; Kwon et al., 2018), fibromyalgia (Yuan et al., 2021), hypertension (Liu et al., 2018), inflammatory rheumatic diseases (Haglo et al., 2021), metabolic syndrome (Wong et al., 2021), progressive multiple sclerosis (Nasseri et al., 2020), osteoarthritis (Bossen, Veenhof, et al., 2013), and venous leg ulcers (Kelechi et al., 2020). Table 7 provides details for all included studies.

Outcome measures

Outcomes of interest were those related to the PA or exercise interventions that measured an activity or body function (World Health Organization, 2002). These were grouped into change in PA that was self-reported and change in PA that was measured by instrumentation. Changes in body functions and symptoms were also reported. Change in PA was meta-analyzed in ten of the included studies. This was measured using self-reported questionnaires (Bossen, Veenhof, et al., 2013; Chapman et al., 2018; Holtdirk et al., 2021; Lee et al., 2014; Maddison et al., 2015; Nasseri et al., 2020; Wong et al., 2020; Wong et al., 2021) and instrumented devices (accelerometers, pedometers, or wearable devices) (Bossen, Veenhof, et al., 2013; Crooks et al., 2020;

Liu et al., 2018; Nasseri et al., 2020). The remaining relevant outcomes varied considerably among studies. Therefore, they were broadly grouped, as per the ICF framework (World Health Organization, 2002), into change in body functions and symptoms and included measures such as walking endurance, measured by the six-minute walk test (Kelechi et al., 2020; Kwon et al., 2018; Nasseri et al., 2020), strength (Kelechi et al., 2020; Nasseri et al., 2020), vestibular symptoms (Geraghty et al., 2017; van Vugt et al., 2017), peak oxygen uptake (Haglo et al., 2021; Maddison et al., 2015), pain (Yuan et al., 2021), foot and ankle mobility (Kelechi et al., 2020), dyspnea (Crooks et al., 2020; Kwon et al., 2018), and range of motion (Crooks et al., 2020; Kelechi et al., 2020; Kwon et al., 2018; Liu et al., 2018; Yuan et al., 2021). Self-reports of perceived effect and self-efficacy of exercise were also measured (Bossen, Veenhof, et al., 2013; Wong et al., 2020; Wong et al., 2021). Bossen et al. (2013) and Kwon et al. (2018) used the Knee Osteoarthritis Outcome Score and Hip Osteoarthritis Outcome Score and the assessment test. These measure symptoms, activities of daily living and quality of life; the scoring of each outcome precludes the ability to report these constructs separately.

Table 7

Characteristics of the randomized controlled trials, participants, and interventions

Author, year, country	Inclusion criteria	Sample size (n) mean age (yr) females (F) males (M)	Intervention details and use of theory	Comparison	Outcomes of interest	Intervention duration (D) Frequency of delivery (F) Intended frequency of exercise (E)
Bossen et al., 2013, Netherlands	Self-report OA knee/ hip, 50-75 yrs, self-report inactivity, no treatment in last 6 months, no contra-indications to exercise, internet access	n=199 age=62 yrs F=129 M=70	8 weekly modules of Behavioural Graded Activity (Join2move) of participant's identified favourite activity. Automatically increased graded activity depending on answers from pain and performance scale. Intervention based on operant behaviour principles with aim of increasing PA.	Wait list	PA (self-reported) via PASE PA (instrumented) via ActiGraph GT3X accelerometery KOOS /HOOS Self-perceived effect	D=9 weeks F=1 x week E=determined by users
Chapman et al., 2018, Australia	Breast cancer survivors, > 18 yrs, completed treatment, no contra-indications to exercise	n=101 age=59.1 yrs F=101	Online volitional help sheet (VHS) which presents most likely barriers to PA. Participants prompted to select possible coping strategies to be more equipped if situation arises. Intervention based on TTM and implementation-intention with aim of increasing PA.	Online standard implementation intention version that presents most likely PA barrier scenarios but requires participant to self-generate possible coping strategies.	PA (self-reported) via GSLTPAS to determine moderate PA: LSI-MSPA	Once off intervention E=not applicable

Author, year, country	Inclusion criteria	Sample size (n) mean age (yr) females (F) males (M)	Intervention details and use of theory	Comparison	Outcomes of interest	Intervention duration (D) Frequency of delivery (F) Intended frequency of exercise (E)
Crooks et al., 2020, UK	COPD, 40-80 yrs, FEV_1>50% and FEV_1/FVC<70% predicted or COPD diagnosis within 12 months, current or ex-smoker, internet access, able to use web platform in English	n=60 age=66.1 yrs F=29 M=31	myCOPD online application and tile platform covering variety of self-management topics. Users able to input data for more tailored advice. Intervention not based on theory. Aims to improve areas of body structure and function and activity.	Usual COPD management for study duration. After study completion, offered app access.	CAT 7-day step count via Fitbit at baseline and at completion	D=12 weeks F=variable, some expected daily (like exercise related content) others every few weeks E=unclear, likely daily
Geraghty et al., 2017, United Kingdom	Dizziness lasting 2 yrs made worse with head movement, ≥ 50 yrs, access to internet	n=296 age=67.4 yrs F=197 M=99	6-week balance retraining, vestibular rehabilitation, adaptation, and habituation program on improving symptoms. Includes head movements to promote reduction of movement provoking dizziness and reduce avoidance behaviours. Intervention based on SRT, CBT.	Standard non-web-based care consisting of reassurance, symptomatic relief with or without educational information.	Symptom severity via VSS-SF	D=6 weeks F=1 x week E=2 x day x 10 min

Author, year, country	Inclusion criteria	Sample size (n) mean age (yr) females (F) males (M)	Intervention details and use of theory	Comparison	Outcomes of interest	Intervention duration (D) Frequency of delivery (F) Intended frequency of exercise (E)
Haglo et al., 2021, Norway	Inflammatory rheumatic diseases, ≥18 yrs, diagnosed with either RA, SpA, SLE, not familiar with HIIT	n=40 age=49 yrs F=23 M=17	Myworkout GO smartphone app to guide and deliver 4x4 min HIIT at a % of HR max. App provides display of progression and estimation of work performed automated scheduling of next exercise time. Intervention not based on behavioural theory. Aims to improve areas of body structure and function and activity.	Supervised 4x4 HIIT	VO_2 max via Metamax II	D=10 weeks F=2 x week E=2 x week
Holtdirk et al., 2021, Germany	Breast cancer survivors, 30-70 yrs, diagnosis < 5 yrs ago, completed acute treatment > 1 month prior to study entry with discharge letter proof, able to speak and read German	n=363 age=49.9 yrs F=363	16 multimodal web-based modules that registered users can select and work through. Subsequent content is continuously tailored based on user response. Daily text messages remind and motivate users to use the program. Intervention is based on CBT.	Usual care and wait list of 3 months for access to the intervention.	PA (self-reported) via IPAQ	D=12 weeks F and E= self-paced

Author, year, country	Inclusion criteria	Sample size (n) mean age (yr) females (F) males (M)	Intervention details and use of theory	Comparison	Outcomes of interest	Intervention duration (D) Frequency of delivery (F) Intended frequency of exercise (E)
Kelechi et al., 2020, United States	Venous leg ulcers, ≥ 18 yrs, impaired mobility resulting in inability to walk 100 feet without resting, no current PA, requiring wound care, no arterial insufficiency, able to don the slipper to which BEAT accelero-meter is affixed	n=24 age=64.9 yrs F=14 M=10	COMPARISON 6-week progressive exercise intervention delivered through app (FOOTFIT). Non-exertional exercises (Conditioning physical Activities for lower Leg Function-CALF) tracked with Bluetooth Enabled triaxial Accelerometer Tracking (BEAT). Intervention not based on theory. Aims to improve areas of body structure and function and activity.	INTERVENTION FOOTFIT+ is FOOTFIT, CALF and BEAT with added phone, email, or text messaging connectivity to wound care providers. Intervention not based on theory. Aims to improve areas of body structure and function and activity.	ROM of ankle Strength of ankle FAAM 6MWT	D=6 weeks F=all at once E=3 x day x 15 sec progressed every 2 weeks
Kwon et al., 2018, Korea	COPD, ≥ 20 yrs, FEV <80%, >150m in 6MWT, Android smart-phone user	n=85 age= 64.3 yrs F=15 M=70	efil breath fixed-interactive app uses participant data from baseline and current exertion level feedback to tailor walking prescription. Intervention not based on theory. Aims to improve areas of body structure and function and activity.	efil breath fixed app uses pre-determined walking distances and progresses when participant achieves certain targets. AND usual care with no app.	6MWT CAT mMRC	D=12 weeks F= daily E= 7 x week x 30 min

Author, year, country	Inclusion criteria	Sample size (n) mean age (yr) females (F) males (M)	Intervention details and use of theory	Comparison	Outcomes of interest	Intervention duration (D) Frequency of delivery (F) Intended frequency of exercise (E)
Lee et al., 2014, Korea	Breast cancer survivors, haemoglobin over 10g/dl, not meeting exercise or healthy eating goals, access to computer, home internet, mobile phone user	n=57 age= 42.4 yrs F=57	Health Planner 5 portions: assessment that leads to tailored plan for each participant: education (tailored info provision), action planning (goal setting, scheduling, keeping a diary), automatic (tailored) feedback. Intervention based on TTM with aim of increasing PA.	50-page educational booklet on exercise and diet.	PA (self-reported) via 7-day exercise diary (minutes per week ≥ 4 METs)	D=12 weeks F= 2 x week E= 5 x week x 30 min
Liu et al., 2018, Canada	HTN (stage 1 or 2), 35-74 yrs, stable meds before enrolment, if on antihypertensives: SBP 130 and DBP 85	n=128 age=56.9 yrs F=61 M=67	Automated e-counselling: Participant identifies areas to address and is provided with pre-determined expert driven suggestions which are informed by foundation questionnaire. Intervention based on TTM with aim of increasing PA.	Automated e-counselling: Participant identifies areas to address but is self-reliant (user-driven) for suggestions. AND Control group	SBP PA (instrumented) via daily step count via XL-18CN pedometer	D=16 weeks F=1 x week E= 5 x week x 30 min

Author, year, country	Inclusion criteria	Sample size (n) mean age (yr) females (F) males (M)	Intervention details and use of theory	Comparison	Outcomes of interest	Intervention duration (D) Frequency of delivery (F) Intended frequency of exercise (E)
Maddison et al., 2015, New Zealand	IHD, ≥ 18 years, clinically stable, able to perform exercise, able to understand and write English, access to Internet.	n=171 age= 60.2 yrs F=32 M=139	Personalized, automated package of text messages via mobile phones aimed at increasing exercise behaviour. Intervention based on SET with aim of increasing PA.	Usual care	Peak VO_2 via Moxus PA via IPAQ	D=24 weeks F=6 x week E= 5 x week x 30 min
Nasseri et al., 2020, Germany	Progressive MS, 18-60 yrs, EDSS below 6.5	n=38 age=51.1 yrs F=19 M=19	12-week app-based information package on exercise including text, figures, videos and accelerometery activity feedback. Intervention not based on theory. Aims to improve areas of body structure and function and activity.	Paper based leaflet with information on generalized exercise.	6MWT 5xSTS PA (self-reported) via GSLTPAS to determine moderate PA: LSI-MSPA PA (instrumented) via Actigraph accelerometer	D=12 weeks F=not specified but assumed delivered all at one time E=not specified but assumed daily

Author, year, country	Inclusion criteria	Sample size (n) mean age (yr) females (F) males (M)	Intervention details and use of theory	Comparison	Outcomes of interest	Intervention duration (D) Frequency of delivery (F) Intended frequency of exercise (E)
Van Vugt et al., 2019, Netherlands	Dizziness ≥ one month and increased with head movement, ≥ 50 yrs, Dutch speaker, access to internet and email	n=322 age= 67 yrs F=197 M=125	6-week stand-alone online vestibular rehabilitation, adaptation, habituation with relaxing, cognitive restructuring, engagement features. Intervention based on CBT, SET, exposure-based behaviour.	Usual care with no vestibular rehabilitation	Symptom severity via VSS-SF	D=6 weeks F=1 x week E= 2 x day x 10 min
Wong et al., 2020, Hong Kong	CHD, ethnic Chinese 45-65 yrs, regular treatment for CHD, able to use internet at home	n=438 age=52.3 yrs F=149 M=289	eHES website representing constructs such as 'cues to action' and 'enhancing self-efficacy' that allow self-monitoring of individual health and exercise. Intervention based on HBM.	Usual care including routine medical visits and a paper based educational leaflet.	PA (self-reported) via GSLTPAS Self-efficacy for exercise	D=24 weeks F=not specified but assumed delivered all at once E=5 x week x 30 min
Wong et al., 2021, China	Metabolic Syndrome, ≥ 50 yrs, ethnic Chinese, had MetS as defined by waist circumference, triglycerides, HDL, BP and fasting plasma glucose measures, own smartphone access	n=77 age=58 yrs F=43 M=43	MetS app to support initiation and maintenance of healthy behaviours relating to monitoring weight, diet, and exercise. Intervention based on HBM.	Booklet providing MetS management information.	PA (self-reported) via GSLTPAS Self-efficacy for exercise	D=12 weeks F=not reported E=5 x week x 30 min

Author, year, country	Inclusion criteria	Sample size (n) mean age (yr) females (F) males (M)	Intervention details and use of theory	Comparison	Outcomes of interest	Intervention duration (D) Frequency of delivery (F) Intended frequency of exercise (E)
Yuan et al., 2021, Brazil	Fibromyalgia, 19-59 yrs, diagnosis by American College Rheumatology diagnostic criteria, smartphone user, completed elementary school education	n=40 age=43 F=39 M=1	ProFibro App providing self-management through animation, self-monitoring, family adjustment, sleep hygiene scheduling, graded exercise, hints through notifications. Intervention not based on theory. Aims to improve areas of body structure and function and activity.	64-page booklet to replicate app.	Pain via WPI Pain via VAS Symptom severity via SS	D=6 weeks F=not reported E=not reported

2MWT two minute walk test**, 4 MET** moderate aerobic exercise that consumed at least 3.5 ml/O_2/kg/min or $\geq$ 150 min/week**, 5 STS** five time sit to stand, **6MWT** six minute walk test, **app** application, **AROM** active range of motion, **BP** blood pressure, **CAT** COPD assessment test, **CBT** cognitive behavioural theory, **CHD** Coronary heart disease, **COPD** chronic obstructive pulmonary disease, **DASH** Disabilities of the Arm, Shoulder and Hand, **EDSS** Extended Disability Severity Scale, **ext** extension, **FAAM** Foot and Ankle Mobility Measure, **g/dl** grams per decalitre, **GP** general practitioner, **GSLTPA** Godin-Shephard Leisure-Time Physical Activity Score, **HBM** health belief model, **HOOS** Hip Osteoarthritis Outcome Score, **HTN** hypertension, **IHD** ischemic heart disease, **IPAQ-LF** International Physical Activity Questionnaire-Long Form, **Kg** Kilogram, **KOOS** Knee Osteoarthritis Outcome Score, **LSI-MSPA** Leisure Score Index of moderate-strenuous exercise, **m** meters, **MET** metabolic equivalent, **mMRC** Modified Medical Research Council Dyspnea Scale, **MS** Multiple Sclerosis, **OA** osteoarthritis, **op** operative, **OT** occupational therapy, **PA** physical activity, **PASE** Physical Activity Scale for the Elderly, **prn** as deemed appropriate, **RCT** randomized controlled trial, **ROM** range of motion, **SBP** systolic blood pressure, **SET** self-efficacy theory, **SRT** self-regulatory theory, **TTM** transtheoretical model**, VO_2** maximum rate of oxygen consumption, **VSS-SF** vestibular symptom scale-short form, **yrs** years.

Characteristics of the interventions

Modes of delivery

There were a variety of modes of delivery and technologies used across interventions. Eleven of the interventions involved computers (Bossen, Veenhof, et al., 2013; Chapman et al., 2018; Crooks et al., 2020; Geraghty et al., 2017; Holtdirk et al., 2021; Kwon et al., 2018; Lee et al., 2014; Liu et al., 2018; Maddison et al., 2015; van Vugt et al., 2017; Wong et al., 2020). Mobile or smartphones were used in nine studies (Haglo et al., 2021; Holtdirk et al., 2021; Kelechi et al., 2020; Kwon et al., 2018; Lee et al., 2014; Maddison et al., 2015; Nasseri et al., 2020; Wong et al., 2021; Yuan et al., 2021). Almost half the studies were testing a website specific to the study (Bossen, Veenhof, et al., 2013; Geraghty et al., 2017; Holtdirk et al., 2021; Lee et al., 2014; Maddison et al., 2015; van Vugt et al., 2017; Wong et al., 2020) while three used existing platforms (Chapman et al., 2018; Kwon et al., 2018; Liu et al., 2018). Applications specifically designed for the study were used in seven studies and involved a smartphone or computer (Crooks et al., 2020; Haglo et al., 2021; Kelechi et al., 2020; Kwon et al., 2018; Nasseri et al., 2020; Wong et al., 2021; Yuan et al., 2021). Communication with participants was carried out via automated email (Bossen, Veenhof, et al., 2013; Crooks et al., 2020; Geraghty et al., 2017; Liu et al., 2018; van Vugt et al., 2017; Wong et al., 2020), automated SMS text messaging (Holtdirk et al., 2021; Lee et al., 2014; Maddison et al., 2015) or the study app features (Haglo et al., 2021; Kelechi et al., 2020; Kwon et al., 2018; Wong et al., 2021; Yuan et al., 2021). Biosensors were used in five studies (Bossen, Veenhof, et al., 2013; Crooks et al., 2020; Kelechi et al., 2020; Kwon et al., 2018; Maddison et al., 2015).

Parameters of intervention delivery

Table 7 provides details on key intervention parameters. Intervention duration ranged from a one-off session to 24 weeks. The expected frequency of the physical activity or exercise performance varied. This ranged from a one-off instructional session (Chapman et al., 2018) to asking participants to participate repeatedly throughout the day (Geraghty et al., 2017; Kelechi et al., 2020; van Vugt et al., 2017), once daily (Crooks et al., 2020; Kwon et al., 2018; Nasseri et al., 2020), several times a week (Haglo et al., 2021; Lee et al., 2014; Liu et al., 2018; Maddison et al., 2015; Wong et al.,

2020), or as determined by the participant (Bossen, Veenhof, et al., 2013; Holtdirk et al., 2021; Kwon et al., 2018).

Theoretical basis

Just over half of the included studies reported using theory to inform their interventions, with three referencing more than one theory. The transtheoretical model was the most frequently cited (Chapman et al., 2018; Lee et al., 2014; Liu et al., 2018). Self-regulatory theory, cognitive behavioural theory, social cognitive theory, exposure-based behaviour principles, implementation-intention-based principles, health belief model and operant behaviour principles were also each used once (Bossen, Veenhof, et al., 2013; Chapman et al., 2018; Geraghty et al., 2017; Holtdirk et al., 2021; Maddison et al., 2015; van Vugt et al., 2017; Wong et al., 2020; Wong et al., 2021). No underpinning theory was reported for six of the self-guided interventions (Crooks et al., 2020; Haglo et al., 2021; Kelechi et al., 2020; Kwon et al., 2018; Nasseri et al., 2020; Yuan et al., 2021).

Behavioural intervention strategies and features

The interventions used a combination of behavioural strategies and features to support PA&E behaviour (Table 8). A commonly used feature was instruction on how to perform the PA or exercise (n=14). Variations included generalized automated PA or exercise information, tailored exercise provision, and tracking and recording of PA or exercise performed. The use of feedback and monitoring (n=13) was also used in most interventions. Other strategies involved goal setting (n=11) and the use of prompting features (n=10). Fewer than half the interventions incorporated action and coping plans (n=5), online resources of supplemental PA or exercise information (n=4) or testimonials or case studies (n=5). None of the included studies used gamification approaches. Most interventions employed several strategies concurrently.

Table 8

Behavioural intervention strategies and features used

	Instruction on how to perform PA or exercise	Use of feedback and monitoring in PA or exercise	Use of goal setting for PA or exercise	Use of prompts for PA or exercising	Use of action and coping plans for PA or exercise	Use of online resources for additional PA or exercising	Use of testimonials in benefits of PA or exercise	Use of gamification to encourage PA or exercise
Bossen et al., 2013 Netherlands	✓	✓	✓	✓		✓		
Chapman et al., 2018 Australia			✓		✓			
Crooks et al., 2020 UK						✓		
Geraghty et al., 2017 United Kingdom	✓	✓	✓				✓	
Haglo et al., 2021 Norway	✓	✓	✓	✓				
Holtdirk et al., 2021 Germany	✓	✓	✓	✓	✓		✓	

	Instruction on how to perform PA or exercise	Use of feedback and monitoring in PA or exercise	Use of goal setting for PA or exercise	Use of prompts for PA or exercising	Use of action and coping plans for PA or exercise	Use of online resources for additional PA or exercising	Use of testimonials in benefits of PA or exercise	Use of gamification to encourage PA or exercise
Kelechi et al., 2020 United States	✓	✓		✓				
Kwon et al., 2018 Korea	✓	✓	✓					
Lee et al., 2014 Korea	✓	✓	✓	✓	✓			
Liu et al., 2018 Canada	✓	✓	✓	✓	✓			
Maddison et al., 2015 New Zealand	✓	✓	✓	✓	✓	✓	✓	
Nasseri et al., 2020 Germany	✓	✓					✓	
Van Vugt et al., 2019 Netherlands	✓		✓	✓		✓	✓	

	Instruction on how to perform PA or exercise	Use of feedback and monitoring in PA or exercise	Use of goal setting for PA or exercise	Use of prompts for PA or exercising	Use of action and coping plans for PA or exercise	Use of online resources for additional PA or exercising	Use of testimonials in benefits of PA or exercise	Use of gamification to encourage PA or exercise
Wong et al., 2020 Hong Kong	✓	✓		✓				
Wong et al., 2021 China	✓	✓	✓					
Yuan et al., 2021 Brazil	✓	✓		✓				

Effectiveness of interventions

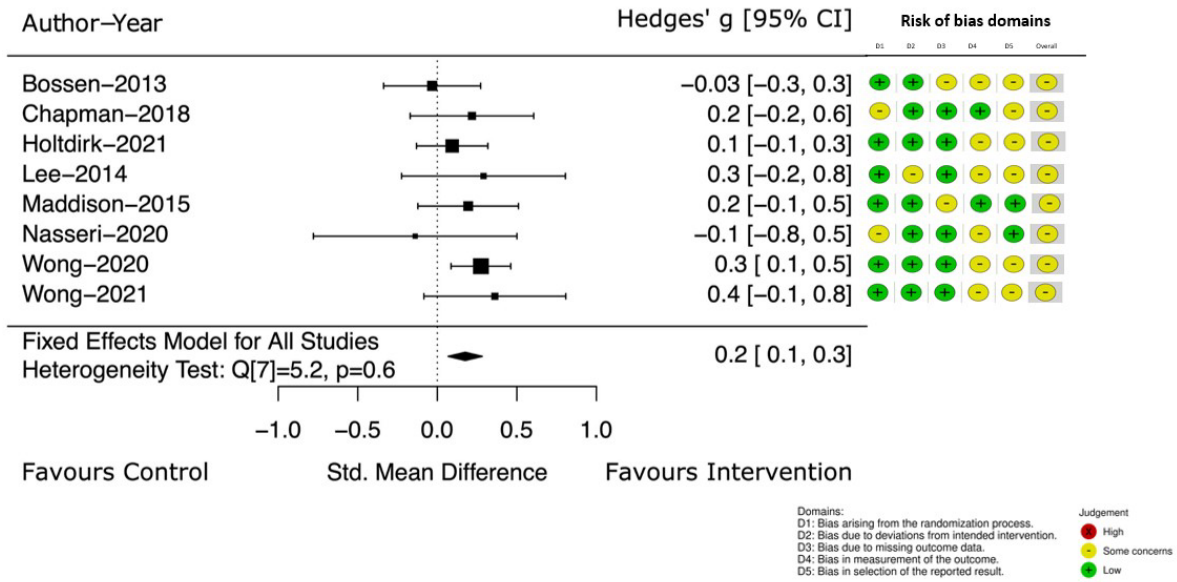
Effectiveness was measured by change in PA&E and change in body function and symptoms. These were defined and measured in a variety of ways.

Physical activity

Change in self-reported PA was the outcome of interest in eight of the included studies (Bossen, Veenhof, et al., 2013; Holtdirk et al., 2021; Lee et al., 2014; Maddison et al., 2015; Nasseri et al., 2020; Wong et al., 2020; Wong et al., 2021). Figure 5 details the Hedge's g between group difference, with 95% CI, at the earlier assessment point, taken at the end of intervention (which ranged from 4-24 weeks). The Hedge's g between groups favoured the intervention group with a small, estimated effect of 0.2, 95% CI [0.1, 0.3].

Figure 5

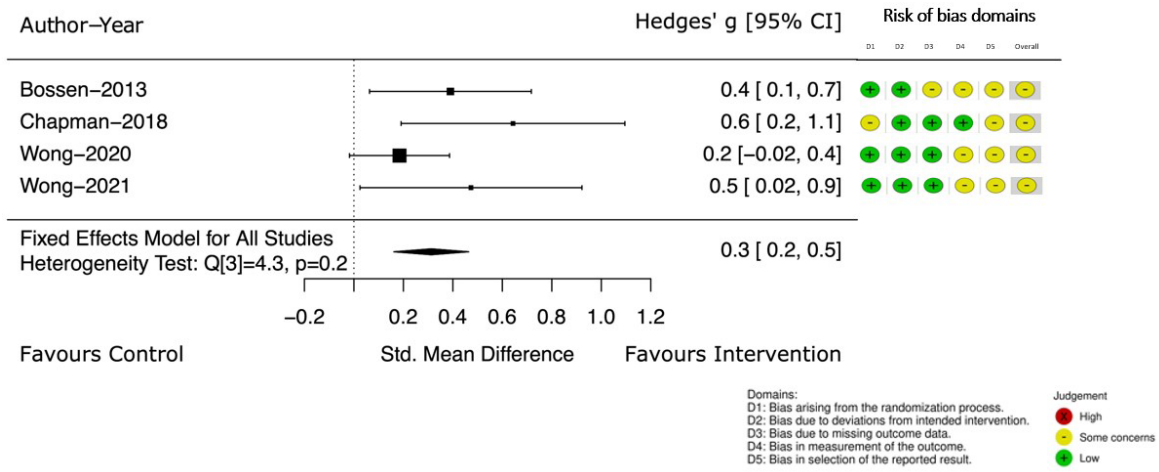
Self-reported PA and end of intervention



Four of these studies (Bossen, Veenhof, et al., 2013; Chapman et al., 2018; Wong et al., 2020; Wong et al., 2021) continued to measure self-reported PA at a follow up point (12-52 weeks from the end of intervention). Pooled results demonstrate the effect of the intervention. The Hedge's g between groups continued to favor the intervention group with an increased estimated effect (Hedge's g 0.3, 95% CI [0.2, 0.5]). See figure 6.

Figure 6

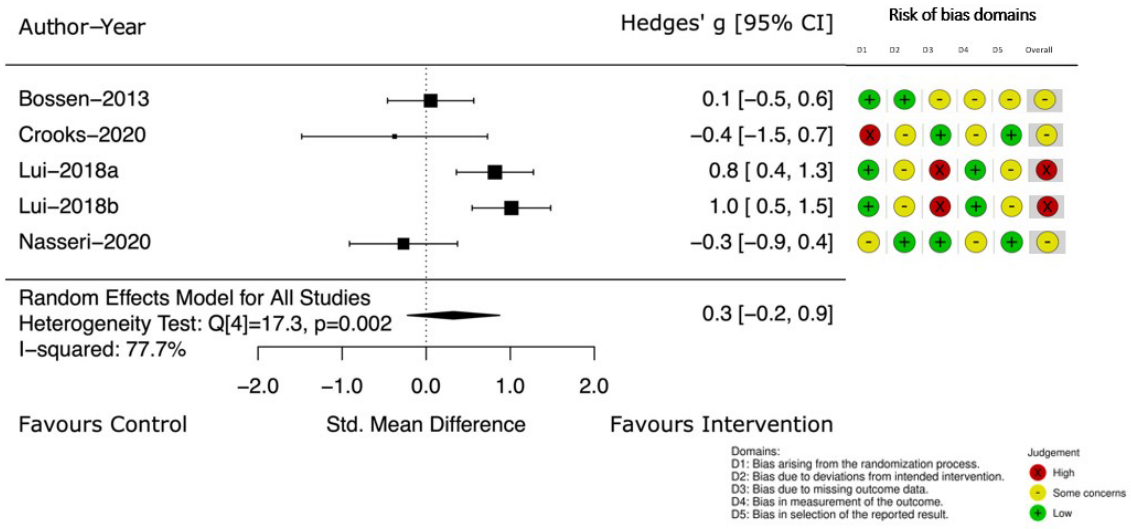
Self-reported PA at follow-up



Change in PA, measured by instruments such as accelerometers or pedometers was described in four studies (Bossen, Veenhof, et al., 2013; Crooks et al., 2020; Liu et al., 2018; Nasseri et al., 2020). The Hedge's g between groups and 95% CI, at the completion of the intervention, are displayed in Figure 7. The small treatment effect on PA was in favor of the intervention group (Hedge's g 0.3) but the CI crossed the no effect line (95% CI [-0.2, 0.9]) and heterogeneity was 77.7%.

Figure 7

Instrumented measurement of PA at end of intervention



Body functions and symptoms

Meta-analysis was not conducted on outcomes related to body functions and symptoms due to the high heterogeneity of measures employed. There was variation

in the size of effect and statistical significance across the studies. Refer to Appendix I for details of each study, the extracted outcome measures, assessment points, mean group differences and estimated effects. Despite studies showing some risk of bias, there are some results that were of note. Effects (Hedge's g 0.3 to 0.8) were reported in two separate studies evaluating six-week vestibular interventions at the 12- and 24-week post intervention time points (Geraghty et al., 2017; van Vugt et al., 2017). Both interventions had a theoretical basis and incorporated several behavioural strategies. There was also evidence of a small positive effect of graded-activity on physical function at 12 weeks (Hedge's g 0.4, 95% CI [0.1, 0.7]) but not at the 52-week follow up in a nine-week PA intervention for people with knee and hip OA (Bossen, Veenhof, et al., 2013). Self-perceived effect and exercise self-efficacy were measured in two studies (Bossen, Veenhof, et al., 2013; Wong et al., 2021). A moderate effect (Hedge's g 0.6, 95% CI [0.3, 0.9]) was noted for self-perceived effect after the nine-week PA intervention. Similarly, a moderate effect was seen in self-efficacy for exercise (Hedge's g 0.5, 95% CI [0.1, 1]) at the end of a four-week intervention and maintained (Hedge's g 0.6, 95% CI [0.2, 1.2]) at the 12 week follow up. Theoretical underpinnings and behavioural features were also incorporated in these interventions. Studies that did not have a theoretical basis did not report any effects.

When looking across study exercise parameters, there was a large variation in dosage (amount x frequency x duration) of prescribed exercise. There did not appear to be a clear relationship between dosage and effect.

4.3 Discussion

4.3.1 Principal findings

This is the first systematic review to conduct a meta-analysis of outcomes following self-guided digital PA&E interventions in people living with chronic conditions. This work advances the evidence in digital interventions for PA&E. The more stringent inclusion criteria for minimal contact used in this review meant that none of the studies in the review by Bossen and colleagues (2014) met the threshold to be included.

The findings of our review indicate a positive effect of self-guided digital interventions on PA that were seen at the end of intervention and sustained at follow up, for people living with chronic health conditions. These findings differ from the findings of Bossen and colleagues of conflicting evidence on the effectiveness of web-based PA interventions in this population (Bossen et al., 2014). Our findings reflect the developments in technology that have enabled persuasive and engaging elements to be embedded into digital interventions (van Gemert-Pijnen et al., 2011; Yardley, Ainsworth, et al., 2015). These may help overcome some of problems of low uptake and adherence (Kohl et al., 2013).

There was a small but significant effect seen with self-reported PA at the end of interventions. Direito and colleagues (2017), investigating the effect of mHealth technologies on self-reported PA in healthy participants, found a comparable effect that was not significant. Kwan et al.'s (2020) review of eHealth interventions promoting PA in older adults found that self-report PA was significantly increased compared with the control groups. However, since the interventions in both reviews included contact and personal consultation, a cautious approach to comparison is needed.

Objectively measured change in PA in the current review showed a small effect that was not significant. This has also been reported by others (Direito et al., 2017; Romeo et al., 2019) who have found insignificant effects favouring mobile and app-based interventions that were not strictly self-guided. There is an assumption that objective PA measures more accurately reflect actual changes in PA. However, Kayes and McPherson (2010) argue measurement tools such as accelerometers and pedometers have not always been validated in people living with chronic health conditions. Despite significant advances in the objective measurement of PA in these populations, questions remain regarding the validity and reliability of these devices in some groups, such as people with slow walking speeds or those with higher levels of disability (Sasaki et al., 2017; Sliepen et al., 2017).

Our findings of sustained PA improvement beyond the intervention, is in contrast with previous work. In-person PA interventions have been shown to increase PA levels in the short to medium term (seven weeks to one year) but not in the long term (at or

over one year), in community dwelling adults with or without a long-term health condition (Kunstler et al., 2018; Richards et al., 2013). Our findings are supported by Davies et al. (2012) who conducted a review of web-based PA interventions and found an overall small but significant mean effect of sustained PA when looking at a follow up of at least 6 months after the intervention. Regardless of the length of follow up, the persistence of change seen, despite the removal of intervention, is encouraging.

The prolonged effect observed in some studies may be linked to the use of behavioural strategies in the interventions. The most common intervention strategies and features used were instructions on how to perform the PA or exercise, goal setting, and the use of feedback and monitoring. These align with the behaviour change techniques (BCT) taxonomy clusters proposed by Michie and colleagues (2013). The self-guided interventions with the larger effect sizes employed strategies from at least three of these clusters (Bossen, Veenhof, et al., 2013; Geraghty et al., 2017; Lee et al., 2014; Liu et al., 2018; van Vugt et al., 2017; Wong et al., 2020). This finding is supported by research showing that the use of techniques from three BCT clusters are needed to produce effects on PA in face-to-face interventions (McEwan et al., 2019; Stockwell et al., 2019). For self-guided digital interventions, employing self-regulatory techniques may be the most effective way to support PA engagement (Michie et al., 2009; Morrison et al., 2012; Webb et al., 2010). Michie et al. (2009) found that interventions combining self-monitoring (using feedback) in combination with other features that encouraged self-regulation (goal setting, action and coping plans) were more likely to lead to intervention effectiveness (Conner et al., 2010). These strategies can influence behaviour via mechanisms such as problem-solving, promoting self-efficacy or diminishing the impact of barriers to behaviour change (Lippke et al., 2009). They may also address the intention behaviour gap (Gollwitzer, 1999). In this review, fewer than half the interventions reviewed used action and coping plans or other strategies that promote self-regulation. The lack of theoretical underpinning found in many of the studies may help explain their choice of intervention features and non-significant results. While we did not explicitly set out to determine the effectiveness of behavioural features, interventions that were effective did include behavioural features. Determining which specific features might best be implemented to support

sustained use and engagement with self-guided interventions would be a future research direction.

The lack of an apparent relationship between exercise dose and effect suggests that the prescribed dose may be only one factor of an intervention that influences participant outcomes. The behavioural strategies embedded in the interventions influence exercise completion and, therefore, are an important factor in the reported interventions. The lack of reporting of exercise completion makes it difficult to appreciate how these factors contributed to outcome.

4.3.2 Strengths and limitations

This review focused on investigating the effect of digital self-guided interventions on PA&E and fills a gap in the literature in this growing area. We included all forms of digital interventions that could be delivered remotely, without ongoing human interaction. The comprehensive search, using several databases, identified studies previously not included in similar reviews, and the broad range of outcomes make the findings generalizable to a wider range of populations, interventions, and environments. We identified behavioural strategies using well established frameworks (Michie et al., 2013) that allows for transparency and a clear understanding of intervention features that may help to explain reported effects. This review has also reported metrics for discrete end of intervention and follow up outcomes and meta-analyses for PA outcomes for self-guided digital PA interventions for people living with chronic conditions.

People living with chronic conditions face additional challenges in undertaking PA&E compared to a healthy population. Acknowledgment of the inherent heterogeneity that comes with each health conditions should sit alongside any the generalization of these findings, particularly when a significant portion of the people included in this review were living with cardiorespiratory, neurological or oncology conditions and were under the age of 60. Despite this, there is much we can learn by looking across populations, particularly when those populations share characteristics beyond diagnosis such as chronicity and complex barriers to engagement with PA&E.

To be included in the review, papers needed to have been peer reviewed to address the question of effectiveness, which may have introduced publication bias. Other criteria were that interactions with the intervention had to be automatically generated. Screening of the papers for this criterion was not straightforward due to the lack of a standard definition of what constitutes minimal contact. We selected papers based on our operational definition and consequently many interesting and valuable digital PA&E interventions were excluded. For included papers, data were frequently incompletely or inconsistently reported, and some were analysed as intention to treat while others were not. This made analysis of the results difficult and necessitated computation using reported data. The wide variation in health-related body function and symptoms outcomes prevented us from pooling this data. Therefore, we synthesized the results in a way that allowed the magnitude and range of effects to be appreciated.

The studies included in this review demonstrated some or high risk of bias and so findings should be interpreted with caution. The nature of the minimal contact digital intervention creates increased opportunities for bias with attrition, and the reporting of outcomes remotely.

4.3.3 Future recommendations

Future work should continue to investigate which intervention features and exercise parameters lead to the best effect. Effort should continue to ensure complete reporting of the intervention, the behavioural interventions used, and treatment fidelity, including recording the participant's completion of the prescribed dose. Authors also need to ensure that adverse events are explicitly sought and consistently reported. This was not the case in many of the studies included in the current review. For interventions that are self-directed and have minimal contact with health professionals, understanding intervention safety is an important component of the trialling phase.

The proportion of participants lost to follow up in the studies in this review demonstrates that maintaining engagement with low contact digital interventions is challenging (Eysenbach, 2005; Leslie et al., 2005). Given the added barriers

experienced by these people (Bullard et al., 2019), tailoring the intervention to the individual needs to be considered and addressed (Allen et al., 2018).

Researchers are encouraged to broaden the scope of populations involved in this type of research. For the current review, the population of interest focused on people living with chronic conditions that included a range of non-communicable diseases. Of note was the lack of studies involving people living with disabilities, a large group who also would benefit from self-guided and digital interventions. Finally, the participant's voice is notably absent from much of this research.

Our research group is currently exploring many of these areas. For example, we are applying an Interpretive Descriptive study design to explore what makes a self-guided digital intervention more acceptable to users, with the aim of developing interventions which increase uptake and engagement (Stavric et al., 2019). The findings from this current review and the Interpretive Descriptive study will inform our development of a self-guided digital intervention to help treat shoulder pain for people living with spinal cord injury (Stavric et al., 2019).

4.4 Conclusion

This review found a positive effect in favour of self-guided digital PA&E interventions on PA outcomes and a selected number of body functions and impairments at the end of intervention and at follow up, in people living with chronic conditions. Interventions that employ behavioural strategies, underpinned by a theoretical framework, have the potential to support self-regulation and sustained PA at least as well as interventions with supervision.

End of published manuscript

4.5 Chapter summary

In this chapter I presented the systematic review and meta-analysis demonstrating the effectiveness of self-guided digital interventions to improve physical activity and exercise outcomes for people with chronic conditions. The following chapter will present the second part of the planning phase of my doctoral work: An Interpretive

Descriptive qualitative study exploring the perceptions of a self-guided web-based exercise programme for shoulder pain after spinal cord injury.

Chapter 5 Perceptions of a self-guided web-based exercise programme for shoulder pain after spinal cord injury: A qualitative study

5.1 Chapter overview

In this chapter I report findings from an Interpretive Descriptive qualitative study as part of the data I gathered in the planning phase. There is no known existing evidence on what factors may encourage pwSCI who have shoulder pain to engage with self-guided digital exercise interventions. As such, in this study, I explored their experiences and perceptions when presented with the possibility of such an intervention.

This chapter addresses objective 2: to identify factors perceived to encourage or facilitate engagement in self-guided, digital exercise interventions.

Addendum to the published work: Given the limits on word count in the published works, I provide some further explanation of some aspects of the research here.

Stakeholder advisory group: The make-up of stakeholder advisory group has been explained in further detail in Chapter 3, page 27.
Sample size: As noted in the manuscript (see page 79), I drew on Information Power to determine sample sufficiency. This approach uses information power as the reference for sample size calculation because it refers to the quality and richness of the data collected by seeking breadth and diversity of perspectives (Malterud et al., 2016).
Data analysis: Further details on the analysis and coding of the data can be found in Appendix J.
Sample characteristics: Information on the sex distribution of participants was not included in the original publication. There were thirteen males and three females in the sample.

The manuscript reporting the qualitative findings was published in *Spinal Cord* (Stavric et al. 2023). The full citation for the manuscript is:

Stavric, V., Saywell, N. L., Kayes, N. M. (2023). Perceptions of a self-guided web-based exercise programme for shoulder pain after spinal cord injury: A qualitative study. *Spinal Cord.* https://doi.org/10.1038/s41393-023-00877-3

The manuscript is included here as published; however, the citations, figures and tables have been formatted to be consistent with the thesis. A copy of the published article is found in Appendix K.

5.2 Beginning of published manuscript: Interpretive Descriptive qualitative study

5.2.1 Abstract

Objectives: The benefits of exercise to reduce shoulder pain in people with spinal cord injury (SCI) are well documented. Digital health interventions offer a potential solution to overcome barriers to access rehabilitation support for exercise. The aim of this project was to gain people's perspectives to inform the development of a self-guided web-based exercise intervention. Shoulder Pain Intervention delivered over the interNet (SPIN) is a self-guided web-based intervention to prescribe, monitor, and progress evidence-based exercises for people living with SCI and shoulder pain.

Setting: Community in Auckland, New Zealand

Methods: The Person-Based Approach was used as the framework. Using an Interpretive Descriptive methodology, data were collected in individual and focus group interviews, exploring participants' perceptions of this intervention idea. Data were analysed using conventional content analysis.

Results: Sixteen participants took part and asked *Is it right for me?.* This had three main sub-themes. *Should I use it?*, whether I believe it will work for me right now; *Can I use it?*, whether I can operate the intervention competently and confidently and *Will I use it?*, whether it will be responsive to my unique needs, and keep me coming back.

Conclusions: Participants expressed their expectations and tipping points when considering using an intervention like this. These findings will inform and guide design and development of an acceptable technology-based intervention to increase the

likelihood of engagement with a self-guided web-based exercise programme. The model developed from these themes could be used to inform future self-guided intervention development.

5.2.2 Introduction

Management of shoulder pain in wheelchair users living with SCI often includes exercise-based rehabilitation. A programme of stretches and strengthening exercises has been shown to significantly reduce shoulder pain (Cratsenberg et al., 2015; Curtis, Tyner, et al., 1999; Mulroy et al., 2011; Wellisch et al., 2021). However, many people with SCI (pwSCI) who experience shoulder pain do not engage in these exercises (Ditor et al., 2003). They cite barriers to exercise and rehabilitation opportunities including limited access to knowledgeable health professionals, poor physical accessibility, and transportation difficulties (Cowan et al., 2013). Even when these barriers are addressed, persisting with exercises is difficult (Ditor et al., 2003).

Self-guided web-based interventions could address these barriers and have been implemented successfully in other populations experiencing persistent pain (Brooks et al., 2014). However, existing web-based interventions (Coulter et al., 2016; Shepherd Centre, 2017; Singh et al., 2019) for pwSCI require ongoing input and monitoring from a clinician or do not provide structured exercise progression for shoulder pain intervention.

Shoulder Pain Intervention delivered over the interNet (SPIN) is planned to be a self-guided web-based intervention using decision tree algorithms (Al Fryan et al., 2022) to prescribe, monitor, and progress evidence-based exercises for pwSCI with shoulder pain (Stavric et al., 2019). The development of SPIN is supported by the Person-Based Approach (PBA) (Stavric et al., 2019; Yardley, Morrison, et al., 2015). The PBA approach seeks a deep understanding of the perspectives and psychosocial context of potential users through employing iterative qualitative research (Yardley, Morrison, et al., 2015) and incorporating existing behavioural theories. Keeping users' needs and contexts in focus maximises engagement and effectiveness of an intervention (Michie et al., 2011; Webb et al., 2010). As such, understanding the psychosocial context of future users of SPIN is a critical component in this intervention development process. To that end, this

study explored the experiences and perspectives of pwSCI regarding the possibility of a self-guided web-based exercise programme to inform the development of SPIN.

5.2.3 Materials and method

Study design

This Interpretive Descriptive study (Thorne, 1997) explored impressions and opinions of the possibility of a self-guided web-based exercise programme to treat shoulder pain. The project was approved by the Auckland University of Technology Ethics Committee (AUTEC) 18/263 (Appendix L). A stakeholder advisory group, formed as part of the larger project, was consulted to gauge how findings resonated with personal insights and experiences (Appendix D)

Participants

People living with SCI were eligible for inclusion if they resided in New Zealand; were not engaged in a rehabilitation programme; were over 16 years old; had the capacity to give informed consent; were predominantly wheelchair users; and had experienced shoulder pain within the past two years. Participants were excluded if they were unable to communicate with the researcher for data collection.

Sampling and recruitment

Purposeful sampling was used for diversity in demography and to capture a breadth of perspectives and experiences. Advertisements were distributed within SCI community and rehabilitation providers (e.g., Spinal Support New Zealand, Neuro Rehab Results) (Appendix M) and were also circulated through social media sites and professional and personal networks. Participant information sheets were provided to those who expressed interest (Appendix N). Our sample size was primarily determined by our goal to capture a breadth and range of experiences and we aimed to continue sampling until sufficient diversity was reached. We also drew on the concept of information power as a final check on sample sufficiency (Malterud et al., 2016).

Data collection

We obtained and recorded consent before data collection began (Appendix O). We collected data using individual and group semi-structured interviews (see Table 9 for interview guide) at participants' preferred location. We used probes to explore

concepts of usability, safety, motivation, action planning, and progression. Participants were also asked about helpful features from websites or apps they currently used. We took notes and interviews were audio recorded, then transcribed verbatim.

Table 9

Interview guide

Part 1 Sample of progressive interview questions
"What is your initial thought when you think of using a web-based exercise programme to treat your shoulder pain?"
"Now what if it is intended that you use this programme entirely independently?"
"What if the exercise programme will be set up and progressed without you seeing or being in contact with a health professional?"
Part 2 Probes and images of current web-based or app-based programme features are presented for feedback and comment
"What do you think of these features when thinking of a web-based exercise programme?"
"How would these features help with any of the concerns you raised earlier?"

Data analysis and synthesis

We analysed the data using conventional content analysis (Hsieh & Shannon, 2005), reading transcripts in conjunction with the field notes. VS inductively coded the data, using exact words from the text, to capture key concepts and maximise descriptive and interpretive validity (Sandelowski, 2000). A coding framework was derived from initial coding of the majority of transcripts (n=9). VS exported all transcripts and the coding framework into NVivo 12 (QSR International Pty Ltd, 2018) and analysed the remaining transcripts, identifying meaningful clusters. All authors met regularly to discuss and contribute to theme construction. Preliminary themes were presented to the stakeholder group to check for resonance (Lincoln & Guba, 1985), and inform final refinements. See Appendix P for images reflecting stages of the analysis process.

5.2.4 Findings

Participant demographics

Sixteen pwSCI with shoulder pain took part in individual (n=8) and focus group (n=8, 4 groups) interviews (Table 10). In one focus group, a support worker also contributed. Participants ranged from 30 to 67 years. We achieved diversity on the majority of key

characteristics as reflected in Table 10, and the final sample has good information power in the context of the study aims, sample specificity, quality of dialogue, and analytical strategy.

Table 10

Participant demographics

Demographic item	Category	Number of participants
Age (years)	30-44	4
	45-59	9
	60+	3
Ethnicity	NZ European	12
	Māori[a]	1
	Pasifika	3
Level of injury	Tetraplegia	7
	Paraplegia	9
Completeness of injury	Complete	11
	Incomplete	5
Time since injury (years)	0-10	2
	11-20	5
	20+	9
Living setting	Urban	12
	Rural	4
Wheelchair type	Manual	15
	Power	1
Interview type	Focus Group	8
	Individual Interview	8

[a]Indigenous population of New Zealand

5.2.5 Main findings

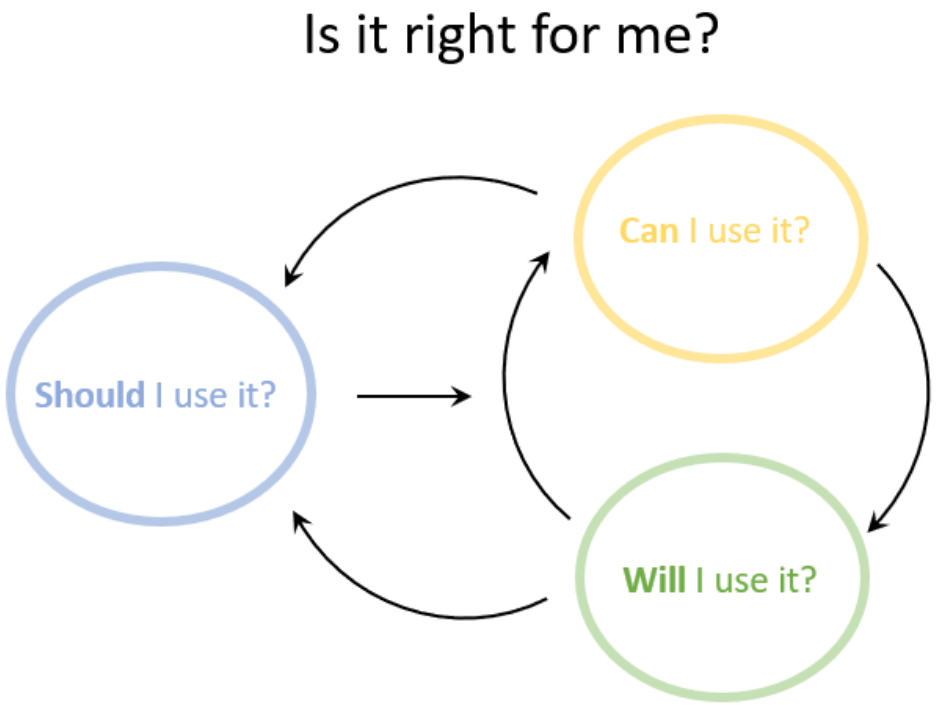
Participants engaged in an evaluative process when considering the programme, asking *Is it right for me?.* Our findings suggest this was a nuanced and multi-layered process that consisted of supporting questions or themes to help inform the overarching question. These were: *Should I use it?*, *Can I use it?* and *Will I use it?*.

The relationship between these themes is presented in Figure 8. *Should I use it?* reflects the first step in deciding to take up SPIN. If participants determine that the

SPIN has fit for them, they ask *Can I use it?* and *Will I use it?.* If their evaluation suggests that the programme is not responsive to their needs, they may cycle back to questioning *Should I use it?.* This in turn may make them reconsider *Is it right for me?.* The model reflects this cyclical process in deciding if the programme is right for them.

Figure 8

Evaluative process when considering a self-guided web-based programme



Theme 1: Should I use it?

Should I use it? represents the first step, deciding whether to start using the programme. Participants identified several factors that were important in their initial appraisal.

Credibility

Participants required their first impression to be of a credible programme which will meet their needs. Having the programme recommended by a trusted source was preferable to randomly finding it and having to evaluate it independently. Participants identified professional endorsement to be of value but highlighted that connection with and learning from peers with lived experience was even more powerful.

> … if you've been set up for it by someone you know and trust, either the spinal unit or the physio you've been working with for a while, that would be

> different but … if it's just something you stumbled across because you Googled for it … somehow it wouldn't carry the same weight or have the same authority. (Jeremy, C6 tetraplegic)

Safety

Safety of the programme was important. Clarity on how each user would be screened, without human oversight, helped to determine safety and engender trust. Despite an inherent assumption that exercise programmes delivered and monitored by humans would be safer and be able to be tailored to the unique needs of users, it was acknowledged that this was not always the case.

> Mind you, you can get that with human factor anyway. You might diagnose me wrong too so who cares. And one physio might recommend something different to another, doctors are exactly the same. (Tony, C6 tetraplegic)

Perceived value

Perceived value included the benefits of exercise generally, the extent to which exercise could address shoulder pain, and whether the proposed programme would address outcomes of value. Participants acknowledged that reduced access to other traditional or preferred treatments would increase the appeal and value of this programme.

> I have shoulder pain … eventually it goes to the [case manager who] makes a referral to the physio. Then there's a stand down period of time. Meanwhile I've just got to figure out my own kind of remedy. … probably we're looking at maybe 4-6 months … there's a loss of that whole period of time where I could have got some help. (Eleanor T12/L1 paraplegic)

Past experience with exercise shaped how the programme was perceived, influencing the value placed on exercise and a person's intention to exercise. While participants were overwhelmingly positive about the value of exercise for addressing shoulder pain, in some situations exercising was not always considered as important or achievable. There was a range of factors, including timing and competing demands, believed to influence uptake of an exercise programme.

> As you get older … looking after your health is the most important thing. When you're younger … it's on the list but it's not as high up the list. (Michael, T12/L1 paraplegic)

Theme 2: Can I use it?

Participants identified factors that would influence their interaction and ongoing engagement with the programme. *Can I use it?* captures the notion of using the programme and performing the exercises with confidence.

Feeling competent

Participants expected the programme to guide them to perform and progress the exercises correctly, for best effect. Support workers also wanted guidance from the programme to assist pwSCI to exercise accurately and effectively. Participants related concerns they experience in their daily life with respect to provision of support, including challenges with consistency of personnel, and confidence in how their care is delivered, which had the potential to affect programme uptake. This was considered particularly pertinent in the context of high support worker turnover or when therapy is provided by less experienced clinicians.

> You know when something didn't quite go right, they [support workers] didn't have the training and the knowledge to know which way to jump to sort it out, so we'd give up on it you know. (Jeremy, C6 tetraplegic)

Technological competence and usability of the programme also influenced participants' answer to *Can I use it?.* Recurrent technical issues were factors that were believed to influence ongoing engagement with the programme. The usability and clarity of the programme must maximise the chance of successful use and effective exercise performance by users of all levels, with minimal support.

> I think that something you'd have to consider, is it's a lot easier not to ask for help and not do the exercise … Yeah just give up. (Robert, C5 tetraplegic)

Having control

Participants recognised the autonomy this programme could bring. They endorsed programme features which put them in charge, allowing them to personalise the programme and meet individual needs and preferences. Having agency to make decisions best suited to each individual, could reinforce engagement through a sense of ownership and control.

> Being able to tailor your own solutions, I think is a very important aspect. I hate the term that gets bandied around a lot, empowering you to do this thing or the other, but I mean that is precisely what that's doing, and I believe it's important. (Jeremy, C6 tetraplegic)

Practical considerations were important, like procuring and securing equipment, and the support they would need to carry out the exercises. Participants who relied on support from others expressed that the helper's capacity and beliefs influenced exercise completion, positively and negatively. The need to preserve the relationship has the potential to outweigh the drive to request help with an exercise routine, as it can become an additional demand to the usual list of cares.

> … and then, the exercises rely on having the TheraBand™ set up in such a way that you can do the exercises, now somebody has to set me up with that TheraBand™, and that person has to be a willing participant. (Robert, C5 tetraplegic)

Theme 3: Will I use it?

Will I use it? reflects participants' views on the importance of being engaged by the programme to encourage them to keep coming back and complete the exercises for the duration of the programme.

Fostering positive experiences

Participants discussed how positive emotional experiences would be an important hook to encourage users and keep them interested. Participants suggested that early success and progression of exercise performance was one mechanism to achieve this. Being able to track performance and progress was seen as feedback that would encourage users.

The use of messages that give feedback on performance was also considered important. The tone, language and timing of this information were discussed. Some participants felt they would respond to a supportive tone whereas others felt a challenging and competitive tone was more motivating.

> You could have of fun with it, you know, and to engage and use it, they could customise it. So, I might have mine that says, 'you know, come on, you haven't done it for two days, 'the ** you doing?!' And it's kind of their own reminder so it's part of the whole orientation. Do you want to remind yourself? I do. (George, C6 tetraplegic)

The use of rewards to encourage return to the programme and focus on the goal was also discussed. Several participants suggested using gamification principles like awarding points for tasks to provide a positive experience and encourage regular use.

> It would give me my points for doing the exercises regularly, 3 days a week, 3 times a week, … if I miss a day then I drop a few points, so that there's a desire to not miss a week you know, and I'm beating that guy so I'm doing better than he is … The gaming aspect is to try and engage most people's inherent competitive nature, even if they're only competing against themselves. (Lawrence, T12/L1 paraplegic)

Seeing progress

Seeing progress in exercise performance or function, was important in promoting programme value. Participants spoke of their sense of success when they realised, they could perform more exercises than they thought. This gave them the confidence to do more exercise and engage more in everyday activities. There was an understanding that progress can vary, and the goal may be to increase daily activity or function, while keeping pain under control, rather than eliminate all pain. Ensuring meaningful progress is captured was considered formative to providing a personalised programme that accounts for user's needs and preferences. This was important to ensure ongoing engagement when there is no clinician involvement.

> Yeah, I think the feedback that I would want to see, is a graph of my progress, so that I can see that I'm actually improving. (Robert, C5 tetraplegic)

Feeling connected

Participants spoke about how feeling connected helped them stay engaged and feel supported. While they felt this should come from their health professional, they valued support and encouragement from anybody who was interested and invested in their success. This support helped them stay on track and be accountable.

> I know from my previous life experience, that I always work better when I've got somebody to encourage me, or somebody that's interested, because they're interested in how I'm getting on. They don't want to see me suffering from sore shoulders. Yeah, so that connection might be really important. (Robert, C5 tetraplegic)

If accountability could be built into the system, participants were challenged to consider whether it mattered where it came from. Connection and accountability could come from nominated people, other users, and from the programme despite there not being a health professional involved. However, this was not universally endorsed.

> … if it was totally autonomous and there was no personal interaction whatsoever, they may not have all that interest in it, or they lose interest too quickly or whatever, it's just a soulless computer programme, nobody at the other end. (Robert, C5 tetraplegic)

5.2.6 Discussion

We used the PBA to explore perceptions, of pwSCI, when considering using a self-guided web-based exercise programme to treat shoulder pain. The overarching question participants asked was *Is it right for me?.* Reinforcing this was a continuous process of revisiting the supporting questions of *Should I use it? Can I use it?* and *Will I use it?.*

Should I use it? highlighted the importance of credibility and safety when using a web-

based intervention. People living with SCI accessing web-based physical activity information have expressed a preference for knowing material came from a reliable source (Pancer et al., 2019). Features that promote credibility and guidance have been shown to increase trust in an intervention in other populations (Bossen, Buskermolen, et al., 2013).

Can I use it? reflected participants' views about using the programme competently, confidently, and autonomously. The ability to tailor features, including prompts, has been employed by other self-management interventions after SCI (Mortenson et al., 2019; Pancer et al., 2019), increasing the programme's personal relevance. Our findings confirm those of Singh et al. (2019) who reported that a self-management app for pwSCI would need to be intuitive and offer user flexibility and control.

Will I use it? related to ongoing engagement and motivation to keep returning to the programme and exercises. Strategies that were identified were consistent with findings from previous studies: being able to monitor progress to measure improvement and stay accountable (Pancer et al., 2019; Webb et al., 2010), and using peer connection (Mortenson et al., 2019; Pancer et al., 2019). Perski et al. found that features which facilitated social support positively influenced engagement (Perski et al., 2017).

In addition to the identified themes, three concepts were interwoven throughout the data: needing to feel connected, feel competent and have autonomy. These concepts align well with Self-Determination Theory, which proposes that three basic psychological needs have to be met to be self-determining and autonomously motivated: a need for competence, relatedness, and autonomy (Ryan & Deci, 2000). In the context of SPIN, users would need to feel competent using it, feel connected to it or others while using it, and have a sense of control or choice when using it. Development of SPIN will incorporate these concepts into its design.

SPIN development and roll-out implications

The design goal of SPIN is to incorporate features that can create experiences without a clinician being present. This requires intentional use of intervention features that engender confidence that SPIN is a safe, effective, and personalised programme. This

study's findings confirm previous findings that interventions need to be tailored, theory-based, multimodal, and incorporate behavioural strategies (Morrison et al., 2012; Webb et al., 2010). Drawing on the PBA, our next step is to use what we have learned in this research, and from existing theory and evidence, to develop a set of guiding principles which articulate the intervention design objectives and the features needed to achieve these objectives (Stavric et al., 2019). Using the PBA in pwSCI with shoulder pain has highlighted what they need from this self-guided exercise intervention. Our findings suggest that when SPIN is developed and ready for implementation, our roll out plan should include liaising with SCI clinicians and services to promote SPIN as an evidenced-based tool to augment current intervention options. Recommendations of SPIN from these credible sources would increase trust and uptake.

Strengths and limitations

Strengths

The tiered process of questioning in this study allowed a depth of discussion and analysis in keeping with the PBA. The range of participants, coupled with the stakeholder group, ensured that findings have transferability to pwSCI. The robust methodological and analytic approach ensured that our findings went beyond a semantic level, to identify a deeper decision-making process, explaining a clinical phenomenon. This model could be applied when reflecting on the development of any intervention.

Limitations

Our findings may not be representative of the entire SCI community who live with shoulder pain. The perspectives of Māori, or indeed other indigenous and culturally diverse populations, and those who live rurally were not fully captured in this research. Future work will purposively work with these sub-groups.

5.2.7 Conclusions

This study used the PBA to investigate the perceptions and experiences of pwSCI with shoulder pain to inform the development of a self-guided web-based exercise

intervention. The involvement of participants in the early development phases has enabled us to identify key decision-making points when considering intervention uptake and ongoing use. This will inform the design of the SPIN programme and will act as a model which could inform the development of other self-guided interventions.

End of published manuscript

5.3 Chapter summary

In this chapter, I presented the findings from the Interpretive Descriptive qualitative study exploring what pwSCI think of and want to see, when thinking of a self-guided digital intervention to help manage shoulder pain. The information gathered in the planning phase, from this and the previous chapter, informed the subsequent phases of the PBA. The following chapter moves from data collection and analysis and introduces the next phase of my doctoral work, the SPIN design and development phase.

Chapter 8 Integrated discussion

8.1 Chapter overview

In this chapter, I will present my contributions to current understanding and practice. In addition, I will describe how the findings and outcome of this work have the potential to contribute to future practice. I will also reflect on the strengths and limitations of my doctoral work. I will then propose some next steps including future SPIN development and opportunities for further related research.

8.2 Current contributions

In this doctoral work, I set out to translate an evidence-based exercise programme into a self-guided digital intervention to help manage shoulder pain for pwSCI. Three specific objectives were outlined to address this overarching aim including to:

1. determine the effectiveness of existing self-guided digital exercise interventions in people living with chronic health conditions;
2. identify factors perceived to encourage or facilitate engagement in self-guided, digital exercise interventions; and
3. develop an evidence-informed and self-guided digital intervention drawing on the Person-Based Approach to intervention development.

In meeting these objectives, by developing SPIN, I have produced several contributions that I will detail below.

8.2.1 A blueprint for self-guided digital intervention development

I have developed a blueprint for the development of an evidence informed self-guided digital intervention for pwSCI who have shoulder pain.

This is a novel approach in providing accessible and credible health care to a group of people for a specific problem. More broadly, it provides an opportunity to address the limitations of current care delivery. People living with SCI experience high (up to 70%) prevalence of shoulder pain (Bossuyt et al., 2018; Curtis, Drysdale, et al., 1999; Jain et al., 2010; Sie et al., 1992) making it a very common condition that prompts people to seek intervention. The care required can be difficult to find and pwSCI experience

barriers accessing care even when services are available (Burkell et al., 2006; Cowan et al., 2013; Munce et al., 2014). Limited treatment options and barriers often result in delays in treatment. Even short delays in treatment for shoulder pain have been found to result in worse functional ability in the general population (Ginn et al., 1997). This is compounded for pwSCI.

In developing SPIN, I have followed the PBA approach. People living with SCI and shoulder pain who will use SPIN will likely have minimal to no contact with a health care professional. Therefore, successful development and use requires an understanding of how SPIN would meet their needs and how pwSCI would use it in daily life (Yardley, Morrison, et al., 2015). While elements of user-centred design are contained within the PBA, especially during testing of usability in the final development phase, PBA is also interested in the longer-term use in the context of the users' lives (Massanari, 2010). The PBA therefore, draws from participatory approaches (Nelson et al., 1998) and participatory design or co-design (Massanari, 2010; Sanders, 2006). This person-centred approach encourages collaboration with and understanding of the person for whom the intervention is designed. This will optimise the likelihood that the final product is tailored for and responsive to user's psychosocial context. Price Waterhouse Cooper's first named digital health trend for 2023 is "People and whānau: nothing about us, without us" (PWC, 2023) signalling the move to consumer involvement in the co-design of digital solutions. My approach aligns with this movement towards person- and whānau-centred digital heath solutions.

I have been overt in SPIN's intervention planning, design, and development. Of the 16 self-guided interventions that were included in Chapter 4's systematic review and meta-analysis, only six provided any information on the methods used to plan, design, and develop them (Holtdirk et al., 2021; Kelechi et al., 2020; Kwon et al., 2018; Lee et al., 2014; Nasseri et al., 2020; van Vugt et al., 2019; Yuan et al., 2021). Of these, there was little supporting detail on how the design of the intervention was carried out, and not one of the included studies stated the exploration of the behavioural needs of the users before designing the intervention. The explicit and robust process of planning, design and development for SPIN has ensured that my intervention development

addresses many of the limitations in the reporting on the development process for existing self-guided digital exercise and physical activity related interventions.

I have also added to current published literature that has used the PBA framework (Ana et al., 2019; Band et al., 2017; Heron et al., 2021; Yardley, Morrison, et al., 2015) and made explicit the steps in that process (as operationalised in my doctoral work). This will enable others to apply this approach in future intervention development. For example, the explicated steps of the translation of qualitative findings into overarching intervention objectives that informed intervention design objectives, the behavioural analysis of target behaviours to identify intervention functions, the synthesis of evidence into intervention features, and the analysis of 'think aloud' sessions based on the theoretical framework derived from the planning phase have all been clearly documented. These will allow others to appreciate the distinct steps in intervention design and refinement.

In developing SPIN, I have also integrated other approaches and methods to enhance the PBA process. The PBA supports methodological and epistemological pluralism that best suits the context and the people for whom the intervention is being developed (Yardley, Morrison, et al., 2015). Examples of how I have augmented the PBA in my doctoral work include: using Interpretive Descriptive methodology (Thorne et al., 1997) in the planning phase to reflect the clinical pertinence and application; adopting design and user-interface design and heuristic principles in the design and development phase to support the usability aspects of SPIN (Nielsen, 1993; Nielsen, 1994); applying persuasive systems design principles in the design phase to maximise engagement in SPIN (Oinas-Kukkonen & Hariumaa, 2009); using 'think aloud' methods in the development phase to ensure people's thoughts, challenges and suggestions on the SPIN wireframes were captured (Jaspers, 2009); and drawing on behavioural science and theory such as the Behaviour Change Techniques taxonomy V.1 (Michie et al., 2013) to inform behavioural strategy categories, and the Behaviour Change Wheel and COM-B framework (Michie et al., 2011) to validate behavioural intervention feature selection. These all provided opportunities for the best available evidence to be integrated into SPIN's design and development to ensure the overarching intervention objectives were met.

8.2.2 Making explicit the evaluative process pwSCI go through when considering uptake and use of an intervention: *Should I use it? Can I use it? Will I use it?*

My findings have produced important and practical insights into how pwSCI consider uptake of a self-guided exercise programme. These findings highlight a complex evaluative process which has high potential for transferability when pwSCI consider the uptake and use of any intervention. When it comes to engaging with rehabilitation or exercise, pwSCI experience a range of barriers that include problems with physical access to facilities and equipment, and cost (Letts et al., 2011; Scelza et al., 2005; Vang et al., 2020). These also extend to perceived lack of available expertise about their condition, concerns about making the pain worse and the attitudes and perceptions around exercising both from themselves and from others, all of which affect their comfort and confidence with exercise (Cowan et al., 2013; Vang et al., 2020). These concerns are exacerbated for pwSCI living outside urban settings (Guilcher et al., 2010). The findings from my Interpretive Descriptive qualitative study provide a framework or heuristic tool which could guide clinicians to make sense of the factors that may be impacting on their patients' ability to consider and participate in rehabilitation more generally (Stavric et al., 2023). Clinicians could integrate features that address each of the *Should I use it? Can I use it?* and *Will I use it?* elements into their intervention preparation making it more relevant for their patient. This heuristic tool could also be incorporated into and guide clinical interviews, to inform treatment planning and follow up. This ready to use tool has been empirically developed, and advances the work of others such as Canori et al. (2021), Ortenblad et al. (2022) and Walsh et al. (2022) who have explored various methods of encouraging engagement in pwSCI by using support strategies, goal setting, and providing rehabilitation that is person-centred, at the right level of challenge and in which patients have agency. My doctoral work provides an important contribution in this space by providing a usable framework by which these factors can be considered for each person, in a way that can be applied to a number of clinical scenarios.

8.2.3 A prototype ready for SPIN app software development

The SPIN digital wireframes have been designed and created with specifically selected intervention features and have already been refined based on user feedback. This will

streamline the subsequent design and frontend and backend programming software steps in the app development process, maximising the chances of successful transition from wireframes to SPIN app. Nielsen (1993) reported on four case studies which demonstrated, on average, an improvement of 38% from one version to the next with each iteration, because of the process of iterative testing cycle of prototype design, user feedback, and refinement. The rapid and agile series of progressive versions used for SPIN is consistent with best practice digital product development (Wilson et al., 2018) and will contribute to SPIN's next phases of development as well as future dissemination and research.

8.3 Future contributions

SPIN is ready for the next stage of development. A fully developed and working SPIN intervention has the potential to contribute to a number of future impacts and outcomes which are discussed below.

8.3.1 An intervention that will meet user need

This project will lead to the SPIN app, specifically designed for pwSCI. It will improve access to care by supporting and guiding pwSCI to manage their own shoulder pain using an intervention that has been designed with them, to keep them engaged. SPIN extends the work by Mulroy et al. (2011), Middaugh et al. (2013) and Van Straaten et al. (2014) in the area of shoulder pain intervention in pwSCI. It has applied the exercise intervention used by Mulroy et al. (2011), integrating concepts of technology-supporting feedback (Middaugh et al., 2013), and technology-supporting remote care (Van Straaten et al., 2014). SPIN's self-guided and digital approach adds to the scoping review by Mason et al. (2020) on conservative treatments options for shoulder pain in manual wheelchair users. More recently, a mobile app for supervised home-based exercises for SCI has been developed (Bizzarini et al., 2022). SPIN builds on this work, creating a self-guided shoulder self-management tool, using user-informed behavioural features, and adds to a growing number of SCI-specific digital tools. SPIN will also add to the field of work in digital interventions for related conditions and populations. For example, Choi and colleagues (2019) have reported on an app designed for the rehabilitation of frozen shoulder. SPIN has expanded on this by being self-guided and containing behavioural features to encourage engagement. Nelligan et

al. (2021) have developed a web-based exercise intervention incorporating behavioural strategies for people with knee osteoarthritis. SPIN has built on this work by, firstly, designing its intervention through an app, which aligns with trends in digital consumption by the SCI population. Secondly, it can be completely self-guided, removing the need for clinical oversight.

8.3.2 An intervention that will support clinicians working with pwSCI who have shoulder pain

SPIN can be a tool used as an adjunct to clinical practice. The rehabilitation time patients spend with their therapists is often limited and inactive (Thomspon & McKinstry, 2009; West & Bernhardt, 2012). Being able to extend rehabilitation opportunities beyond those provided in therapy time would allow for increased volume of training, creating the potential for improved outcomes (Figueiredo et al., 2018; Hornby et al., 2020). In the SCI population, there have recently been initiatives such as an independent online wheelchair transfer training programme (Rigot et al., 2021) that could enable clinicians to focus on more individualised, complex, or urgent matters when they are with their patients. Shoulder pain prevalence increases with time for pwSCI (Curtis, Drysdale, et al., 1999; Sie et al., 1992). Access to SCI health professionals significantly decreases over time after discharge (Burkell et al., 2006), particularly when the needs of those with chronic SCI begin to increase. Therefore, SPIN may not only allow a first line of access to care for an increasingly prevalent problem (shoulder pain) but, when face-to-face care does occur, allow for more time to be prioritised to other pressing or multifaceted needs that occur with chronic SCI.

8.3.3 An intervention that is well placed within a reforming health service

SPIN being used by pwSCI who have shoulder pain is befitting for a health service that is trying to support people to live well, stay well or get well (Ministry of Health, 2016). Shoulder pain conditions in the general population were found to be the third most common musculoskeletal complaint that prompted a visit to Australian general practitioners (Britt et al., 2016), providing evidence of the burden it imposes on people with shoulder pain. Kuijpers et al. (2006) investigated the financial cost of shoulder pain in The Netherlands. They noted that although initial direct medical costs were not great, probably because of clinical pathways dictating conservative management,

almost half the cost was attributed to indirect costs such as lost productivity. The additional consequences of shoulder pain in pwSCI would add to these indirect costs. For example, indirect costs incurred such as equipment or environmental modifications, provision of power wheelchairs and additional personal support requirements would add substantially to the cost. Worthy of equal consideration are the personal costs: the loss of function and mobility which affect participation, self-perceived health, and confidence (Mortenson et al., 2012). If SPIN is able to support pwSCI to manage shoulder pain, it has the potential to reduce both direct and indirect costs.

SPIN will be accessible to people wherever and whenever they need it. Other forms of digital heath interventions are currently being used in primary care. They are acknowledged for their ease of access, lack of stigma, low cost, and convenience (Griffiths et al., 2006). The use of digital health technologies in primary care has been reported to decrease disease severity and associated comorbidities, and lower the number of emergency room visits, hospitalisations, and 30-day re-admissions in a number of chronic conditions (Willis et al., 2022). Gentili et al. (2022) found that the majority of digital health interventions were found to improve quality-adjusted-life-years with either less cost or at an acceptable increased cost (as measured by the Median-Based Incremental Cost-Effectiveness Ratio) in a variety of patient populations.

The World Health Organization (2019)'s recommendations on digital interventions for health system strengthening displayed the Tanahasi framework of 1978. This framework demonstrates the layered health system performance gaps for universal health coverage. The report proposes that digital health interventions, like SPIN, could contribute to the efforts in addressing the gaps. SPIN's automated, self-guided format would potentially have a wide reach due to low ongoing costs (Munoz, 2010). By doing so, SPIN also aligns with priorities of Te Pae Tata 2022, the interim Aotearoa New Zealand health plan: keeping people well in their communities; and developing greater use of digital services to provide more care in homes and communities (Te Whatu Ora, 2022).

8.3.4 An intervention whose foundation can be used more broadly

SPIN's contribution to the way self-guided and digital interventions for pwSCI are perceived and used, could guide additional future intervention development for pwSCI and other health conditions. For example, PhysiotherapyExercises.com (Harvey et al., n.d.) is an online and freely accessible exercise database that contains over 1,000 physiotherapy exercises, appropriate for people experiencing disability, including pwSCI. The exercises come with accompanying illustrations and instructions for a prescribing therapist to use when they devise a programme of exercises. There are concepts from SPIN that could be incorporated into the database including suggestions to clinicians on factors that influence patients' ability to engage with their programme (*Should I use it? Can I use it? Will I use it?*); embedding behavioural strategies; and applying processes of design and development to further develop the digital app that has been produced using PhysiotherapyExercises.com (Lambert et al., 2017).

8.3.5 A catalyst for future research and commercial opportunities

The creation of SPIN is in line with a strategic priority of the Aotearoa New Zealand Health Research Strategy 2017-2027 (Ministry of Business Innovation and Employment & Ministry of Health, 2017) to support transformative and innovative ideas that will create industry partners and lead to commercial prospects. This will include multidisciplinary collaboration for app software development and investment to put it to market. Potential markets include physiotherapy practices and primary care organisations. These groups already use digital platforms and provide self-management packages for their patients and support a "completeness of care" strategy (Willis et al., 2022). A third potential market is the SCI community. The SCI network is small with both national and international relationships and connections. As such, the roll out of a digital intervention like SPIN will have both domestic and global opportunities.

8.4 Strengths and limitations

8.4.1 Strengths

My doctoral work has several strengths. The concept of SPIN is timely. When the idea of this topic was conceived and work began, pre-COVID-19 pandemic, the notion of

self-guided digital interventions was novel. In the time since, the appetite, interest, and acceptance for evidence-informed and engaging digital health interventions that are delivered remotely, has grown from all sectors.

Using the PBA ensured a robust and structured process, with a strong commitment to each phase. There was continual collaborative consultation with the people who will be using the intervention, through a rigorous approach to qualitative data collection and analysis at key phases. This has kept users' needs at the core of SPIN development throughout.

Moreover, the use of collaborative analysis all through my doctoral work (individual, supervisory team, stakeholder advisory group) ensured that my assumptions did not overshadow my interpretations. This facilitated findings that had resonance for pwSCI who have shoulder pain.

In addition, the *Should I use it?, Could I use it?, Would I use it?* framework closely aligns with Self Determination Theory, demonstrating that SPIN has been based on a framework that has congruence with well-established theory. This not only supports the theoretical basis for SPIN, but also suggests that SPIN's framework may have a degree of transferability to other applications.

Also of note is the positive feedback SPIN has received from pwSCI and clinicians. These reactions indicate the receptiveness of clinical settings to incorporating or recommending SPIN.

Finally, the ten outputs from this doctoral work (page x) demonstrate a commitment to disseminating findings. Doing so has brought the SCI community along the SPIN planning, design, and development processes, increasing confidence and acceptance of the final SPIN product when it is available.

8.4.2 Limitations

The scope of this doctoral work did not allow the SPIN app to be built or trialled in a feasibility pilot. This would have involved a software programming component which was beyond the scale of this project. Outsourcing for this specialised input will be

required and is planned as post-doctoral work, in a collaborative and multidisciplinary project.

Another consideration is that SPIN addresses an impairment-based complaint of shoulder pain. At present, it does not address wider environmental or social elements that may be contributing to users' pain experience. For example, causes of shoulder pain such as lack of suitable equipment, inappropriate environmental adaptations, or concerns within the user's support network will not be directly addressed by SPIN. SPIN's framework of *Should I use it? Can I use it? Will I use it?* does recognise that a user may be facing some of these factors when engaging in the decision making of uptake and use of SPIN. Addressing these wider issues would require awareness and resources at a systems level, along with a multidisciplinary approach.

A potential limitation was that data collection for the development phase occurred over a period of isolation due to the COVID-19 pandemic, which was disruptive. However, it had the unexpected advantage of creating a more realistic situation (for example, not having the facilitator available in person to help with set up) when trying to explore how usable a self-guided digital intervention is likely to be for people using it independently.

Despite strenuous efforts and engagement with the SCI population across Aotearoa New Zealand, the breadth of participants did not reach expectations. More representation from Māori and people living in rural settings would have captured all likely scenarios and reflected the SCI profile in Aotearoa New Zealand. This will be addressed in the mixed methods feasibility trial planned once the SPIN app is developed.

There were also challenges in implementing the PBA during this doctoral work. While Yardley and colleagues (2015) provide helpful guidelines about each of the phases, at the time this doctoral work was being carried out, there was limited published work that provided explicit examples of how each of the phases could be operationalised. In this work, I have been clear on my interpretation of the PBA and provide detailed reporting of each of the steps as I moved through each phase, to ensure there was a replicable process that could be followed.

8.5 Implications for clinical practice

SPIN offers another intervention alternative to help pwSCI manage their shoulder pain for pwSCI. It is an acceptable option when in-person rehabilitation is not possible or desired. Interestingly, patients may be more converted to the idea and practicality of rehabilitation technologies than clinicians (Niknejad et al., 2021). Considering that referrals and endorsements are key factors influencing uptake and inform the elements of *Should I use it?*, future dissemination and collaboration with health professionals will be required for successful implementation.

It will be important to consider for whom SPIN may be suitable as it may not suit every person. For example, beliefs about technology, experiences with exercise, or readiness for change and exercise could all be factors that would influence SPIN's suitability. Also to remember is that shoulder pain in pwSCI can dissipate and reappear. As such, people should be able to access SPIN as and when they need it, when they are ready for it. Many features in SPIN have been designed to be useful for users. These should help them recognise SPIN's value and help prompt a return to it if pain reappears. SPIN's accessibility means that it will be available and act as a booster, using its behavioural features to support pwSCI to manage their shoulder pain if and when they need it.

When thinking about how SPIN may be integrated into current clinical practice, perhaps a hybrid option would allow the benefits of access along with minimising the concerns of being completely isolated from human input. This suggests a reconsideration of the interpretation and operationalisation of what a truly self-guided intervention may look like in practice. The systematic review included in the planning phase of this doctoral work (see Chapter 4) excluded some interventions that had low levels human contact, preventing their inclusion. In reflecting on the data that has informed the *Should I do it? Can I do it? Will I do it?* framework, and the evidence from these excluded studies, there is room and SPIN has the flexibility to be incorporated in a variety of clinical practice and minimal contact settings. Another aspect of SPIN that is relevant for clinical practice are the principals of *Should I do it? Can I do it? Will I do it?* as described earlier. This heuristic tool can be integrated and used in a variety of clinical scenarios.

8.6 Recommendations for SPIN future development and research

Future SPIN development will be part of my post-doctoral work and will comprise several areas of further research. These will be led by me in close collaboration with a multidisciplinary team of researchers. SPIN has now been developed to a point where app frontend and backend programme software development can begin. I will gain support and funding through contestable grants and early career researcher opportunities. For example, Te Tītoki Mataora has Research Acceleration Programme grants for early-stage digital health development, and HealthTech Capability Programmes with capability-building modules including Māturanga Māori, Pacific engagement, clinical translation and commercial translation (MedTech and CMDT, n.d.). This collaborative work with app developers and software engineers to create a minimally viable product will continue in partnership with pwSCI who have shoulder pain, ensuring the app continues to meet the overarching intervention objectives and guiding principles. Another avenue of funding will be through HRC Health Delivery Research Activation Grant through opportunities that support early health delivery research including relationship development, priority setting and skill and capacity building (HRC NZ, n.d.).

The next phase of SPIN research will progress to a mixed methods pilot trial. This will be conducted in a real-life context and held over 12 weeks with pwSCI who have shoulder pain and who have not been involved with any of the planning, design, and development phases. The aim will be to explore the feasibility, acceptability, safety, and engagement in SPIN. Further feedback and learnings from pwSCI who have used SPIN over an extended period of time will be sought. Findings from this will go back into further refinements of the SPIN app, into a product ready for general dissemination and marketing. Earlier identified research opportunities, from the systematic review in Chapter 4, of determining which specific features might best be implemented to support sustained use and engagement with self-guided interventions, could also be addressed here.

This will subsequently lead to further exploration, testing, and refinement with participants and app developers. Components such as behavioural intervention features and an exercise bank that were not originally included in the wireframe

prototype can be added. Work on making SPIN exercise equipment more easily accessible to users would also occur during this refinement period. This will allow SPIN to cater for a greater range of users and situations, increasing its ability to adapt to users' circumstances. This will support several elements of the *Should I use it? Can I use it? Will I use it?* framework by helping users find and choose what works for them and stick with SPIN when their circumstances change.

SPIN should go through a validating process (Mathews et al., 2019) and regulatory steps if it is to be eligible to be included in digital app libraries like those found in the NHS and Health Navigator New Zealand (Greaves et al., 2018; Health Navigator New Zealand, n.d). The Aotearoa New Zealand Ministry of Health offers guidance on app development that includes references to clinical and technical standards (Ministry of Health, n.d.). The National Institute for Health and Care Excellence have produced an evidence standards framework for digital health technologies that recommend standards that an intervention like SPIN will need to meet for it to demonstrate its worth in the clinical market (National Institute for Health and Care Excellence, 2022). The World Health Organization also provides guidance to improve the quality and value of monitoring and evaluation (World Health Organization, 2010). Once the SPIN app is publicly available to pwSCI, additional work on both the analytics and the ongoing maintenance and updates required will need to be considered (Raghupathi & Raghupathi, 2014).

Another area of research within our wider team, generated from this work, is the exploration of measuring work performed. Being able to monitor and provide feedback on exercise performance and volume of work performed would support several aspects of the *Should I use it?, Can I use it?, Will I use it?* framework. Inbuilt smartphone sensors, EMG sensors, wearables, and connected resistance bands are all sources of feedback being explored by our wider team and I have been part of this emerging work. My role has been to bring a clinical perspective and to keep the users' needs at the centre, referring to the overarching intervention objectives and guiding principles. This thread will run parallel to work with others in defining and measuring engagement in connected health interventions.

One further area of my research interest is clinicians' perspectives of self-guided digital interventions that enable people to self-manage impairments. Given clinicians' roles in recommending and supporting interventions like SPIN, understanding their perspectives, perceived barriers, and welcoming their suggestions, will help with its refinement and implementation.

8.7 Conclusion

This work is the first to plan, design and develop a self-guided digital intervention to help pwSCI manage their shoulder pain using the PBA. SPIN has incorporated a deep understanding of the user's needs and best available evidence throughout the design and development process to maximise engagement and outcomes. This has resulted in SPIN and laid the foundation for future work by developing understanding of the thought processes and decision-making people use when considering self-guided digital interventions. These key findings have resulted in a prototype ready for app development, a conceptual framework, and a blueprint that can be applied to any future development of self-guided and digital exercise interventions. These have applications to current clinical practice and future research opportunities.

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Appendices

Appendix A

Full transcript of pre-assumption interview

GT: So hmm. So tell me about your project.

VS: My project is looking at trying to translate some evidence-based exercises into a web-based platform for people who are wheelchair users who experience shoulder pain. yeah, so that's it in a nutshell really and we know that these shoulder exercises seem to work but in a face-to-face delivery model, but people with spinal cord injury face, I suppose many barriers to accessing face-to-face delivery, whether it be Transportation, whether it be cost, whether it be physical, access. So we want to explore this idea of having something a bit more convenient a bit more accessible and in a different model of delivery.

GT: How did you identify this particular issue as one which would be Salient and important to your participants.

VS: Through discussions with other clinicians

GT:. Okay yep and you are talking to you going to be talking to participants about this sort of thing. Yeah. And what is the methodological approach you're going to be using

VS: were going to be the overarching framework is going to be Person Based approach and so we're going to be looking at a mixed model generally. But initially looking at some focus groups that are Going to be using semi-structured questionnaires and semi structured questions to try to understand their first of all, what makes it easy what makes it difficult to exercise? What makes it easy and difficult to interact with web based interventions of what of sorts, and then Analyze That. We thought, through thematic analysis approach. But after The workshop that you and Nick ran, I need to go back and talk to Nick and Nikki because I feel like it is quite, I feel like the issues are quite semantic, and I feel like it's quite experiential. I feel like, I feel like it's, I wonder if it's a bit more content or I think it straddles between the two. So we were planning on the thematic analysis, but we're going to revisit that little bit more.

GT: Okay, so how many focus groups?

VS: Hoping to have it that up to 20, participants were probably 3 focus groups.

GT: Yeah, I would go with 4 focus groups? Try Five in each one. Or 5 focus groups with 4 in each. and that's primarily I think just because you want to get richness and interaction. Yeah. And in a group of above five people that can remain quiet do and it takes a lot of work to facilitate that.

VS: I think. I don't know who's going to come out and who's going to, you know, volunteer. So I think I'm waiting to see if there's groups of people that may group themselves eventually. Like I'm hoping, you know, to get a bit more of a Māori perspective and maybe that will eventually self-select themselves into a group, you more a group that's physically located, somewhere else. So, I don't know how that will work out, but and I think I think a small may lend itself. Like I'm also trying to have a group that's not just about talking, but that there are some activities that will enable a little bit more. And I don't know how this is, how this works at and how you record, you know, it's an audio recording, how you then transcribe it, if there's some pairing up, and there's some discussion and But I'd like there to be some of that as well. So that there is some engagement for the quieter ones. So that there's some a little bit more opinion that comes out within those discussions that that. Yeah that occurs within the focus group let along just whole group and me talking in them answering and back and forth like that. So so I think maybe smaller group would work, I guess. Yeah, yeah. Okay, that's fair enough

GT:. And what? What are you hoping or expecting to get from the focus groups in terms of information?

VS: The first question is whether or not whether or not this idea has any Merit whatsoever. I think that's the first one

GT: and what are your thoughts around that? Because it because you said that you got the information from clinicians to start with rather than it being a participant driven thing? Yeah. So how are you hoping to tap into?

VS: I've casually talked to other to wheelchair users about it and they've expressed, that sounds like a good idea, but I know that I've sold it, you know, and and I think in my reading and in my thinking about it, I think that there are some going to be some certainly, some issues around The trust Factor you know you remove the person and I think how are you going to, how somebody with pain going to feel when they're not sure who to turn to? They're not going to maybe feel comfortable turning to a device and and so I am not sure how they're going to feel about that. And what I want to know is well what would it take for you to feel comfortable with that?

So that's sort of what I want to know as well. I feel like that's a little bit. I don't want to say coercive but I feel like I'm really trying to sell this idea to you. What are the trade-offs are? What do you, what would it take for you to get there?

I don't know. I don't know if that's still sounding. Like, I'm trying to push my idea. And what are the trade-offs? Are you willing to? Or I feel like I'm, I don't know what happened. Know how to express myself in that, but I feel like I'm, I feel like I'm still trying to convince them that it's a good idea. But I guess I'm just trying to understand, is there a way to make it work? Or is there not a way to make it work?

So to me, that's the biggest message and then in what way would it work like I don't even know. If they would like it on the phone if they would prefer it and in a laptop and I have no idea, you know, is it an app? Is it a website situation? I have no idea. So those are, those are the sort of broad questions that I would want to start with.

GT: So it's almost a little bit Co designee in some respects in that that you're approaching it as something, which you're trying to generate a way of exploring, this particular issue using, what with users, the type of people that would benefit from an exercise program of some kind. Assuming that's what, what works, and all that sort of stuff. And I'll come back to that in a bit. and then using that to produce a product of some kind and you're not quite sure what that is yet.

VS: There are other populations or other conditions in which this idea has been used. And I guess it was initially the conversation with clinicians and that has made me think of this. But it's since that conversation that I've looked and seen that there that this has been able to be applied to other health conditions, okay?

GT: So we just an interesting base of evidence as well. So starting with a problem that You've been oriented to by clinicians. You have an Evidence base that suggests that doing these exercises work in a particular way. I'm just reiterating what you've said. But that exercise program is usually done face-to-face and you're trying to find whether there is another Avenue to produce the same types of effects is that correct?

VS: Yeah and I think perhaps I need to clarify the face to face. I think the first affairs Perhaps the first to face interaction happens, perhaps not a continuously through there is a face-to-face interaction at the start where a program is set, then there is an independent program and then there is a visit, I think I think you're not in. Oh I think that's a pretty common type of scenario where then program is Revisited, progress, progressions are either decided or regressions, depending on how somebody's responded. And then independent exercises and then that cycle continues for the duration. Yep. And so I think that middle bit continues on what we're trying to do is we're trying to see, can you stop. Can you assume the Digital the platform, the digital platform assumes those. Yeah, so that the person can continually exercise independently with the support of the digital platform doing those initially.

GT: So for the original the original consultation of example, will be done face-to-face?

VS: No. that's that's that's the unique that's novelness. The idea that I have my mind is that through the smartness of the computer algorithm e type system that there will be no need for face-to-face. Now, whether or not we have to somehow meet in the middle, yeah, whether participants will find that absolutely not acceptable. And that we do have to have There doesn't have to be some sort of real-life face-to-face for this to ever fly. Then we have to go back to the drawing board.

GT: So in terms of your questions about this, then, are you going to talk about the issue itself with with participants

VS: the issue of the face face?

GT: the issue of the shoulders?

VS: I've pulled up by questions because I don't think that they are really that that specific right?

GT: Okay. So for me, this this is there are two things going on. There is a particular physiological issue problem that you're seeking to resolve and alongside that is the time burdens and stuff like that around lots of face-to-face treatment and all that sort of stuff. And so, the second issue is the acceptability of a way of replacing human contact with a digital platform, on some hand. So for me, those are two absolutely independent spheres, does that make sense? Yeah, and it's about. So, for one, I'd be interested in terms of understanding that participant experience. In terms of the need for something, in terms of exercises related to shoulder pain, or what sort of stuff, I mean, you must have information on prevalence and all that sort of stuff as well is that all there. Yeah, and again, is that clinician fed, or, is that self-report from from work, wheelchair users?

VS: A bit of both. I supposed to be there in the literature. Yeah, it's Prevalence of shoulder pain would be. I would imagine it comes from the users because it's subjective. So like I'm I don't think I don't think the users have led the research, but it would be. So there's there. There's quite a lot of research on prevalence of shoulder pain in people with SCI. It's very high. Yeah, I think it's it's very very very high. Yeah. Okay. So it's been well researched. Okay, so I don't I don't know that I need to revisit that. I think it's quite well established.

GT: So what the primary orientation and of the project would be the acceptability of this as an intervention in some respects and it sounds like the co-design of the of an intervention. So what would what do you want from your participants? Like you know there's you've talked a bit about that in terms of acceptability and you know what might work for them but but what do you want in terms of richness that …if you had a bunch of things that you wanted to cover in your focus group and they had levels of richness and Terms of the responses interaction around it and that sort of stuff. Where do, you want your most depth?

VS: I think I would want it around. I'm assuming that they are interested in pursuing this Avenue. Yeah, then I would want it around. Around features and things that they

think it would be helpful in in a digital platform. So things that they would find useful and encouraging and helpful for them to carry on doing an exercise of this this way in this method, in this

GT: Yeah. Okay. And so exploration around the place of the personhood of a clinician versus the personhood of Your platform is that something that you're interested?

VS: Can you explain that?

GT: So you're essentially replacing a person doing the clinical work and yeah. And so in terms of the evidence base, I mean, we talked we do a lot of research around interventions and stuff like that, we drop an intervention into space and we see that there is an improvement and shoulder pain because of exercise. But what happens if the independent variable is not necessarily, the exercises, but interaction with their clinician and then facilitating stuff. So I guess what I am asking is, how important is that to you?

VS: Yeah, that's very important. They well, Yeah. That's that's one of my biggest worries about this whole project is that I feel like it's that. It's that magic ingredient.

GT: Yeah, yeah. Okay. So what does it mean, what we put in order to get to that and determine whether that's actually a major ingredient or not? The therapeutic relationship has a lot to plan to it. Are there ways that you can tap into that in terms of asking questions around that from a features perspective. …is this even the right pathway to take It's the. So I guess, I guess it comes down to, you know, the various things that are interacting:

Ok. So you've got the exercises itself which are evidence-based or they seem to be. Yeah. Evidence-based you have the features of particular product which are doing things to help reinforce and establish this as a thing. So things like gamification and all that sort of stuff that may make play a part in it. Similarly to learning a new language like duollingo you can replace having, you know, classroom teaching and all that sort of stuff on class with the teaching Around The Language, by having a software package. But then there's also the personhood of the clinician here. Uh-huh. And from what I'm hearing from you, these these things relate to one another. Yeah. And I think they're

potentially all features of the project and I guess where. Do you see what you want to achieve from the participants? Is it something where, you know, there's the participants are here and so this is these are things, you're asking, is it more over here? Is there an overlap here or is there something where the right in the middle? And therefore you want to be trying to get All of these things at once?

VS: once. In this focus group, I would say it would be more. It would be more here because I feel like later on, we can, we can unpack this, yes, but these are pretty much established. It'll be a little bit titrating, down the road with that. So it is definitely around here. Okay, okay. And in Reading in Reading, it's definitely round out. What features can help with the personhood. Really? Yeah.

GT: So reproduce a sense of personhood.

VS: Yeah. And so it's again what would it take to feel? What would it take to trust to trust the digital platform? Yeah, and you know, so it does it take and it's a features like does it take things like testimonials? It does it take a endorsement or does it take good? You know, a support line to call, or does it take a that that's the sort of stuff that I, you know, you read about that other papers have used in order to support people.

GT: Yeah, so from my perspective it feels like the one of the things I explored on that secondary analysis that I did was the notion of trusting like a currency that it can be built up. It can be I'm spent depending on the expectations of the clinician on a patient. So if you're asking them to do a lot, it might draw down on some of the tractors built up, all that sort of stuff, but also that it can be transferred. So if you have a really positive interaction with physiotherapist, and they help you make steady gains, and then you have to move to another physiotherapist. You might, it might take less time to build up trust because you had a positive experience with the previous one. And then might be true of doctors and nurses, And all that sort of stuff as well. So I guess there's some potential for there needs to be, you know, almost needs to be a sense of personhood wrapped around the product and that that it is, there's an endorsement. But then we see endorsements all the time. So what does that mean? And so I think asking questions about what you know, the that's within what would create trust would be really important based on my reading one of Other and also

offering a suggestion and then letting them talk about it. So you know, if you had a positive experience with the clinician and the spinal unit for instance, and they endorse this product, you know, let's talk about that sort of thing because that makes yeah.

VS: Like we were even thinking I was even thinking of using images or you know I'm discouraged and ranking them. So working in pairs. Yeah. And and then depending on What was brought up in the initial discussion? Almost pulling some things out and then having them work in pairs and saying out of these 10, you know, put the top three or four that you think would be most important to you and website and then that would be and then that's where the discussions between Pairs. They could discuss what they think would be most important and one But something to symbolize. I don't know the trust aspect or the you know, maybe having a Physio face or somebody who walks them through each one or something like that and and then putting that versus tracking the progress throughout or something. That's just so that, then there could be, you know? And it may be if if reminders was another one was never even mentioned, then I kind of get a sense of what's most important in the website versus aesthetic. So you know, one that looks beautiful and I can see generally, why did you put that one? Why didn't you put that one? And but I don't know how any way that that was one of my ways of trying to draw in or exclude. Features that instead of me bringing ones up repeatedly or not or having to come up with a list of, they didn't think of themselves. They could visually see them and then start to decide rank them and and then have a discussion about them that way. Okay, that was just a activity that when I've heard of card sorting as an activity, it just made me start to think about a different way of doing. Doing it. I know card, sorting is a slightly different thing. I know it's about website architecture, is it not?

GT: So from my perspective card, sorting as a design tool, and it can be used across a bunch of activities. So, you know, people use them for websites and web site architecture, right? Sort of stuff. But when guy was developing the website for the MC, oh yeah, it was there as a component of it, but he Would use card sorting more Generally across the board. What are the things that are useful for you? Particularly when it's dealing with a clientele who Maybe Can't necessarily articulate. What their experience is like or what they want from a particular experience. And I think this is

one of the things you probably going to run into in terms of dealing with a participant base like this. One, how important is this particular thing to them you know, selling it as a this is going to be saving you time but it's also Potentially going to mean that you actually getting more intensive opportunities to do the exercises on your terms and all that sort of stuff. But yeah, does that all? So yes.

VS: So do you think that idea would would fit with this with this idea of exploring them?

GT: Like, it really does sound like you need to be doing some reading around codesign and participatory approaches. Yeah, usability testing, sort of stuff.

Because you have part of the things that you're not you're not developing a new exercise program, you're not trying to identify whether you know you're not trying to do something that's going to improve or the quality of their exercise. What you're trying to do is improve their willingness to engage with something that's not a person. I think that's a core of what's going on, I think so. And so what features are going to Help. Fill the gap between a digital platform and the person of the clinician and generate something that's a little bit, like the therapeutic relationship and it produces something for you where people are going to be committed to it. And are going to see it as motivating and relevant. And what's with? So this is a quite like it seems like sorry seems like at a at a superficial level, you know, this feature that feature plugging in this, this is going to work. How would you like to visually see the wet sort of stuff? Isn't isn't as important as some of the deeper level? As you said, the latent stuff that's there. What, what is Central to the experience of improving strength, improving, you know, reducing reducing pain, or that sort of stuff. So, I mean, I think you can start with questions around, you know, the day-to-day of living with pain, the day-to-day of living with, you know, tap into those fundamental things that are core to the experience of being in a wheelchair and then what difference does it does a clinician make, you know, asking going in that particular to attack and then then can those things be transferred to a digital platform and if so how let's convert that that's entirely different way, to, to address it, I'm just asking. Yeah, and obviously, you don't have to buy into that, but I'm just wondering, is that is that an Avenue? Yeah,

VS: I think it's really worth thinking about because I feel like the questions I'm asking many of them. R. Are quite. I've I think there's already research on the barriers to exercise in this population.

GT: Absolutely. Yeah, I think it's one of the things that, you know, constantly we're up about we're not making much ground in terms of changing that, right? And it's the same with even general population, you know getting people to do physio exercises past the limits of their pain. So I'm a classic example in pain at moment and I know the exercises I need to do to fix it, and but once I've done the exs, for long enough, and I reach a certain point and I'm not feeling the pain anymore, even though I know in my head, I need to do stuff and keep going in order to build up that strength so that I'm not just falling into deficit every time I, you know, tweet tweet my neck slightly, so, therefore my back hurts, do know what I mean. And so if healthy populations are doing that, how much more is there of fatigue and, you know, cognitive burden and all that sort of stuff. So I wonder if you're as well as tapping into the personhood, Out of the clinician, you need to tap into the personhood of the participants as well, what matters most to them? What is at the core of their experience? And and you know and then reproducing, you know, finding that something that that might have the capacity to reproduce that. Yeah, I don't know. And I think so in that case, you might have to think about hypotheticals, you know, if the technology existed there may not exist. Now, in terms of AI, you know what would it take you to trust in AI over a person? You know are there elements to which you could invest the same degrees of trust and computer-generated images of people, or do you need to have a highly regarded physiotherapist doing videos that are tailored? Which means would mean hundreds of videos and you have like a chain of potential Pathways you can follow and it, you know, are you doing the exercises regularly? No then you've got to follow this particular pathway? And you can reduce the number of times as you're doing exs per day, in which case, you know, there has to be an incredibly tailored program. So instead of having, okay, you've done these two exercises that's great for supporting a strength. Now we'll add some more in order to keep you moving on the right track if they're not doing that. Then what are the other options? So and that's the stuff that the that the experience of a clinician the person out of a clinician enables in a way that

Digital platform. Can't necessarily easily replace. Yeah, it's going to be thinking about that sort of stuff anyway. Sorry. This is me talking a lot?

VS: No, no. But like, that's what we're trying to say is that in, you know, if if a rehab program goes to plan, yeah, the decision tree can mimic a clinical decision-making process, but we're trying to build in some Alternative Pathways depending on and it's only going to be dependent on their pain. So it's not on their. Feeling a bit blue today, I don't feel much like exercising you know, all those other things that clinicians are really, some clinicians are really skilled at motivating or finding alternative ways or I'm bored or changing things up. So in an Ideal World. Yes, you would. You would have the ability to tap into You know what, I have I'm on bed rest today so that's another thing that this population often has to spend time on bed. Rest. Yeah. Switch up the exercise to meet that. Yeah, so that was one thing that I would want to do is I wanted to have a, you know, a different set of exercises that could all be transferred. And so that they are in a different position and they can still carry on the exercises so that because it's not so flexible, right? It's it doesn't have that same. Ability to sense and adjust quite so, quite so easily. I suppose given the context, it doesn't have the context and it only relies on it. Relies on the input that the user gives into it. And we're only going to have one question. I think are one answered that, that is going to dictate what's going to be provided for them. So it's not going to be well at this point. Again maybe something else. Something else will come out because some other programs have talked about the goals and there are a few other things that perhaps can give context. But right now it's all just about pain and that doesn't talk about my dog died, or I lost my job or the things.

GT: We know, we know that pain is, is not just a physiological thing. We know to hugely psychological. We know that it's contextual We know that there's massive amounts of subjective personhood stuff that goes on there that influences a person's resilience with pain, their ability to tolerate it with a the physiological signals that you can identify as being pain, equal to another person's people's ability to manage that and live with that are entirely different completely. Yeah.

So what I guess, I guess what I'm getting at with that is that you've got, you know, you've got 20 Into participants in a focus group context. I think if you're pitching the

questions here about what's motivating. What's interesting without getting in beneath? What's what's at the core of your experience? And having pain on top of this with the core of your experience of being in a chair and and you know, your shoulder gives out at some point in time or you have to move around. I think there's some stuff that and I don't know whether that stuff's been covered in depth. If either, but it almost feels like you have to, you have to start with sort of loose discussion around what you want to do, but then you're gonna have to get quite deep before you can get to features. That would be my thoughts around it.

VS: How long do you think it would take to cover all that?

GT: I don't know. I mean, it's going to be dependent on the group. I think, if you do a focus group with people in just talk about the features of a software platform that would work for them in terms of motivating them to exercise and it's pitched at that particular level. Then I think, you know, you would be able to do a half hour, 45 minutes, focus focus group, you know, just get people to talk about stuff in it, but if you're doing activities, you know, an hour. But if you're getting them more latent stuff, the stuff that underlies the experience and I heard what you said in terms of dog's died, you know, Blues all that sort of stuff, what happens when you're already at the end of your tether with a bunch of stuff and something like that happens. You know, how do you even view exercises? So it's not, it's not even a matter of, would you do the exercises or would this help you do the exercises? How do you understand exs? Because when someone says this is the only way you can prove how do you understand exercise? I think you could be doing focus groups of up to a couple of hours. So, you know, even starting with the notion of, you know, what do you think of Rehabilitation exercise? You know what's more, what's more most important in the experience of Rehabilitation? And we know from the research that we've been doing here that it's people as people its people and what does that mean? And how do you, how do you get at that? And then yeah, I guess sorry. There's quite a lot going on and I'm talking quite a lot.

VS: No but that's That's, it's really important that I think. You're raising some of these things because I do think it's a Once over lightly so far and this is probably an opportunity missed if we haven't covered some of the stuff.

GT: I think it's an opportunity to miss Rich data that may well have the potential to give you something quite significant in terms of a product at the other end. And so you know, and this is why these presumption interviews. Good you know what are you hoping to get out of it? And and I guess from an intrinsic personal perspective to you not just as an academic, not just about doing a PhD, what are you hoping to get out of it?

VS: I'm out of the whole project, right? Of this interview, the project.

Oh, I guess a sense of achievement, certainly, you know, something that you see something through that. I'm that I've helped a group of people that that are near and dear to my heart that I I can see some. Some issues, you know, I cannot, I've always done that they've got this issue, and if we can help that, I think that would be really cool besides the actual academic achievement. I think it's, I think it's pretty much those things. I think it's nice to have a product at the end of it as well, something that there's actually tangible product and I think the learning that I think my personal development among learning my My growth, my personal growth, I think would be really nice out. Come out of all this as well. Yeah. Okay.

Yeah, just the way you've were, you know, even even this this interview I was thinking just just before I was thinking, you know, here I am going to suggest this this different mode of delivery and I don't even know that their participants even acknowledged that exercise is helpful for the shoulder. Just on the very bare basic. Very semantic idea of a presumption interview. I thought I don't even know that are I'm here. I am dividing this whole project and I see what the evidence says but I don't know if my participants agree with that. No, they may say tried, it didn't work.

GT: Yeah yeah yeah. And I think I think there's there's got to be some potential for you to be open to that and open to the surprises that might produce. And it might be that the The design of the project changes. As a consequence of this and I think that you have to potentially be willing and open for that to happen, it might be and I say this relatively Loosely without any sense of this is the particular direction you go in but the end product might be something like a way of increasing social support, amongst people that are doing this sort of stuff and that becomes the primary mode through

which they engage in things like exercise. So it might be that rather than dealing with a face to face thing, it's like the equivalent of this Guy type thing where it's a class orientated thing where people are doing more exercises than they ever did

VS: you know, I mean like,. And there's been, there's been stuff written about that and that's what I that's why. I said, my ideal was this for these reasons but we may find that we meet somewhere else.

GT: Yeah. And so, I mean, XX came back from doing an interview for my men's health project and he was surprised by How passionate the guy who's in with interviewing was about the interview itself, accomplishing a certain end their life. So they have not got to talk about some of these issues with anybody before and he's not had that sort of interaction before I've had it a number of times. So it's almost like this is. So when I write about in an Ethics form, you know, what are the benefits of participating in research. Interviews change people, they it operates as an intervention in and of itself. And I think it's under under recognized and so I think being open to that and asking a question in the focus group, you know, was there anything about this focus group experience which you found beneficial for your thinking about this whole issue and that can that can often end and discussion around. You know, the people that are with the group of four or five people that have a similar orientation to the m, talking about an issue that is important to them. And that's how, you know, you have to take them to you. What is the, what is the thing that they are orientating around? Don't don't get limited by your. or you know your questions and yeah direction of the product but you know what are the things that they orientate around that are important to them what matters most to them and what might a product that is produced out of that look like

VS: Yeah, so take so listen to what, what's resonating with them and make sure that that product reflects that more. So take it in that direction.

GT: So it is a semi-structured interviews sometimes, the schedule is wrong. You know, you've developed a schedule in relation to a literature base, and all that sort of stuff. And sometimes you just have to let it go. And let the group go where it wants and that should shape your next focus group.

VS: I was going to ask you then in subsequent groups do you go back to the original script or do, you modify?

GT: I mean you might you might find the second group does something entirely differently. So I wouldn't throw out. But the orientations around you know what, you're trying to get it. Might be shifted so much that you have to edit a number of questions or have a different starting point. Sometimes if the starting point is, you know, you start off with, we've got this exercise, we know it works. This is what we're thinking of doing. What do you think about that might become. What's the most complicated or complex issue around dealing with pain when you're in a wheelchair, when your primary motive of movement is using your arms and shoulders and back. And, you know, no quarter speak of all, that sort of stuff. So all those sorts of things are things that might but they must shift the orientation to the beginning rather then you know later on in place/piece or something like that.

VS: Yeah, it makes me now. I'm just going to have to really think quite carefully about my questions.

GT: Yeah, a lot more. I mean, I think the overall consciousness of design, the design that you've developed is, there's no sense in which that has to change, but it's what you've got to be open to openness to flexibility, and the openness to to shifting in a potentially unexpected Direction. So one of the things that's happened with with Nada's project on the increase in the amount of exercise intervention in a hospital outpatient setting and in those, some qualitative interviews. Ruth did the analysis or and what the analysis threw up was that there were issues within the way, they are being treated by the nursing staff and the doctors that were preventing them from even thinking about the exercise program that they're being involved in. What they orientated to was something entirely different from what the intervention was related to. And so Nada came up to me and just said, I don't know what I'm supposed to do with this. You know, we've been asked to do this particular project and then deliver in terms of evaluation of this project but what our findings are are entirely, not what we expected and the intervention itself is secondary. So and so then what you do in terms of, does the intervention change or does the act of having done the interviews actors and intervention and in some way? And that means that the next step is finding ways

to enhance the way that that's people within clinical environments are treated without an understanding of who they are. And what's most important to them?

VS: I don't know anything about those results, but I know that I know that they've had difficulty at that site at that research, that the staff have been, I think. Not on board. And and so, and I think so hearing that bit, and then hearing what you've just said, I think seems to make sense.

GT: Yeah. And so so the thing is that they there's a moment of being flummoxed but now it's like, well, these are great findings. We need to publish these. We need to see these as the output of what we did there. But intervention itself is by the by. And I'm not saying that your intervention is going to be by the by, but one of the things oriented to, was being passionate about, A group of people that you have worked with for a long time that you care deeply about and wanting to see change occur in their lives. Because you've seen the struggles that they've gone through and so, tapping into that means that you're at risk of doing something quite different than what you think you're doing at the moment. And as I said, I don't think that means to needs to change the design, but I think it might change the output. And being conscious around that. So I don't know. I'm just, Mmm.

VS: So you're saying because of that, because I want to see a change. I'm a steamroller ahead with what I want to do? the opposite?

GT: think I think if that is, is your intrinsic value. You will you you're probably in order to stay What's the word? You want to stay aligned with the project because that's what you designed in your head cognitively but it sounds like heart stuff. Emotion stuff, I want to do what's right for them actually, you want to see change occur in their lives and it doesn't, it doesn't necessarily have to be through the exercise component and if we keep orientation back to that and it's missing the fact of what you want, is something in here. And this might mean that this becomes less important and ends the personhood and the features of something that helps shape their experience might be more important. I hope I'm not completely throwing everything into the wind

VS: into the so ends up becoming more of this then. And less about that, because that's the digital part. So you're saying that these become…

GT: well potentially. Because if you think there's a strong evidence base here and this stuff here is, so the person or the clinician, I would bypass them and say actually the personhood of the participants, the patient base that you've got here. And that fact, this works the fact that you're passionate about recognizing, this is something which works in space, but there might be a missing ingredient. In here, which helps link these things together where the features are a by-product of something that you determine in this space. That's as yet unknown. But if you are orienting yourself to the features, I think that you will you could end up with some interesting data that will tell you a lot about what people like about certain things, but it doesn't necessarily tell you about. You know, what matters most which is in the core of this thing.

VS: I think it's true. Because if it's not about what matters most then it's not going to lead to use,

GT: no and long-lasting change and all that sort of stuff, you know. So at a really superficial level, I pick up Duolingo to practice my French because I'm going to spend a weekend New Caledonia and so if you see, why are you practicing French? I was like, well yeah I've studied French in the past and I want to just, you know, re-establish my skills around that sort of stuff. But what's at the core of it is, is I would feel I feel embarrassed because I have studied French turning up in a French-speaking context and then forcing the people in that context to speak English to me in order to communicate when it's there the second or even third language. So what it comes down to is is not necessarily my skills and wanting to perform. In a particular way it's about my interests and not imposing myself on other people.

VS: There's a there are two meanings. but I think that's true of every action that we probably do.

GT: absolutely. So it's but I think the rest of risk with with a project like this is that you don't get that second layer. Yeah you know what is what is at the heart of it? Yeah. Yeah and I think that's the stuff that I think would be most interesting and the stuff that you could remain passionate about over the course of a three or four year project.

VS: And That's always been my I felt like my whole discussion would end up being really about The lack of the therapeutic, the person therapeutic relationship and the

discussion of the computer, patient relationship and comparing the two and understand. Because I do think that that's that's the, that's the biggest leap I suppose in all of this.

GT: Yeah. Yeah.

VS: And the demise of it or you know, what's going to happen with the future and our, you know, I know we have all these gadgets and whatnot, but so I've just felt like that was where my ponderings are going to take me so might as well start at the beginning and be quite overt about it.

GT: Yeah, absolutely. And you know the things that you know, when I came to the end of my PhD, the things that were important to me. At the end, were the things that brought me into it in the first place. And there weren't necessarily that I wanted men to talk to me about vasectomies. What I was interested in was taught at talking to men about issues that were meant about with men about issues that were important to them that were also important to me and and that was evident in the way I wrote the whole whole thing. You know, I started with a story about their my relationship with my in the introduction of story or relationship between my father and my stepfather in terms of the way they interacted with my mother and stepmother with regard to contraceptive engagement and all that sort of things and the different types of masculinity that played out there quarter who, yeah, it's pretty experienced. Yeah, and I didn't recognize that was a necessarily a thing going on. That was a story. You know, it only really came came to me at the ends of the thing, but it was there the whole time, you know? So it shapes who you are, and what drives you and What Makes You passionate about this stuff stuff rather than. And if you, if you are passionate about programming and interested in little features, then you know, by all means go for it. But that's doesn't sound like, that's what you know.

VS: Well that's what I've been writing in my journals that. That's my biggest. Concern about this whole project. Like I feel like I'm a bit of a fraud pushing this one. I feel so strongly about the therapeutic relationship with yeah.

GT: And I think, Don't ever let that go. Because I think that will check you that will keep you in balance and it might be that you're not necessarily replacing the therapeutic

relationship. But you know, the centrality of that relationship. And what that means in the meaningfulness for people might still become evident to them through this project. Even if there's a product that comes out the other end and, you know, it's almost like this product is acting as an intervention in some regards, but not necessarily the intervention you initially thought it might be you is related to making people do more shoulder exercises, to improve their overall well-being. But what you end up tapping into is, you know, what is it? The core of the therapeutic relationship So it's a way of accessing information about that, so, you know, don't let go of that. Yeah.

VS: Because I haven't gone there at all, but I, but I just do feel like What am I pushing this one? I don't feel like I feel not that I don't but you know, I can see the potential positives, but I can see all the potential. why I can see all the potential reasons why it would never work but that's I guess watch worth testing

GT: yeah yeah and I think You know. Yeah. That's

VS: that's all I guess. That's why it's worth asking the question to know is it is it?

GT: But in your findings might not be again what you were expecting and so I think there's scope for some real depth there and I think you should be when you're writing up ethics and all that. Think about the amount of time the time bit of people because it might be greater than you initially though it was going to be.

VS: That's why I was asking about the time because I think in an hour and a half to two hours. Okay. That's but I just thought that's a long time for somebody.

GT: Yeah, if you've got activities in there and you're doing things like, you know, let's make a collage of all the, you know, and to give them through this in their own content context and then bring them to the focus group. So, do the pre-work sort of thing, make a, collage of stuff that's related to your experience of, of movement and moving around, using your arms in shoulders, pain, and all that sort of stuff, you know, maybe even making a collage of the pain stuff, you know, what's important and getting them to orientate to that. These are things which people have access to magazines and newspapers. You know, they can be printing stuff out from the internet. All those sorts

of things that allow them to talk about the wider experience of being a person that's lost the use of their lower body and sometimes more. And and what happens when you feel limited and using a particular level, that sort of stuff, it's like, you know, just the disability thing, you've already got a sense that you've been disabled, but in what happens when you are even more so because, you know, something like a shoulder tweak of some kind. Yes. I think there's some real scope to be really.

VS: Yeah. I've been thinking about how to Sensitize them to it or you know, or to. If there's a way that I could. ask them to come with something to either, get them in the in the the mindset to come prepared to talk about something or to move things along or to. Yeah, just have something that they could present or just add to my, you know, whether it's. Yeah. I just I just wasn't sure really what they could do. That would be minimal time for them.

GT: Yeah, yeah. And so I would be looking for co-design tools and there's a couple of ways you can access those sorts of things. So you could even talk to one of the designers, you know, we've got contacts with good design team here so you can talk to them. You can talk to Guy. I will. Yes. And yeah, you know what, are some mechanisms to get people thinking about stuff. So seeing this is a CO design project I think will help your orientation to it a bit and framing it in that particular way and so Guy. And then ask you know past people to point you to the direction of good books that have co-design mechanisms in place. You know, I think Kelly has one on her desk. Yeah, whether it's just games you can plan and all that sort of stuff about and all that sort of stuff. Yeah,

VS: it's about still becomes. If it's still focus group even though they do activities, it's not like a workshop. It's or focus groups of folks

GT: room. Yeah. Yeah. and the thing is, if they're doing the activities in their own time when they've got energy to do them and all that sort of stuff and bring it to the group means that you're able to get into the deeper stuff, much more quickly, your orientated towards it and you can be talking about these things and using it. To help frame discussion and therefore, you're more able to be surprised and less wedded to your, your question list, which you might feel the need to go through, to make sure

you've checked all the boxes. But as I said, you could be surprised by what turns up and I don't know how you would do that and what your orientating towards. But you know, Yeah. I mean you could choose the particular issue like, I just, you know, suggested, you know, the The idea of the you know talking about pain and its relationship to experience and all that sort of stuff. But you could be thinking any one of these things, you know, how do you think about exercise to improve your well-being? For instance there could be another thing. You know, and get into a collage or draw a picture or take photos. Even. Yeah because you know we used to You know, the photo elicitation stuff, and interviews used to be limited by things, like access to cameras and stuff like that. But most phones now have a camera in them to them and most people have a cell phone. Yeah, you know, even taking pictures and then doing a slideshow by some clients that just talks about their experience might be a way for you to frame up the conversation

VS: and there would there send those to me beforehand and bring them because they may not feel comfortable presenting in a group

GT: So I mean, they would have to know that this is, this is part of a group thing. So then, you know, they might take a bunch of photos. They share all of them with you but then they only present the ones which they're willing to talk about in the group. And it might be that you you ask them to show 4 of the ones that they feel comfortable with but keep in reserve some that might help the conversation later on. So if they feel comfortable and built enough rapport with the other in the group or they already know each other. Te Whanau or a group of young Maori that had been in the spinal unit together, all that sort of stuff. They they may already have a bond intact where they can they can share and later as guards come down one sort of stuff.

VS: If they are working in pairs on an activity, do you have separate recorders for those? Do you say, do you mind? If I record your interaction? How did that work?

GT: It depends on what you want to do. Yeah. But but you're getting them to come back and talk to stuff. So I think that may help. You don't need to have the recorder. It did every point but if you're if you're asking them to explain each game like you know it's like talk along tight.

VS: Oh no! That that would be at that and that's Later group that has that later on.

GT: Yes. I think I think that's that's different, that's more sort of thing that you do at usability.

VS: Yeah. And that's that's depending on what happens and with this initial group, that was our plan to do later on with some sort of some sort of product or prototype of Product or wireframes, or whatever, at that point. Yeah. Yeah but it's this is just a It's just that co-design. Let's just say proof-of-concept type of.

GT: Yeah. So so and I think Nic she's one of your other supervisors. Yes, she has access to a bunch of stuff related to co-design. Yeah. You know she's written up projects with Steve Ray. They have lots of that sort of stuff in it, so just ask her to start sending stuff to you and I suspect that she's already had an influence on how things have been written already. Yeah, and she may not have articulated that as such but that's the sort of thing will be informing her. Reading up around that sort of stuff yourself. Yeah. What can be achieved at how and and the surprising nature of the co-design in terms of what sort it finds? Yeah as opposed to the research agenda, where you've got your hypothesis and you were arranging to test it. Yeah. Which sounds like when you started this, that's what it sounded like you were up to do. You know my hypothesis is, you know, this digital design platform will enable the participants to be able Able to do the exercise. Whereas as we've talked I think it's got a little bit more complex. Yeah. And so it's less hypothesis-driven and more, let's find out what's going to facilitate improved, you know, whether it be exercise or whatever, that may not involve the digital platform doing the work of the clinician because that can't be replaced. So something else has to be done.

VS: done. Yeah, yeah I think I think you summed it up pretty well. Cool. Yeah.

GT: Okay good. Yeah, great. Sorry. I this is what these things should be doing. Yeah, and I know I've talked a bit about it but I have been conscious of people beginning to do projects, particularly PhD projects and getting halfway through them and then coming to speak to people then, whereas I think the pre assumptions than can be quite Central to making a project work out really well and tap into who you are rather than just doing a project. So you can take off the PHD

VS: box. No, I think this is really good. It's I just feel like now I need to really Go back and think I'm going to. Listen obviously. Yeah several times and go back and think a bit more about. I feel like I need to reframe quite a quite a few bits and pieces. I think it's good though.

GT: I think yeah this this will save you trauma at the later stages where you're torn between doing the project, what you thought you're doing. And then this is at this is what I, you know, I'm finding most interesting. This potentially very early on sets the stage, for, what can I find is going to be most powerful in terms of changing something? That is important to you. And that's the lives of People that, you know, are in wheelchairs. Yeah. So keeping hold of that I think is quite easy. Mmm.

VS: Excellent. Thanks very much for your time. I really appreciate. It was really makes me think. Why didn't I think of those things?

GT: I think I've been thinking about some of the stuff for a while and in terms of people starting projects and then finding it out you know, through all the way through things have changed him, Carolyn was a really good example. You know, her original project was not what she ended up doing. Yeah. And, you know, that ended up standing stuff out as a consequence and now she passed the flying colours. But it took a major crisis in the middle for things to recognize and I'd rather instigate a minor crisis. Now then then you know, you feeling like you've got to drop it or the pieces are too difficult to handle and what sort of stuff. Yeah.

VS: I don't think it's a crisis. I think it's more of a revelation or it's just, it just a different light because it's everything. You said is true. I think that that model I've never. I've never seen that model, but it makes total sense. So, and I think it's If I could take a photo of that, I'd love that just too and it's just, it's just very straight…. It just is. I think you've just articulated the the jumble of things. You've kind of organized them in a slightly different way that has helped me realize instead of just going through the motions of some things, I think I've you're right, it's not just the latent in there something deeper, which ultimately, I think it makes a lot more meaningful sense

GT:. Yeah, I think so.

VS: Yeah. So that, that, that ultimately is why we're supposed to be asking questions, you know, a bit more of that. That's why we're not just looking at doing a lit review, really?

GT: Yeah. Because you can do that sort of stuff, and you can add to the literature over literature-based by condensing something down and in producing a particular. Yeah,

VS: well I could do that. I could put if I could put a web digital but I think I could design something right now based on them.

GT: Absolutely.

VS: I already have something in mind based on the literature.

GT: Yeah. No, yeah, yeah,

VS: cool. Okay, yeah, cool. Okay, thank you. Yeah. I appreciate it. Yeah, yeah.

Appendix B

Published manuscript: Protocol

Open access Protocol

BMJ Open

Development of a self-guided web-based exercise intervention (SPIN) to treat shoulder pain in people living with spinal cord injury: protocol of a mixed methods study

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ABSTRACT

Introduction Chronic shoulder pain is common after spinal cord injury (SCI) and limits community mobility. This leads to loss of independence and reduced quality of life. Evidence suggests that exercises can help reduce shoulder pain. However, cost, expertise and transport barriers frequently limit access to treatment services. The objective of this study is to develop an evidence-based, acceptable, usable and persuasive self-guided web-based exercise intervention to treat shoulder pain in people living with SCI.

Methods and analysis An iterative and phased person-based approach (PBA) will capture users' perspectives on usability and acceptability to develop guiding principles that will shape the design of the intervention. The intervention will be based on key elements identified through participant input and from evidence identified through systematic and narrative reviews, to ensure the intervention addresses participants' needs and increase the likelihood of uptake. The prototype will be iteratively refined through focus groups and think-aloud sessions. Review data will be synthesised drawing on systematic and narrative review conventions. Qualitative data will be analysed using conventional content analysis (planning phase) and directed content analysis (development phase) to inform intervention design and refinement.

Ethics and dissemination Ethical approval has been granted by the Auckland University of Technology Ethics Committee (AUTEC) in Auckland, New Zealand. The results of the study will be published in a peer-reviewed journal and presented at relevant national and international conferences. A summary of findings will be presented to key stakeholder groups. We will progress to a definitive trial should the findings from this intervention development study indicate the intervention is acceptable and usable.

Strengths and limitations of this study

- Using the perspectives of potential users in intervention design drawing on the person-based approach may increase the likelihood of engagement and usability.
- Having a stakeholder advisory group has the potential to support translation of the findings to real-world application.
- Budgetary restraints may limit the degree of intervention refinement possible, which may slow development of the final product.

INTRODUCTION

People with spinal cord injury or spinal cord impairment (from non-traumatic causes) (SCI) rely on their upper extremities for locomotion as well as performance of daily activities. Consequently, up to 70% of people living with SCI experience shoulder pain, which can have a significant impact on activity that reduces community mobility, independence and quality of life.[1–6]

Exercise-based rehabilitation is often included in the management of shoulder pain. Protocols including stretches and strengthening exercises have been shown to significantly reduce shoulder pain in people with SCI in a series of non-controlled studies,[7–10] a randomised controlled study[11] and a systematic review.[12] Despite the known benefits of exercise to reduce shoulder pain, many people living with SCI who experience shoulder pain often do not engage in these exercises.[13] They cite barriers to accessing exercise and rehabilitation opportunities that include limited access to knowledgeable health professionals, poor physical accessibility and transportation difficulties.[14 15] Digital health interventions offer a potential opportunity to overcome many of these barriers in a cost-effective way.[16] They can provide automated and remote personalised feedback and support for self-guided exercise, in a person's own time and environment.

Although web-based exercise resources are currently available for people living with SCI,[17 18] they have some limitations. For

PBA Description	Phase	Current Study	
		Purpose	Planned Outcome
Use of primary and secondary **qualitative evidence** to understand users' behavioural and psychosocial needs and challenges in using the intervention.	Planning	To determine **factors that need to be included** to **encourage or facilitate engagement** with this self-guided web-based exercise intervention.	A rich description of key **needs, challenges and facilitators** of engagement in web-based tools and exercise for people living with SCI who experience shoulder pain to **underpin the design phase's guiding principles and features**.
Formulation of **key guiding principles** that capture the main intervention objectives as identified in the planning phase and that are continuously referred to throughout the development of the intervention.	Design	To design an **evidence-based, self-guided, web-based** intervention. Exercise, behavioural support and self-guided components will be included within the intervention features.	Key intervention objectives. Key intervention features. 1st iteration of SPIN prototype (wireframe version).
Intervention components are evaluated and optimised based on user feedback.	Development	To develop an **evidence-based, self-guided, web-based** intervention. Iterative feedback and prototyping to **refine the intervention** through **wireframe focus group testing** and then further refined with **think-aloud testing.**	Final SPIN prototype (digital version). Ready for trialling.
Intervention is evaluated in **real-life context** and modified to improve future implementation.	Trialling	To carry out a mixed methods pilot trial. This phase will be dependent on the preceding phases.	A brief outline entitled '**future work**' is included in this paper.

Figure 1 Phases of intervention development. PBA, person-based approach; SCI, spinal cord injury; SPIN, Shoulder Pain Intervention delivered over the interNet.

example, they require the ongoing support of a clinician, are not specific to treating shoulder pain or do not have the capability to automate exercise progression. Shoulder Pain Intervention delivered over the interNet (SPIN) is being developed to address these limitations. To our knowledge, this will be the first web-based, self-guided intervention that will prescribe, monitor and progress evidence-based exercises for people living with SCI who experience shoulder pain. The intervention will be an interactive tool using responses from users on their pain or degree of exercise difficulty to tailor the programme.

Translation of an existing evidence-based intervention into a web-based format presents a number of challenges.[19] For example, attracting users and encouraging engagement with the intervention can be further complicated by how usable the technology is and how quickly it continues to evolve. Therefore, the development of SPIN will be theory-driven, evidence-based and underpinned by the person-based approach (PBA) to intervention development.[20] The PBA seeks a deep understanding of the perspectives and psychosocial context of potential users through iterative qualitative research.[20] The PBA draws on evidence from primary and secondary sources to identify barriers and facilitators to uptake. As Yardley *et al*[20] suggest, it makes use of behavioural evidence and theory,[21] while keeping the user's needs and context in focus, increasing the likely engagement in and effectiveness of the intervention.[22–24] SPIN is planned to be self-guided and so will be used with minimal health professional contact. As such, ensuring the design is underpinned by a clear understanding of the perceptions, assumptions, behavioural needs and challenges of the user will increase its relevance and usability. The aim of this project is to develop an evidence-based, acceptable, usable and persuasive self-guided web-based exercise intervention to treat shoulder pain in people living with SCI.

METHODS AND ANALYSIS

Patient and public involvement

The research question was developed from clinical experiences and then further refined through consultation with the Burwood Academy of Independent Living End User Consultation Committee, a consumer group with

the expertise of living with SCI who advises on research projects.[25]

A stakeholder advisory group (SAG; more details are provided below) will also be formed to help support the study at key points. Key findings will be presented by researchers and participants at community and academic meetings.

Study design

The PBA proposes four phases of intervention development that include planning, design, development and trialling. The current study is focused primarily on the first three phases. Figure 1 provides a definition of each phase according to the PBA and an overview of how they map onto the current study. The iterative nature of intervention development implies that phases are not discreet, and movement will occur between them.

Participants

Eligibility

Participants will be eligible if they reside in New Zealand; are living with SCI; have completed active rehabilitation; are over 16 years of age; have capacity to give informed consent; are predominantly wheelchair users; and are experiencing or have recently (within 2 years) experienced shoulder pain. Participants will be excluded if they are unable to communicate with the researcher for the purposes of meaningful engagement in data collection.

Recruitment

Posters will be distributed within SCI community networks and SCI services and rehabilitation providers. Information will also be circulated through social media sites and professional and personal networks. People who express interest in the study will be invited to contact the researcher or give permission for the researcher to contact them. The sampling approach specific to each phase is provided in more detail below.

Stakeholder advisory group

An SAG will be formed to support this project. The composition of the group will include a person living with SCI, a clinician with experience in SCI rehabilitation, a representative of a relevant non-governmental organisation and a computer engineer with knowledge in web design and decision tree development. They will meet at least four times during the study including at the outset and following each phase. Their primary role will be to gauge how findings resonate with personal insights and experience, to make recommendations for the subsequent phases and to inform refinements to the intervention. For example, in the planning phase, they will be able to make recommendations for recruitment.

Planning phase: collecting and synthesising evidence

Purpose

- To determine the effectiveness of existing self-guided web-based exercise interventions.
- To determine factors that need to be included to facilitate engagement with the current self-guided web-based exercise intervention.

This phase will include collecting and synthesising primary and secondary evidence to inform the design of the intervention. Secondary evidence will include both a systematic and narrative review of the literature. Primary evidence will be collected through an interpretive descriptive study.

Systematic review of effectiveness of self-guided web-based exercise interventions

Yardley *et al*[20] recommend drawing on an existing evidence base. However, there are no reviews currently available that synthesise evidence regarding the effectiveness of self-guided, web-based exercise interventions. Consequently, the first stage in this work is to conduct a systematic review to (1) determine effectiveness of this method of delivery in improving health outcomes for those with chronic health conditions and (2) extract data on key characteristics of those interventions identified as effective. The results will be used to inform intervention development by identifying elements common to effective web-based interventions.

The systematic review will follow the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement.[26]

Eligibility criteria

Studies will be included if they meet the inclusion and exclusion criteria presented in table 1. Initial scoping revealed no applicable interventions involving people living with SCI. Therefore, the search was expanded to include those living with a chronic health condition.

Databases

Literature searches will be conducted in the following databases: Cumulated Index to Nursing and Allied Health Literature (CINAHL), MEDLINE, SPORTSDiscus through EBSCO Health Database, Allied and Complementary Medicine (AMED), Evidence-Based Medicine (EBM) Reviews—Cochrane Methodology Register third Quarter 2012, EBM Reviews—Health Technology Assessment fourth Quarter 2016 PsycINFO 1806 to July Week 2, 2017, MEDLINE(R) Epub Ahead of Print, In-Process and Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to present through OVID, in Scopus and in Web of Science. The Physiotherapy Evidence Database (PEDro) will be searched (using simplified broad key terms) as a checking exercise. Reference lists of relevant reviews and studies will be hand searched.

A search strategy has been devised drawing on the Population, Intervention, Comparison, Outcome (PICO) framework with a focus on key terms relevant to *intervention* (web-based exercise) and *study design* (randomised control trial). The search will not be limited by *population* and *outcome* to keep the reach as broad as possible and ensure

Table 1 Inclusion/exclusion criteria for systematic review

Elements	Inclusion criteria	Exclusion criteria
Study design and reporting	Randomised controlled trial or pilot that contains data addressing effectiveness Full text available	Not in English Publication not peer-reviewed Conference proceeding
Population	Adults with an existing chronic health condition	
Intervention	Designed for the use of people living with a chronic health condition	
	Explicitly supports self-guided physical activity or exercise in a self-guided programme	
	Web-based or app-based	
	Intervention has minimal human contact comprising no more than initial contact for set up or orientation. Has ongoing contact that is generated automatically.	
Outcome	Health related	

studies are not missed. Search strategies will also include Boolean, wildcard, truncation and proximity searching, tailored by database. Table 2 provides an example of a search to be conducted using an OVID database.

Selection of studies

All citations returned in the search will be downloaded and saved into EndNote X8. Duplicates will be removed and then titles will be screened by VS, according to the predefined inclusion criteria. Initially, a selection of titles will be independently screened by a second assessor (NS). Any disagreements will be reviewed and discussed to ensure consensus is reached. Should agreement not be reached, a third assessor (NMK) will serve as arbitrator. The abstracts and then full texts of all those studies potentially meeting the inclusion criteria will be reviewed by VS before settling on a final set of included studies in consultation with NS.

Data extraction and management

Key details from each of the included studies will be recorded in data extraction tables. Details will include author and country, study design, participant numbers and characteristics, treatment intervention (including features and components used) and health outcomes.

Quality assessment

Risk of bias for each of the included studies will be assessed as low, high or unclear drawing on guidelines by The Cochrane Collaboration's tool for assessing risk of bias in randomised trials.[27] Appraisal of the quality of included studies will follow the criteria outlined in the Critical Appraisal Skills Programme Randomised Controlled Trial Checklist.[28]

Narrative review of relevant literature

The planning phase includes using qualitative evidence to inform intervention development. This second review of literature will explore what helps or hinders engagement with (1) exercise and physical activity and (2) web-based interventions for people living with SCI. The findings will be used to generate discussion topics for the Interpretive descriptive study (described further below). Findings will also inform the guiding principles for intervention design.

Table 2 Database search concepts and terms

	Search concept	Likely terms
#1	Web-based exercise	(web* ADJ6 Exercis*) OR (web* ADJ6 Rehabilitation) OR (web* ADJ6 Physiotherap*) OR (web* ADJ6 'Physical therap*') OR (web* ADJ6 therap*) OR (web* ADJ6 'fitness training') OR (web* ADJ6 physical activit*) OR (internet* ADJ6 Exercis*) OR (internet* ADJ6 Rehabilitation) OR (internet* ADJ6 Physiotherap*) OR (internet* ADJ6 'Physical therap*') OR (internet* ADJ6 therap*) OR (internet* ADJ6 'fitness training') OR (internet* ADJ6 physical activit*) OR (online ADJ6 Exercis*) OR (online ADJ6 Rehabilitation) OR (online ADJ6 Physiotherap*) OR (online* ADJ6 'Physical therap*') OR (online ADJ6 therap*) OR (online* ADJ6 'fitness training') OR (online ADJ6 physical activit*)
#2	E-health or physiotherapy	(Ehealth OR e-health) AND (exercise* OR rehabilitation OR physiotherap* OR 'physical therap*')
#3	#1 OR #2	
#4	Study design RCT	'Random* control*' OR RCT OR 'control* trial*'
#5	#3 AND #4	

Table 3 Inclusion/exclusion criteria for narrative review

Elements	Inclusion criteria	Exclusion criteria
Study design and formatting Phenomena of interest	Qualitative study Full text available Exploring experiences and perspectives of physical activity interventions Exploring experiences and perspectives of web-based interventions	Not in English Publication not peer-reviewed Conference proceeding
Participants	Adults living with SCI who experience mobility limitation	

SCI, spinal cord injury.

Eligibility criteria

Studies will be included if they meet the inclusion and exclusion criteria outlined in table 3.

Search strategy

Literature searches will be conducted in the following databases: Cumulated Index to Nursing and Allied Health Literature (CINAHL), MEDLINE, SPORTSDiscus through EBSCO Health Database, Allied and Complementary Medicine (AMED), Evidence-Based Medicine (EBM) Reviews—Cochrane Methodology Register third Quarter 2012, EBM Reviews—Health Technology Assessment fourth Quarter 2016, PsycINFO 1806 to July Week 2, 2017, MEDLINE(R) Epub Ahead of Print, In-Process and Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to present through OVID, in Scopus and in Web of Science. Reference lists of relevant reviews and studies will also be searched.

A search strategy will be devised by breaking the review question down into component parts including key words relevant to patient perspective, the substantive topics (web-based intervention, exercise and physical activity) and study design. Table 4 provides an example of a strategy that combines these components and possible search terms. Searches will be run for each component and then combined to reflect the relevant question (see table 4 searches #6 and #7).

Selection of studies

This review will follow a similar approach to the data selection as the systematic review described earlier.

Data selection and management

Key details from each of the included studies will be recorded in data extraction tables. Details will include author details and country, study design, participant numbers and characteristics, experience explored (eg, exercise or web-based interventions), barriers to engagement and facilitators to engagement.

Quality assessment

Appraisal of the quality of included studies will follow the criteria as outlined in the Critical Appraisal Skills Programme Qualitative Checklist.[29]

Data analysis

A narrative synthesis of data will be performed. Findings from the included studies will be reviewed and key concepts relevant to the review questions identified. These will be grouped into categories and then mapped to the original findings of included papers to check for resonance and identify aspects that either confirm or conflict with the synthesised findings. From this, a more refined set of categories will be generated.

Table 4 Narrative review search concepts and terms

	Search concept	Likely terms
#1	Experiences	barrier* OR facilitator* OR help* OR hinder* OR perspective* OR experience* OR acceptability OR satisfaction OR view* OR perception*
#2	Study design	qualitative OR hermeneutics OR 'thematic analysis' OR interview* OR 'focus group*' OR 'grounded theory' OR 'content analysis'
#3	Physical activity or exercise	exercise* OR rehabilitation OR physiotherapy OR physical therapy OR therapy OR 'fitness training' OR 'training' OR 'physical activity'
#4	Web-based interventions	web OR internet OR online OR e-health OR ehealth
#5	Spinal cord injury	Spinal cord injur* OR 'SCI' OR paraplegi* OR quadriplegi* OR tetraplegi*
#6	#1 AND #2 AND #3 AND #5	
#7	#1 AND #2 AND #4 AND #5	

SCI, spinal cord injury.

Interpretive descriptive study

Primary qualitative evidence will be collected in this phase. An interpretive descriptive[30] study will be carried out to explore the perceptions of people who live with SCI regarding a self-guided, web-based, exercise intervention to treat shoulder pain. The results will inform the guiding principles to underpin intervention design.

Participants

Participants (up to n=20) will be recruited using the eligibility criteria and recruitment process described earlier. We will draw on Malterud's concept of information power[31] to guide sample size. Participants will be purposively selected to ensure diversity in social circumstances, age, ethnicity, gender and impairment to ensure breadth of perspectives and experiences.

Data collection

Individual or focus group interviews will be conducted at a venue convenient to the participant(s), such as their residence, place of employment or another agreed location. Individual interviews may be carried out via other means (ie, Skype, FaceTime) if preferred by the participant. A semistructured interview guide will be used to focus on the phenomenon of interest while allowing enough flexibility for the interviewer to be responsive to participant responses.[32] Topic areas will include participants' perceptions and suggestions of various web-based exercise scenarios, exploring concepts uncovered by the review findings. This will be followed by questions relating to how features of a web-based intervention could support people, for example, how it would need to look, what would encourage participants to use it and to what extent it may overcome barriers identified in the review. Opportunities for problem solving and contribution to the intervention design process will also be integrated into these sessions.[33] For example, participants will be invited to comment on currently available website and app features that could be included in a future web-based intervention. Interviews will be audio recorded and transcribed verbatim.

Data analysis

Data will be analysed using conventional content analysis.[34] The transcripts will be read and reread to allow familiarity with the data and to identify items of potential interest. They will be read in conjunction with researcher notes taken at the time of the interviews so that the data and its context are considered when reading. Next, data from several transcripts will be inductively coded, using exact words from the text, where possible, to capture key concepts. Memos will be used to capture the researchers' initial impressions throughout this initial coding process. The codes and relevant data will then be collated in an iterative process of returning to the original data for recoding and refinement. Initial codes and memos will subsequently be examined to identify meaningful clusters. Following this, a coding framework with associated definitions will be developed. All transcripts, memos and codes will be entered into NVivo V.12.[35] The remaining transcripts will then be analysed by searching for statements that specifically support or challenge the proposed codes to refine the cluster and categorisation. Strategies to ensure robust and rigorous interpretation will be used, drawing on Thorne's notions of epistemological integrity, representative credibility, analytic logic and interpretive authority.[36]

Design phase

Purpose

- To develop an evidence-based web-based prototype intervention.

The design phase will synthesise information from the planning phase, in keeping with the PBA, to formulate guiding principles. These are statements that succinctly reflect what is distinctive about the intervention that meets user needs as identified in the planning phase.[20] They ensure intervention development remains constant and true in its direction towards meeting the earlier identified goals. The guiding principles can be broken down into intervention objectives and the key intervention features needed to achieve them. Data will be drawn and integrated from several sources to underpin intervention objectives and features including (1) existing evidence-based exercise interventions that address shoulder pain; (2) systematic review findings regarding features of effective self-guided and web-based interventions; (3) narrative review and interpretive descriptive study findings regarding aspects that support acceptability and engagement and (4) relevant behavioural theory. For example, if synthesis reveals that valuing independence is important, then an objective of the intervention would be that it can be used autonomously. This will then inform a set of related intervention features such as customisable elements for goal setting, self-monitoring and choice.

The first iteration of the SPIN prototype will be produced during this phase as a set of wireframes. Wireframes are a paper-based visual schematic of the prototype that help participants experience working through the intervention's proposed sequence without live data or graphic design. It therefore allows researchers and participants to discuss the features of the intervention separate to the aesthetics.[37]

Development phase

Purpose

- To develop an evidence-based web-based intervention.

During the development phase, people with SCI will take part in usability testing, providing feedback on the wireframes produced in the design phase. Data will guide the iterative development and refinement of SPIN into a digital working prototype of SPIN, ready for implementation and trialling. There will be a large amount of collaborative work between the participants, computer engineer, web-developer, stakeholder advisory group and the researcher during this phase.

Participants

Up to 10 participants who originally participated in the planning phase will be purposefully sampled to take part in the focus groups. Up to five of those participants will then be further purposefully sampled to be involved in individual think-aloud sessions.[38] Sampling will aim for a range of abilities and levels of comfort when interacting with the prototype. Sample size is based on previous usability work by Nielsen[39] and Virzi.[40]

Data collection

Focus groups will use wireframes as a prompt for discussion. The facilitator will lead exploration of the wireframes and will use exercises to elicit feedback on the intervention features, layout, order and content.[33] For example, initial discussion will be generated around broad topics including initial impressions, including positive and negative feedback. More specific exercises will ask participants to sort prototype features in order of preference and importance. Sessions will be audio and video recorded with notes taken during the process.

Focus group findings will lead to development of a working digital prototype. Following that, individual think-aloud sessions will be used to gain a more in-depth, real-time understanding of how easy the working prototype is to use and follow and how participants interact with the intervention and progress through the stages. In these sessions, we will invite participants to work through a 'live' component of the prototype (eg, one exercise). They will be encouraged to speak their thoughts out loud while performing the representative task, commenting on what they are looking at, thinking, doing and feeling at each moment, in as close to their natural environment as possible.[41] These sessions will be audio and video recorded. Open-ended interviews and postexperience questionnaires may also be used.[41]

Data analysis

Audio recordings from focus groups and think-aloud sessions will be transcribed verbatim. Data will be analysed using a directed content approach,[34] drawing on usability frameworks.[42] Transcripts will be read and key concepts relevant to preidentified usability elements will be highlighted. Consistent with directed content analysis, text that does not fit an existing code will be given a new code.[34] Data from this phase will be used to refine the SPIN prototype in preparation for implementation and trialling (outside the scope of the current proposed research).

Future work

Should findings from the intervention's design and development phases indicate the website is acceptable and usable, we will progress to a mixed methods pilot trial of a 12-week SPIN intervention. The aim of this pilot trial will be to explore the feasibility, acceptability, safety and engagement of the intervention. The full protocol will be informed by the framework proposed by Proudfoot *et al*[43] outlining facets, elements and guidelines of best practice in evaluating and reporting internet interventions.[44] The full scope of this pilot trial will depend on findings from earlier phases. It is anticipated that up to 10 people with SCI who have not been involved with any of the intervention development phases will be invited to take part. Data such as pain and adverse events will be collected concurrently. Data such as shoulder pain and function will be collected pre and post intervention. Post-trial interviews will explore user experiences on the acceptability and the perceived benefits of the SPIN intervention.

CONCLUSION

This paper has described how we plan to develop a self-guided, web-based, exercise intervention (SPIN) to treat shoulder pain in people living with SCI. Using the PBA involves people living with SCI at each phase, increasing the likely engagement and effectiveness of the planned intervention.

DISSEMINATION

The results of this study will be published in a peer-reviewed journal and presented at relevant national and international conferences. A summary of findings will be presented to key stakeholder groups. The findings will also underpin the planned implementation and trialling phase, which will be the subject of future related research.

Acknowledgements The study's concept and aspects of it have previously been presented in poster format at the American College of Rehabilitation Medicine conference in 2017 and are published as a conference abstract (Stavric *et al*, *Arch Phys Med Rehab* 2017;98:e170–e170).

Contributors Concept of the project was devised by all authors. VS wrote the first and subsequent drafts of this manuscript. NS and NMK contributed and commented on it. NS and NMK advised on the study design and data analysis. This manuscript has been read and approved by all authors. All persons listed as authors have contributed to preparing the manuscript and the ICMJE criteria for authorship have been met. No other person other than the authors listed have contributed significantly to its preparation. The content of this manuscript is our original work and has not been published in whole either prior to or simultaneously with our submission to BMJ Open.

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Appendix C

End User Consultation Committee-Burwood Academy for Independent Living

C/o - The Burwood Academy of
Independent Living,
Burwood Hospital,
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Christchurch,
New Zealand
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18th March 2015

Dear Ms Stavric,

Re proposal titled: Shoulder Pain Intervention delivered over the Net (SPIN) after Spinal Cord Injury (SCI).

Thank-you for submitting your research proposal to the Burwood Academy Consultation Committee. The Committee have read and discussed your research proposal and offer the feedback below. Your topic was considered very relevant and a really positive step towards potentially reducing the shoulder pain of persons with spinal cord injury.

The following suggestions are not mandatory and do not replace any issues highlighted by other ethical or cultural consultations that this research has been subject to. The Committee asks that you read the following suggestions in good faith and with an open mind.

Comments & suggestions:

- We wonder if the internet video will be a live communication, or a pre-recorded video that participants can access at a time convenient to them.
- We also wonder if you have considered that some participants (with higher level injuries) will need assistants to conduct any exercises, and whether this will impact on your current study design.
- Lastly, we understand that there may have been Melbourne and Brisbane based studies in the field of SCI research that have used internet-based video communication (sorry we can't provide more specific details). If any of your research team are aware of these studies, they may offer information regarding the barriers/facilitators to internet-based video interventions.

We wish you every success in your research and ask that you supply the Committee with a copy of the research findings upon completion.

Yours sincerely,

John Bourke
Chair
Burwood Academy Consultation Committee

Appendix D

Stakeholder Advisory Group role description

SPIN (Shoulder Pain Intervention over the internet) Study Role description – Stakeholder Advisory Group member

Composition of the Group

The stakeholder advisory group (SAG) will be made up of 4-6 representatives from each of the key advisory groups e.g. patients/clients, service providers, NGOs, technology and computer engineer and researcher.

Purpose of the Role

- Check that preliminary findings from each phase are well supported by data and resonate with personal insights and experience
- Make recommendations for the subsequent phases of the project
- Make recommendations for the ongoing refinement of the intervention

Person profile

A member of the stakeholder advisory group will fit one or more of the following criteria:

- a health care consumer: a person living with spinal cord impairment who has experience of using NZ healthcare systems and services.
- a key representative of an NGO offering support to people living with spinal cord impairment and their whanau/family.
- a healthcare provider with experience in the field of spinal cord impairment rehabilitation as a clinician.
- a computer engineer with knowledge and expertise on website design

Key responsibilities and duties

As a member of the knowledge user group you will be asked to attend a 1 hour meeting every 6 months until the end of the study (end of 2021). We anticipate there will be 8-10 meetings.

Meetings will be held on a day and time convenient to the majority of the group and will take place at a venue that is suitable and central to the majority of the group (e. g. Spinal Unit or AUT University, North Shore Campus).

You will be given a $20 contribution towards your travel costs.

Appendix E

Published manuscript: Systematic review and meta-analysis

frontiers | Frontiers in Rehabilitation Sciences

SYSTEMATIC REVIEW
published: 24 June 2022
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The Effectiveness of Self-Guided Digital Interventions to Improve Physical Activity and Exercise Outcomes for People With Chronic Conditions: A Systematic Review and Meta-Analysis

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Objective: The aim of this systematic review was to determine the effectiveness of self-guided digital physical activity (PA) and exercise interventions to improve physical activity and exercise (PA&E) outcomes for people living with chronic health conditions. Digital health interventions, especially those with minimal human contact, may offer a sustainable solution to accessing ongoing services and support for this population.

Methods: A comprehensive and systematic search was conducted up to December 2021, through seven databases, for randomized trials that evaluated the effect of self-guided web- or internet-based PA interventions on physical activity or exercise outcomes. Included studies had to have interventions with minimal human contact and interaction with participants needed to be automatically generated. All studies were screened for eligibility and relevant data were extracted. Two independent reviewers assessed the risk of bias using the Cochrane risk of bias tool. Standardized mean differences and 95% confidence intervals (CI) were calculated. PA data were pooled, and forest plots were generated.

Results: Sixteen studies met the eligibility criteria and included a total of 2,439 participants. There was wide variation in health conditions and intervention characteristics in mode and parameters of delivery, and in the application of theory and behavioral strategies. Self-reported PA in the intervention group was greater than controls at the end of the intervention [standardized mean difference (SMD) 0.2, 95% CI = 0.1, 0.3] and at follow up (SMD 0.3, 95% CI 0.2–0.5). The difference in objectively measured PA was small and non-significant (SMD 0.3, 95% CI −0.2 to 0.9). All interventions included behavioral strategies and ten of the sixteen were underpinned by theory.

Conclusions: Self-guided digital PA&E interventions provided a positive effect on PA immediately after the intervention. An unexpected and positive finding was a sustained increase in PA at follow-up, particularly for interventions where the behavioral strategies

were underpinned by a theoretical framework. Interventions with minimal contact have the potential to support sustained PA engagement at least as well as interventions with supervision.

Systematic Review Registration: https://www.crd.york.ac.uk/prospero/, identifier: CRD42019132464.

Keywords: physical activity, exercise, behavioral strategies, digital, self-guided, chronic conditions, systematic review and meta-analysis

INTRODUCTION

There is extensive evidence for the benefits of physical activity (PA) in managing chronic conditions given their impact on fitness, mobility and general health (1, 2). Interventions aiming to address physical inactivity do not appear to have been implemented in any meaningful way (3). This may in part be due to the limited availability of clinic-based, face-to-face interventions (4, 5) to address the unique needs of this population. Alternative methods of delivering PA and exercise (PA&E) interventions need to be explored.

Digital technologies and the internet offer a medium to deliver and support PA&E interventions. These can be defined as interventions that are delivered via a digital platform to support or encourage a person to perform PA or exercise, usually with the aims of improved health outcomes. They provide a mode of health care delivery for people who find standard care inaccessible due to physical, economic, or social barriers (6, 7). Advancements in technology and digital content have allowed the development of digital therapeutic interventions that encourage people to use them with minimal support. These interventions have minimal to no ongoing human involvement in their set up and can be delivered automatically. Applications, incorporating behavior change elements and persuasive features (8–11), can be incorporated into devices to offer interactive and personalized approaches (12).

Previous reviews have investigated the effectiveness of digital PA interventions in the general adult population and meta-analyses have demonstrated positive effects on PA (6, 13). However, people living with chronic health conditions face unique challenges accessing and undertaking PA and exercise. They express a desire for specialist knowledge; concern that exercising may exacerbate symptoms; and transport issues (7, 14–17). A previous review by Bossen and colleagues (18) investigated the use of web-based interventions with minimal human contact, designed to increase PA in people living with chronic health conditions. They reported mixed results with no clear conclusion.

Several factors mean that an updated review is warranted. First, all studies in the review by Bossen et al. (18) were published between 2005 and 2010. Innovations in technology and increasing acceptance of its use in therapeutic interactions have led to a change in the definition of minimal human contact. Second, the review did not include exercise-based interventions. Exercise is a subcategory of PA (19) and has proven benefits in many chronic health populations (20, 21). Therefore, in this review, our reporting of PA interventions will include exercise interventions. There has been no review to date investigating digital PA&E interventions that include behavioral intervention features, for people living with chronic health conditions, delivered with minimal human contact.

The aim of this systematic review was to determine the effectiveness of self-guided digital PA&E interventions to improve PA&E related outcomes for people living with chronic health conditions. A secondary aim was to determine key behavioral intervention features that were used in the selected studies.

METHODS

The protocol was registered with PROSPERO; CRD 42019132464. The review has been conducted and is reported following the guidelines of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement Moher et al. (22).

Eligibility Criteria

Papers were included if they met the criteria as outlined in **Table 1**.

The key elements in **Table 1** were used to devise the search strategy. Specifically, key terms were derived for "intervention" (digital exercise) and "study design" (randomized controlled trial). The search strategy did not include search terms for "population" and "outcome" to keep the reach as broad as possible. The criteria for population and outcome were applied during the screening process. Search terms were combined using Boolean, wildcard, truncation, and proximity searching. The search strategy was tailored to specific databases. **Table 2** shows the search conducted using an OVID database.

Databases

Literature searches were conducted in the following databases up until the end of December 2019. This was updated to include any new publications to the end of December 2021: Cumulated Index to Nursing and Allied Health Literature (CINAHL), MEDLINE, SPORTSDiscus through EBSCO Health Database, Allied and Complementary Medicine (AMED), Evidence Based Medicine (EBM) Reviews—Cochrane Methodology, EBM Reviews—Health Technology Assessment, PsycINFO, Ovid MEDLINE(R) through OVID, Scopus, clinicaltrials.gov, Cochrane Central Register of Controlled Trial (CENTRAL), and in Web of Science.

The PEDro database was searched (using simplified broad key terms). Reference lists of relevant reviews and articles were also hand searched.

Data Extraction

All citations returned in the search were downloaded and saved into EndNote X8. Duplicates were removed and then titles screened by VS, according to the pre-defined inclusion criteria. A selection of titles (the first 100) was independently screened by a second assessor (NS). Any disagreements were reviewed and discussed to ensure consensus was reached. A third assessor (NK) acted as arbitrator. Thereafter, VS and NS would meet after every 200 titles. There was high agreement as to which titles warranted further review. This process refined selection criteria. The abstracts and then full texts of studies identified as probably meeting the inclusion criteria were reviewed by VS in consultation with NS to confirm the final set of included studies.

TABLE 1 | Eligibility criteria of papers.

Elements	Inclusion criteria	Exclusion criteria
Study design and reporting		
	Randomized controlled trial (RCT) or pilot that contains data addressing effectiveness	Not in English Publication not peer-reviewed Conference proceeding
	Full text available	
	Published up to end of December 2021	
Population		
	Adults with a chronic condition defined as a human health condition or disease that is persistent or otherwise long-lasting in its effects (23)	Those at risk of developing a chronic condition Those caring for a person living with a chronic condition
Intervention		
	Designed for use by people living with a health condition	
	Explicitly supports physical activity or exercise in a self-guided program	
	Web-based or app-based	
	Intervention has minimal human contact comprising no more than initial contact for set up or orientation AND Any ongoing interaction with the program is generated automatically	
Outcome		
	Any physical activity or exercise related outcome that measures a body function, an activity or a participatory limitation as per the International Classification of Functioning, Disability and Health Framework (ICF) (24)	

TABLE 2 | Search concepts and terms using OVID.

	Search concept	Terms used as keyword OR title
#1	Digital physical activity or exercise	
		("world wide web" OR "web based" OR "web-based" OR website* OR "web site*" OR "web app*" OR internet OR online OR Ehealth OR "e-health" OR telemedicine OR telecare OR telehealth OR "tele-health" OR telerehab* OR "tele-rehab*" OR "digital health" OR mHealth OR "m-Health" OR "mobile health" OR "mobile app*" OR "smartphone app*" OR "digital intervention*") ADJ8 (exercis* OR rehab* OR physiotherapy* OR "physical therap*" OR "physical activ*" OR "fitness train*")
#2	Study design RCT	
		"Random* control*" OR RCT OR "control* trial*"
#3	#1 AND #2	

Key details from each of the included studies were recorded in a data extraction table in Excel. These included: author and country; participant numbers and characteristics; study design; treatment intervention parameters including duration, frequency, and follow up. The synthesis of findings from key papers in the area (25–29) were used to create a framework to guide data extraction and included: theoretical underpinning for the intervention; instruction on how to perform the PA or exercise; recording and tracking of PA or exercise; the use of goal setting; the use of action and coping planning; the type, use, and delivery of feedback and monitoring; the use and delivery of prompts; the use of any additional online PA or exercise resources; the use of PA or exercise testimonials; and the use of gamification. PA&E related outcome measures and results at the end of the intervention, and at follow up, if reported, were also recorded. If multiple impairment level outcomes were measured, only outcomes that have previously been shown to be correlated with the construct being measured (e.g., plantar flexion strength with walking) were extracted. For studies that were comparing more than two arms, data from arms comparing self-guided interventions to a control were included in the analysis.

Risk of Bias

Risk of bias for each of the included studies was categorized as low, having some concerns or high, drawing on the revised Cochrane risk-of-bias tool for randomized trials (RoB 2) (30). Initially, two studies were scored independently by two authors (VS, NK). Scores were compared and key points of disagreement were discussed, to improve interrater agreement on interpretation of the RoB 2 criteria. Following that, all included studies were independently assessed by both authors. Rates of agreement were calculated and are reported below. Disagreements were discussed to achieve consensus, with NS acting as arbitrator.

Data Synthesis

Data were narratively synthesized focusing on the characteristics of the studies and outcomes. Meta-analysis was conducted on all studies that used PA as an outcome. The PA outcome measures were categorized as self-report or instrumented, and the data from each were pooled separately for meta-analysis.

A summary of intervention effects for each study was obtained by calculating Hedge's g standardized mean differences (SMD)s, 95% confidence intervals (CI)s, standard deviations (SD)s and effect sizes (ES). The Hedge's g values were calculated from the post-intervention time points while accounting for the pre-intervention differences. A positive ES indicates a result in favor of the intervention and a negative in favor of the control. When insufficient data were available for analysis, study authors were contacted. If the data were not received or could not be computated from published material, it was not included in any further analysis and was noted as not reported (NR). If standard errors or confidence intervals were presented instead of standard deviations (SD), SDs were calculated using recommended formulae (31). When required, means and SD were approximated from figures using WebPlotDigitizer (32, 33).

Given the clinical heterogeneity of the included studies, both fixed effects and random-effects models were considered for pooling PA data. The extent of heterogeneity was determined using a hypothesis test based on generalized Cochran's Q-statistic (34). High heterogeneity was assumed when the Q-test coincided with a significant value ($p < 0.05$) (35) in which case, a random effects model was used. I^2 statistic was presented if the random effects model was chosen (36). Meta-analysis results were reported as pooled Hedge's g and 95% CIs. Hedges'g $\leq$0.2, $\geq$0.5, and $\geq$0.8 were interpreted as small, medium, or large, respectively (37). A CI which did not overlap zero was considered statistically significant. An intervention was interpreted as effective at improving a construct when the estimated effect size was positive and had a 95% CI which did not cross zero. A category of interventions was considered effective at improving a construct when the meta-analysis effect size was positive and had a 95% CI which did not cross zero. Forest plots were also generated for pooled data. Unpooled data were presented in table format, allowing comparisons between each outcome. Analyses were performed in R (38) using the metafor package (35). UR and VS contributed to and confirmed the synthesis of the extracted data. Discrepancies in data synthesis were discussed amongst the authors until consensus were reached, with NK and NS serving as arbitrators.

With respect to the secondary aim, given the diversity of intervention features, context, and population, it was not possible to make a direct link between intervention features and outcome. Therefore, key behavioral intervention features of included studies were recorded and tabulated.

RESULTS

Selection of Studies

A flow diagram of the identification, screening and selection of papers is presented in **Figure 1**. There was 98% agreement with the co-author (NS) during the screening phase, discrepancies were resolved by discussion. Following the full text review, 177 papers were excluded because they did not meet the a priori criteria (see **Supplementary File 1** for a table of excluded papers). Three papers required discussion with arbitrator (NK). Sixteen papers met the criteria and were included in the review with ten included in the meta-analysis.

Risk of Bias

The risk of bias assessment for included studies is available in **Supplementary File 2**. Agreement between reviewers was high (92%). Consensus was reached where there was discrepancy. Overall, no studies were assessed as having a low risk of bias. The majority were assessed as having some risk of bias (39–48), with the remaining five judged to be at high risk of bias in at least one domain (49–53). As shown in the weighted summary plot (**Figure 2**), this could be attributed to having potential bias in the selection of reported results. Many studies did not have a published protocol, making it difficult to determine if analyses were carried out according to a pre-specified plan. Studies were also at risk of bias due to outcomes of interest being self-reported by participants who were unblinded to intervention status. Missing outcome data (for example, participants lost to follow up) also contributed to the bias.

Characteristics of Selected Studies

Included papers were published between 2013 and December 2021 (end of collection period). Publications in this research area have been increasing recently with half published in the last 2 years (40, 44–46, 51–54). Studies were conducted in Germany (41, 44), the Netherlands (39, 45), the United Kingdom (49, 54), Korea (42, 52), Australia (40), Brazil (48), Canada (53), China (47), Hong Kong (46), New Zealand (43), Norway (50), and the United States (51).

Interventions were compared to usual care or wait list groups in six studies (39, 41, 43, 46, 49, 54), to paper based interventions in four studies (42, 44, 47, 48), to another form of online intervention in three studies (40, 52, 53) and to a supervised intervention (50). One study used the intervention of interest (minimal contact self-guided intervention) as the comparison group when testing versions of online and blended interventions (51). **Table 3** contains characteristics of the included studies.

Characteristics of Participants

Participants were recruited from primary health care, community settings and online databases. The number of participants within studies ranged from 24 to 438, with a combined total of 2,439 participants across studies (median $n = 93$). The average age of participants across studies was 57.1 years with the mean age range from 43 to 67 years. Participants presented with the following chronic conditions: breast cancer (40, 42, 50), dizziness and vestibular syndrome (54, 55), heart disease (43, 46), chronic obstructive pulmonary disease (49, 52), fibromyalgia (48), hypertension (53), inflammatory rheumatic diseases (50), metabolic syndrome (47), progressive multiple sclerosis (44), osteoarthritis (39), and venous leg ulcers (51). **Table 3** provides details for all included studies.

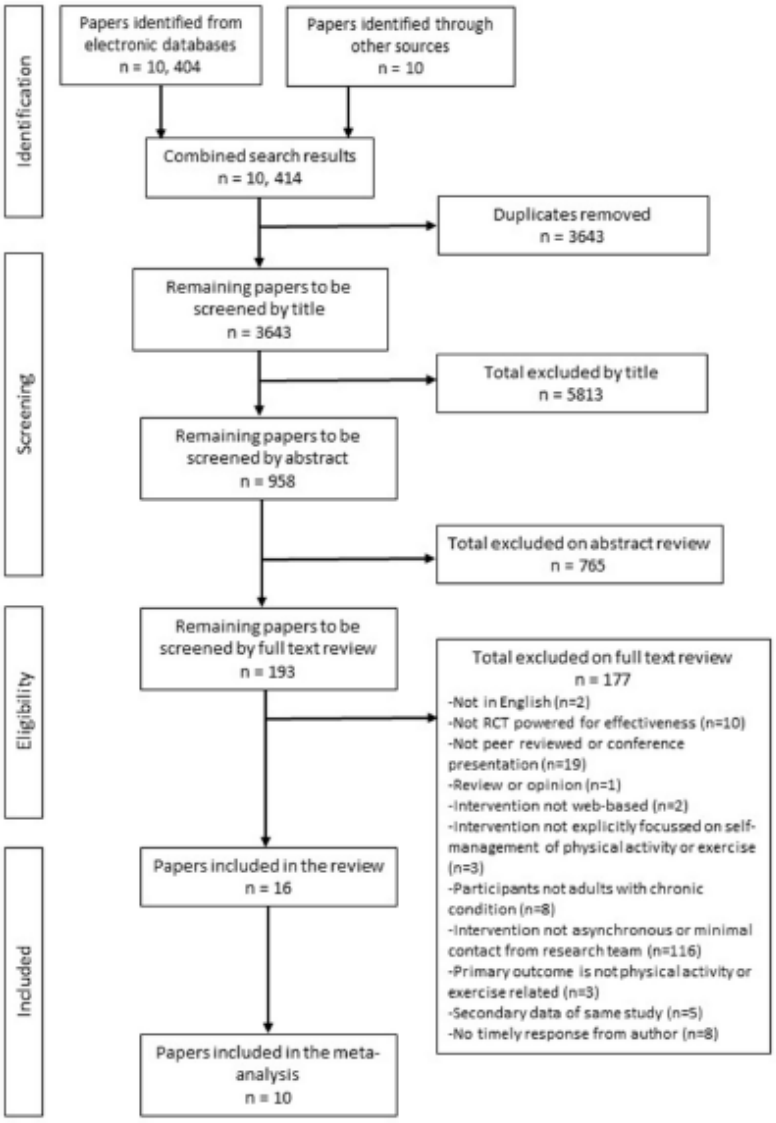

FIGURE 1 | Flow chart summarizing the study selection process.

Outcome Measures

Outcomes of interest were those related to the PA or exercise interventions that measured an activity or body function (24). These were grouped into change in PA that was self-reported and change in PA that was measured by instrumentation. Changes in body functions and symptoms were also reported. Change in PA was meta-analyzed in ten of the included studies. This was measured using self-reported questionnaires (39–44, 46, 47) and instrumented devices (accelerometers, pedometers or wearable devices) (39, 44, 49, 53). The remaining relevant outcomes varied considerably among studies. Therefore, they were broadly grouped, as per the ICF framework (24), into change in body functions and symptoms and included measures such as walking endurance, measured by the 6-min walk test (44, 51, 52), strength (44, 51), vestibular symptoms (54, 55), peak oxygen uptake (43, 50), pain (48), foot and ankle mobility (51), dyspnea (49, 52), and range of motion (48, 49, 51–53). Self-reports of perceived effect and self-efficacy of exercise were also measured (39, 46,

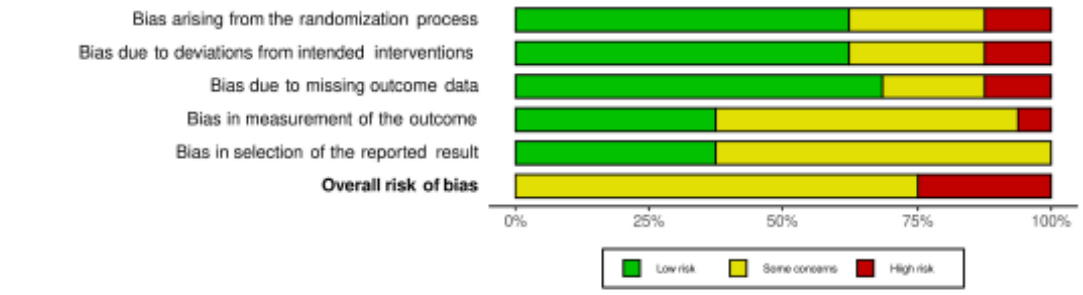

FIGURE 2 | Weighted summary plot of the overall type of bias encountered in the included studies.

47). Bossen et al. (39) and Kwon et al. (52) used the Knee Osteoarthritis Outcome Score and Hip Osteoarthritis Outcome Score. These measure symptoms, activities of daily living and quality of life; the scoring of each outcome precludes the ability to report these constructs separately.

Characteristics of the Interventions

Modes of Delivery

There were a variety of modes of delivery and technologies used across interventions. Eleven of the interventions involved computers (39–43, 46, 49, 52–55). Mobile or smartphones were used in nine studies (41–44, 47, 48, 50–52). Almost half the studies were testing a website specific to the study (39, 41–43, 46, 54, 55) while three used existing platforms (40, 52, 53). Applications specifically designed for the study were used in seven studies and involved a smartphone or computer (44, 47–52). Communication with participants was carried out via automated email (39, 46, 49, 53–55), automated SMS text messaging (41–43) or the study app features (47, 48, 50–52). Biosensors were used in five studies (39, 43, 49, 51, 52).

Parameters of Intervention Delivery

Table 3 provides details on key intervention parameters. Intervention duration ranged from a one-off session to 24 weeks. The expected frequency of the exercise or PA&E performance varied. This ranged from a one-off instructional session (40) to asking participants to participate repeatedly throughout the day (51, 54, 55), once daily (44, 49, 52), several times a week (42, 43, 46, 50, 53), or as determined by the participant (39, 41, 52).

Theoretical Basis

Just over half of the included studies reported using theory to inform their interventions, with three referencing more than one theory. The transtheoretical model was the most frequently cited (40, 42, 53). Self-regulatory theory, cognitive behavioral theory, social cognitive theory, exposure-based behavior principles, implementation-intention-based principles, health belief model and operant behavior principles were also each used once (39–41, 43, 46, 47, 54, 55). No underpinning theory was reported for six of the self-guided interventions (44, 48–52).

Behavioral Intervention Strategies

The interventions used a combination of behavioral strategies and features to support PA&E behavior (see **Table 4**). A commonly used feature was instruction on how to perform the PA or exercise ($n = 14$). Variations included generalized automated PA or exercise information, tailored exercise provision, and tracking and recording of PA or exercise performed. The use of feedback and monitoring ($n = 13$) was also used in most interventions. Other strategies involved goal setting ($n = 11$) and the use of prompting features ($n = 10$). Fewer than half the interventions incorporated action and coping plans ($n = 5$), online resources of supplemental PA or exercise information ($n = 4$) or testimonials or case studies ($n = 5$). None of the included studies used gamification approaches. Most interventions employed several strategies concurrently.

Effectiveness of Interventions

Effectiveness was measured by change in PA&E and change in body function and symptoms. These were defined and measured in a variety of ways.

Physical Activity

Change in self-reported PA was the outcome of interest in eight of the included studies (39, 41–44, 46, 47). **Figure 3** details the Hedge's g between group difference, with 95% CI, at the earlier assessment point, taken at the end of intervention (which ranged from 4 to 24 weeks). The Hedge's g between groups favored the intervention group with a small, estimated effect of 0.2 [95% CI (0.1, 0.3)].

Four of these studies (39, 40, 46, 47) continued to measure self-reported PA at a follow up point (12–52 weeks from the end of intervention). Pooled results (39, 40, 46, 47), demonstrate the effect of the intervention. The Hedge's g between groups continued to favor the intervention with an increased estimated effect [Hedge's g 0.3, 95% CI (0.2, 0.5)] (see **Figure 4**).

Change in PA, measured by instruments such as accelerometers or pedometers was described in four studies (39, 44, 49, 53). The Hedge's g between groups and 95% CI at the completion of the intervention are displayed in **Figure 5**. The small treatment effect on PA was in favor of the intervention group (Hedge's g 0.3) but the CI crossed the no effect line [95% CI (−0.2, 0.9)] and heterogeneity was 77.7%.

TABLE 3 | Characteristics of the randomized controlled trials, participants, and interventions.

References, country	Inclusion criteria	Sample size (*n*) mean age (yr) females (F) males (M)	Intervention details and use of theory	Comparison	Outcomes of interest	Intervention duration (D) Frequency of delivery (F) Intended frequency of exercise (E)
Bossen et al. (39) Netherlands	**Self-report OA knee/hip**, 50–75 yrs, self-report inactivity, no treatment in last 6 months, no contra-indications to exercise Internet access	*n* = 199 Age = 62 yrs F = 129 M = 70	Eight weekly modules of Behavioral Graded Activity (Join 2 move) of participant's identified favorite activity. Automatically increased depending on answers from pain and performance scale. Intervention based on operant behavior principles with aim of increasing PA.	Wait list	PA (self-reported) via PASE PA (Instrumented) via ActiGraph GT3X accelerometer KOOS/HOOS Self-perceived effect	D = 9 weeks F = 1 x week E = determined by users
Chapman et al. (40) Australia	**Breast cancer** survivors, ≥18 yrs, completed treatment, no contra-indications to exercise	*n* = 101 Age = 59.1 yrs F = 101	Online volitional help sheet (VHS) which presents most likely barriers to PA. Participants prompted to select possible coping strategies to be more equipped if situation arises. Intervention based on TTM and Implementation-Intention with aim of increasing PA.	Online standard implementation intention version that presents most likely PA barrier scenarios but requires participant to self-generate possible coping strategies.	PA (self-reported) via GSLTPAS to determine moderate PA: LSI-MSPA	Once off intervention E = not applicable
Crooks et al. (49) UK	**COPD,** 40–80 yrs, FEV_1 >50% and FEV_1/FVC <70% predicted or COPD diagnosis within 12 months, current or ex-smoker, Internet access, able to use web platform in English	*n* = 60 Age = 66.1 yrs F = 29 M = 31	myCOPD online application and tile platform covering variety of self-management topics. Users able to input data for more tailored advice. Intervention not based on theory. Aims to improve areas of body structure and function and activity.	Usual COPD management for study duration. After study completion, offered app access.	CAT 7-day step count via Fitbit at baseline and at completion	D = 12 weeks F = variable, some expected daily (like exercise related content) others every few weeks E = unclear, likely daily
Geraghty et al. (54) United Kingdom	**Dizziness** lasting 2 yrs made worse with head movement, ≥50 yrs, access to Internet	*n* = 296 Age = 67.4 yrs F = 197 M = 99	Six-week balance retraining, rehabilitation, adaptation, and habituation program on improving symptoms. Includes head movements to promote reduction of movement provoking dizziness and reduce avoidance behaviors. Intervention based on SRT, CBT.	Standard non-web-based care consisting of reassurance, symptomatic relief with or without educational information.	Symptom severity via VSS-SF	D = 6 weeks F = 1 × week E = 2 × day × 10 min
Haglo et al. (50) Norway	**Inflammatory rheumatic diseases,** ≥18 yrs, diagnosed with either RA, SpA, SLE, not familiar with HIIT	*n* = 40 Age = 49 yrs F = 23 M = 17	Myworkout GO smartphone app to guide and deliver 4 × 4 min HIIT at a % of HR max. App provides display of progression and	Supervised 4 × 4 HIIT	VO_2 max via Metamax II	D = 10 weeks F = 2 × week E = 2 × week

(Continued)

TABLE 3 | Continued

References, country	Inclusion criteria	Sample size (*n*) mean age (yr) females (F) males (M)	Intervention details and use of theory	Comparison	Outcomes of interest	Intervention duration (D) Frequency of delivery (F) Intended frequency of exercise (E)
			estimation of work performed automated scheduled next exercise time. Intervention not based on behavioral theory. Aims to improve areas of body structure and function and activity.			
Holtdirk et al. (41) Germany	**Breast cancer** survivors, 30–70 yrs, diagnosis <5 yrs ago, completed acute treatment >1 month prior to study entry with discharge letter proof, able to speak and read German	*n* = 383 Age = 49.9 yrs	Sixteen multimodal web-based modules that registered users can select and work through. Subsequent content is continuously tailored based on user response. Daily text messages remind and motivate users to use the program. Intervention is based on CBT.	Usual care and wait list of 3 months for access to the intervention.	PA (self-reported) via IPAQ	D = 12 weeks F and E= self-paced
Kelechi et al. (51) United States	**Venous leg ulcers**, ≥18 yrs, impaired mobility resulting in inability to walk 100 feet without resting, no current PA, requiring wound care, no arterial insufficiency, able to don the slipper to which BEAT accelero-meter is affixed	*n* = 24 Age = 64.9 yrs F = 14 M = 10	COMPARISON Six-week progressive exercise intervention delivered through app (FOOTFIT). Non-exertional exercises (Conditioning physical Activities for lower Leg Function-CALF) tracked with Bluetooth Enabled triaxial Accelerometer Tracking (BEAT). Intervention not based on theory. Aims to improve areas of body structure and function and activity.	INTERVEN-TION FOOTFIT+ is FOOTFIT, CALF and BEAT with added phone, email, or text messaging connectivity to wound care providers. Intervention not based on theory. Aims to improve areas of body structure and function and activity.	ROM of ankle Strength of ankle FAAM 6 MWT	D = 6 weeks F = all at once E = 3 × day × 15 s progressed every 2 weeks
Kwon et al. (52) Korea	**COPD**, ≥20 yrs, FEV <80%, >150 m in 6 MWT, Android smart-phone user	*n* = 85 Age = 64.3 yrs F = 15 M = 70	efit breath fixed-interactive app uses participant data from baseline and current exertion level feedback to tailor walking prescription. Intervention not based on theory. Aims to improve areas of body structure and function and activity.	efit breath fixed app uses pre-determined walking distances and progresses when participant achieves certain targets and usual care with no app.	6 MWT CAT mMRC	D = 12 weeks F = daily E = 7 × week × 30 min
Lee et al. (42) Korea	**Breast cancer** survivors, hemoglobin over 10 g/dl, not meeting exercise or healthy eating goals, access to computer, home Internet, mobile phone user	*n* = 57 Age = 42.4 yrs F = 57	Health Planner 5 portions: assessment that leads to tailored plan for each participant: education (tailored info provision), action planning (goal setting, scheduling, keeping a diary), automatic (tailored) feedback. Intervention based on TTM with aim of increasing PA.	50-page educational booklet on exercise and diet.	PA (self-reported) via 7-day exercise diary (minutes per week ≥4 METs)	D = 12 weeks F = 2 × week E = 5 × week × 30 min

(Continued)

TABLE 3 | Continued

References, country	Inclusion criteria	Sample size (*n*) mean age (yr) females (F) males (M)	Intervention details and use of theory	Comparison	Outcomes of interest	Intervention duration (D) Frequency of delivery (F) Intended frequency of exercise (E)
Liu et al. (53) Canada	**HTN** (stage 1 or 2), 35–74 yrs, stable meds before enrolment, if on antihypertensives: SBP 130 and DBP 85	*n* = 128 Age = 56.9 yrs F = 61 M = 67	Automated e-counseling: Participant identifies areas to address and is provided with pre-determined expert driven suggestions which are informed by foundation questionnaire. Intervention based on TTM with aim of increasing PA.	Automated e-counseling: Participant identifies areas to address but is self-reliant (user-driven) for suggestions and Control group	SBP PA (instrumented) via daily step count via XL-18CN pedometer	D = 16 weeks F = 1 × week E = 5 × week × 30 min
Maddison et al. (43) New Zealand	**IHD**, ≥ 18 years, clinically stable, able to perform exercise, able to understand and write English, access to internet.	*n* = 171 Age = 60.2 yrs F = 32 M = 139	Personalized, automated package of text messages via mobile phones aimed at increasing exercise behavior. Intervention based on SET with aim of increasing PA.	Usual care	Peak VO_2 via Moxus PA via IPAQ	D = 24 weeks F = 6 × week E = 5 × week × 30 min
Nasseri et al. (44) Germany	Progressive **MS**, 18–60 yrs, EDSS below 6.5	*n* = 38 Age = 51.1 yrs F = 19 M = 19	12-week app-based information package on exercise including text, figures, videos and accelerometery activity feedback. Intervention not based on theory. Aims to improve areas of body structure and function and activity.	Paper based leaflet with information on generalized exercise.	6MWT 5xSTS PA (self-reported) via GSLTPAS to determine moderate PA: LSI-MSPA PA (instrumented) via Actigraph accelerometer	D = 12 weeks F = not specified but assumed delivered all at one time E = not specified but assumed daily
Van Vugt et al. (45) Netherlands	**Dizziness** ≥1 month and ↑ with head movement, ≥ 50 yrs, Dutch speaker, access to internet and email	*n* = 322 Age = 67 yrs F = 197 M = 125	Six-week stand-alone online vestibular rehab (VR)-adaptation, habituation with relaxing, cognitive restructuring, engagement features. Intervention based on CBT, SET, exposure-based behavior.	Usual care with no VR	Symptom severity via VSS-SF	D = 6 weeks F = 1 × week E = 2 × day × 10 min
Wong et al. (46) Hong Kong	**CHD**, ethnic Chinese 45–65 yrs, regular treatment for CHD, able to use internet at home	*n* = 438 Age = 52.3 yrs F = 149 M = 289	eHES website representing constructs such as "cues to action" and "enhancing self-efficacy" that allow self-monitoring of individual health and exercise. Intervention based on HBM.	Usual care including routine medical visits and a paper based educational leaflet.	PA (self-reported) via GSLTPAS. Self-efficacy for exercise	D = 24 weeks F = not specified but assumed delivered all at once E = 5 × week × 30 min
Wong et al. (47) China	**Metabolic Syndrome**,>50 yrs, ethnic Chinese, had MetS as defined by waist circumference, triglycerides, HDL, BP and fasting plasma glucose measures, own smartphone access	*n* = 77 Age = 58 yrs F = 43 M = 43	MetS app to support initiation and maintenance of healthy behaviors relating to monitoring weight, diet, and exercise. Intervention based on HBM.	Booklet providing MetS management information.	PA (self-reported) via GSLTPAS. Self-efficacy for exercise	D = 12 weeks F = not reported E = 5 × week × 30 min

(Continued)

TABLE 3 | Continued

References, country	Inclusion criteria	Sample size (n) mean age (yr) females (F) males (M)	Intervention details and use of theory	Comparison	Outcomes of interest	Intervention duration (D) Frequency of delivery (F) Intended frequency of exercise (E)
Yuan et al. (48) Brazil	**Fibromyalgia**, 19–59 yrs, diagnosis by American College Rheumatology diagnostic criteria, smartphone user, completed elementary school education	$n = 40$ Age = 43 F = 39 M = 1	ProFibro App providing self-management through animation, self-monitoring, family adjustment, sleep hygiene scheduling, graded exercise, hints through notifications. Intervention not based on theory. Aims to improve areas of body structure and function and activity.	64-page booklet to replicate app.	Pain via WPI. Pain via VAS. Symptom severity via SS	D = 6 weeks F = not reported E = not reported

2 MWT 2 min walk test, 4 MET moderate aerobic exercise that consumed at least 3.5 mlVO_2/kg/min or ≥ 150 min/week; 5 STS five time sit to stand; 6 MWT 6 min walk test, app application; AROM, active range of motion; BP, blood pressure; CAT, COPD assessment test; CBT, cognitive behavioral theory; CHD, Coronary heart disease; COPD, chronic obstructive pulmonary disease; DASH, Disabilities of the Arm; Shoulder and Hand; EDSS, Extended Disability Severity Scale, ext extension; FAAM, Foot and Ankle Mobility Measure; g/dl grams per decalitre; GP, general practitioner; GSLTPA, Godin-Shephard Leisure-Time Physical Activity Score; HBM, health belief model; HOOS, Hip Osteoarthritis Outcome Score; HTN, hypertension; IHD, ischemic heart disease; IPAQ-LF, International Physical Activity Questionnaire-Long Form; Kg Kilogram; KOOS, Knee Osteoarthritis Outcome Score; LSI-MSPA, Leisure Score Index of moderate-strenuous exercise; m meters; MET, metabolic equivalent; mMRC, Modified Medical Research Council Dyspnea Scale; MS, Multiple Sclerosis; OA, osteoarthritis; op operative; OT, occupational therapy; PA, physical activity; PASE, Physical Activity Scale for the Elderly; prn as deemed appropriate; RCT, randomized controlled trial; ROM, range of motion; SBP, systolic blood pressure; SET, self-efficacy theory; SRT, self-regulatory theory; TTM, transtheoretical model; VO_2, maximum rate of oxygen consumption; VR, virtual reality; VSS-SF, vestibular symptom scale-short form, yrs years.

Body Functions and Symptoms

Meta-analysis was not conducted on outcomes related to body functions and symptoms due to the high heterogeneity of measures employed. There was variation in the size of effect and statistical significance across the studies. Refer to **Supplementary File 3** for details of each study, the extracted outcome measures, assessment points, mean group differences and estimated effects. Despite studies showing some risk of bias, there are some results that were of note. Effects (Hedge's g 0.3–0.8) were reported in two separate studies evaluating 6-week vestibular interventions at the 12- and 24-week post intervention time points (54, 55). Both interventions had a theoretical basis and incorporated several behavioral strategies. There was also evidence of a small positive effect of graded-activity on physical function at 12 weeks [Hedge's g 0.4, 95% CI (0.1, 0.7)] but not at the 52-week follow up in a 9-week PA intervention for people with knee and hip OA (39). Self-perceived effect and exercise self-efficacy were measured in two studies (39, 47). A moderate effect [Hedge's g 0.6, 95% CI (0.3, 0.9)] was noted for self-perceived effect after the 9-week PA intervention. Similarly, a moderate effect was seen in self-efficacy for exercise [Hedge's g 0.5, 95% CI (0.1, 1)] at the end of a 4-week intervention and maintained [Hedge's g 0.6, 95% CI (0.2, 1.2)] at the 12 week follow up. Theoretical underpinnings and behavioral features were also incorporated in these interventions. Studies that did not have a theoretical basis did not report any effects.

When looking across study exercise parameters, there was a large variation in dosage (amount x frequency x duration) of prescribed exercise. There did not appear to be a clear relationship between dosage and effect.

DISCUSSION

Principle Findings

This is the first systematic review to conduct a meta-analysis of outcomes following self-guided digital PA&E interventions in people living with chronic conditions. This work advances the evidence in digital interventions for PA&E. The more stringent inclusion criteria for minimal contact used in this review meant that none of the studies in the review by Bossen and colleagues (18) met the threshold to be included.

The findings of our review indicate a positive effect of self-guided digital interventions on PA that were seen at the end of intervention and sustained at follow up, for people living with chronic health conditions. These findings differ from the findings of Bossen and colleagues of conflicting evidence on the effectiveness of web-based PA interventions in this population (18). Our findings reflect the developments in technology that have enabled persuasive and engaging elements to be embedded into digital interventions (56, 57). These may help overcome some of problems of low uptake and adherence (58).

There was a small but significant effect seen with self-reported PA at the end of interventions. Direito and colleagues (9), investigating the effect of mHealth technologies on self-reported PA in healthy participants, found a comparable effect that was not significant. Kwan et al.'s (59) review of eHealth interventions promoting PA in older adults found that self-report PA was significantly increased compared with the control groups. However, since the interventions in both reviews included contact and personal consultation, a cautious approach to comparison is needed.

TABLE 4 | Behavioral intervention features and strategies used.

References, Country	Instruction on how to perform PA or exercise	Use of feedback and monitoring in PA or exercise	Use of goal setting for PA or exercise	Use of prompts for PA or exercising	Use of action and coping plans for PA or exercise	Use of online resources for additional PA or exercising	Use of testimonials in benefits of PA or exercise	Use of gamification to encourage PA or exercise
Bossen et al. (39) Netherlands	✓	✓	✓	✓		✓		
Chapman et al. (40) Australia			✓		✓			
Crooks et al. (49) UK						✓		
Geraghty et al. (54) United Kingdom	✓	✓	✓				✓	
Haglo et al. (50) Norway	✓	✓	✓	✓				
Holtdirk et al. (41) Germany	✓	✓	✓	✓	✓		✓	
Kelechi et al. (51) United States	✓	✓		✓				
Kwon et al. (52) Korea	✓	✓	✓					
Lee et al. (42) Korea	✓	✓	✓	✓	✓			
Liu et al. (53) Canada	✓	✓	✓	✓	✓			
Maddison et al. (43) New Zealand	✓	✓	✓	✓	✓	✓	✓	
Nasseri et al. (44) Germany	✓	✓					✓	
Van Vugt et al. (45) Netherlands	✓		✓	✓		✓	✓	
Wong et al. (46) Hong Kong	✓	✓		✓				
Wong et al. (47) China	✓	✓	✓					
Yuan et al. (48) Brazil	✓	✓		✓				

Objectively measured change in PA in the current review showed a small effect that was not significant. This has also been reported by others (9, 60) who have found insignificant effects favoring mobile and app-based interventions that were not strictly self-guided. There is an assumption that objective PA measures more accurately reflect actual changes in PA. However, Kayes and McPherson (61) argue measurement tools such as accelerometers and pedometers have not always been validated in people living with chronic health conditions. Despite significant advances in the objective measurement of PA in these populations, questions remain regarding the validity and reliability of these devices in some groups, such as people with slow walking speeds or those with higher levels of disability (62, 63).

Our findings of sustained PA improvement beyond the intervention, is in contrast with previous work. In-person PA interventions have been shown to increase PA levels in the short to medium term (7 weeks to 1 year) but not in the long term (at or over 1 year), in community dwelling adults with or without a long-term health condition (64, 65). Our findings are supported by Davies et al. (8) who conducted a review of web-based PA interventions and found an overall small but significant mean effect of sustained PA when looking at a follow up of at least 6 months after the intervention. Regardless of the length of follow up, the persistence of change seen, despite the removal of intervention, is encouraging.

The prolonged effect observed in some studies may be linked to the use of behavioral strategies in the interventions. The most common intervention strategies and features used were instructions on how to perform the PA or exercise, goal setting, and the use of feedback and monitoring. These align with the behavior change techniques (BCT) taxonomy clusters proposed by Michie and colleagues (27). The self-guided interventions with the larger effect sizes employed strategies from at least three of these clusters (39, 42, 46, 53–55). This finding is supported by research showing that the use of techniques from three BCT clusters are needed to produce effects on PA in face-to-face interventions (66, 67). For self-guided digital interventions, employing self-regulatory techniques may be the most effective way to support PA engagement (28, 29, 68). Michie et al. (68) found that interventions combining self-monitoring (using feedback) in combination with other features

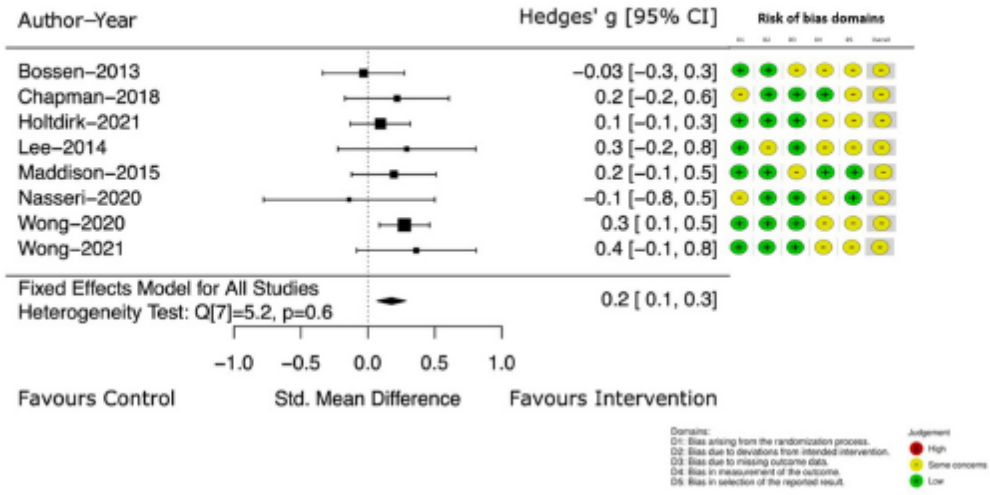

FIGURE 3 | Self-reported PA at end of intervention.

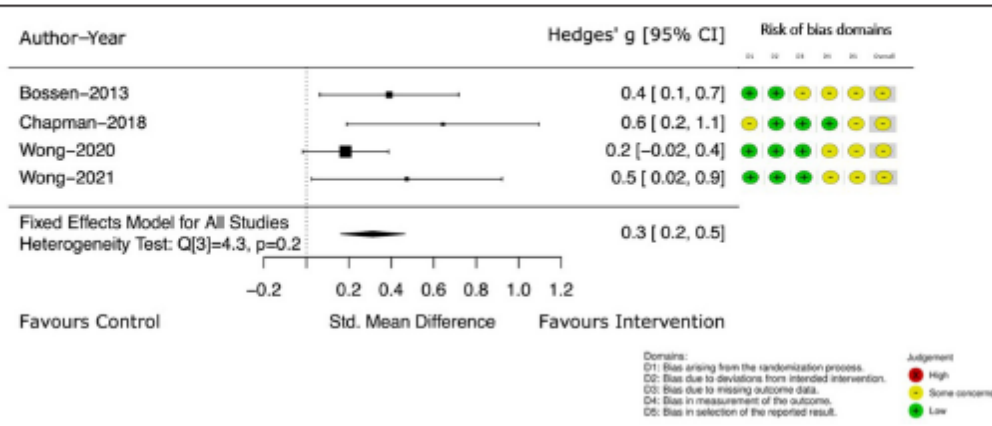

FIGURE 4 | Self-reported PA at follow up.

that encouraged self-regulation (goal setting, action and coping plans) were more likely to lead to intervention effectiveness (69). These strategies can influence behavior *via* mechanisms such as problem-solving, promoting self-efficacy or diminishing the impact of barriers to behavior change (70). They may also address the intention behavior gap (71). In this review, fewer than half the interventions reviewed used action and coping plans or other strategies that promote self-regulation. The lack of theoretical underpinning found in many of the studies may help explain their choice of intervention features and non-significant results. While we did not explicitly set out to determine the effectiveness of behavioral features, interventions that were effective did include behavioral features. Determining which specific features might best be implemented to support sustained use and engagement with self-guided interventions would be a future research direction.

The lack of an apparent relationship between exercise dose and effect suggests that the prescribed dose may be only one factor of an intervention that influences participant outcomes. The behavioral strategies embedded in the interventions influence exercise completion and, therefore, are an important factor in the reported interventions. The lack of reporting of exercise completion makes it difficult to appreciate how these factors contribute to outcome.

Strengths and Limitations

This review focused on investigating the effect of digital self-guided interventions on PA&E and fills a gap in the

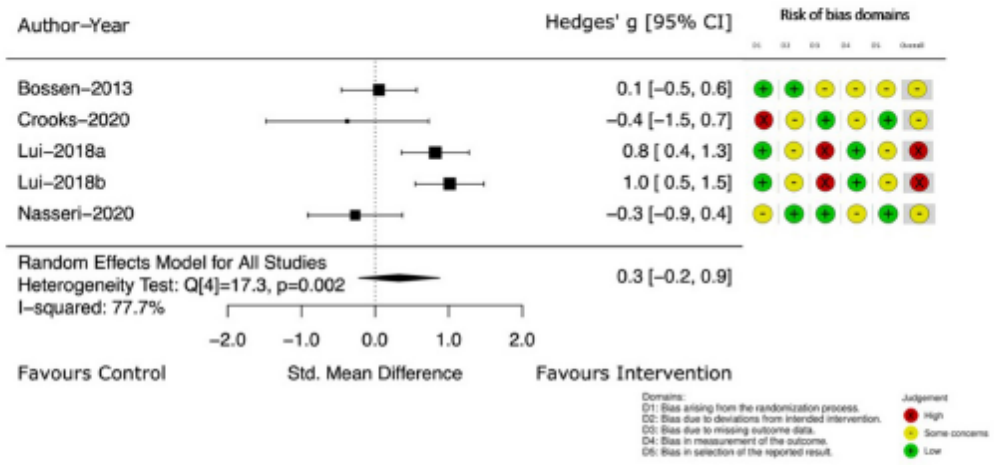

FIGURE 5 | Instrumented measurement of PA at end of intervention.

literature in this growing area. We included all forms of digital interventions that could be delivered remotely, without ongoing human interaction. The comprehensive search, using several databases, identified studies previously not included in similar reviews, and the broad range of outcomes make the findings generalizable to a wider range of populations, interventions, and environments. We identified behavioral strategies using well-established frameworks (27) that allows for transparency and a clear understanding of intervention features that may help to explain reported effects. This review has also reported metrics for discrete end of intervention and follow up outcomes and meta-analyses for PA outcomes for self-guided digital PA interventions for people living with chronic conditions.

People living with chronic conditions face additional challenges in undertaking PA&E compared to a healthy population. Acknowledgment of the inherent heterogeneity that comes with each health conditions should sit alongside any the generalization of these findings, particularly when a significant portion of the people included in this review were living with cardiorespiratory, neurological or oncology conditions and were under the age of 60. Despite this, there is much we can learn by looking across populations, particularly when those populations share characteristics beyond diagnosis such as chronicity and complex barriers to engagement with PA&E.

To be included in the review, papers needed to have been peer reviewed to address the question of effectiveness, which may have introduced publication bias. Other criteria were that interactions with the intervention had to be automatically generated. Screening of the papers for this criterion was not straightforward due to the lack of a standard definition of what constitutes minimal contact. We selected papers based on our operational definition and consequently many interesting and valuable digital PA&E interventions were excluded. For included papers, data were frequently incompletely or inconsistently reported, and some were analyzed as intention to treat while others were not. This made analysis of the results difficult and necessitated computation using reported data. The wide variation in health-related body function and symptoms outcomes prevented us from pooling this data. Therefore, we synthesized the results in a way that allowed the magnitude and range of effects to be appreciated.

The studies included in this review demonstrated some or high risk of bias and so findings should be interpreted with caution. The nature of the minimal contact digital intervention creates increased opportunities for bias with attrition, and the reporting of outcomes remotely.

Future Recommendations

Future work should continue to investigate which intervention features and exercise parameters lead to the best effect. Effort should continue to ensure complete reporting of the intervention, the behavioral interventions used, and treatment fidelity, including recording the participant's completion of the prescribed dose. Authors also need to ensure that adverse events are explicitly sought and consistently reported. This was not the case in many of the studies included in the current review. For interventions that are self-directed and have minimal contact with health professionals, understanding intervention safety is an important component of the trialing phase.

The proportion of participants lost to follow up in the studies in this review demonstrates that maintaining engagement with low contact digital interventions is challenging (72, 73). Given the added barriers experienced by these people (74), tailoring the intervention to the individual needs to be considered and addressed (75).

Researchers are encouraged to broaden the scope of populations involved in this type of research. For the current review, the population of interest focused on people living with

chronic conditions that included a range of non-communicable diseases. Of note was the lack of studies involving people living with disabilities, a large group who also would benefit from self-guided and digital interventions. Finally, the participant's voice is notably absent from much of this research.

Our research group is currently exploring many of these areas. For example, we are applying an interpretive descriptive study design to explore what makes a self-guided digital intervention more acceptable to users, with the aim of developing interventions which increase uptake and engagement (76). The findings from this current review and the interpretive descriptive study will inform our development a self-guided digital intervention to help treat shoulder pain for people living with spinal cord injury (76).

CONCLUSION

This review found a positive effect in favor of self-guided digital PA&E interventions on PA outcomes and a selected number of body functions and impairments at the end of intervention and at follow up, in people living with chronic conditions. Interventions that employ behavioral strategies, underpinned by a theoretical framework, have the potential to support self-regulation and sustained PA at least as well as interventions with supervision.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/**Supplementary Material**, further inquiries can be directed to the corresponding author.

AUTHOR CONTRIBUTIONS

VS, NK, and NS contributed to conception, design of the study, and analyzed intervention features. VS performed the initial search and organized the database. VS and NS reviewed study selection. VS and NK analyzed risk of bias of selected studies. UR provided statistical support. All authors read and approved the final manuscript.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fresc.2022.925620/full#supplementary-material

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Appendix F

Prospero registration

PROSPERO
International prospective register of systematic reviews

NHS National Institute for Health Research

UNIVERSITY of York
Centre for Reviews and Dissemination

Systematic review

1. * Review title.

Give the working title of the review, for example the one used for obtaining funding. Ideally the title should state succinctly the interventions or exposures being reviewed and the associated health or social problems. Where appropriate, the title should use the PI(E)COS structure to contain information on the Participants, Intervention (or Exposure) and Comparison groups, the Outcomes to be measured and Study designs to be included.

The effectiveness of self-guided web-based exercise interventions for people living with chronic conditions: a systematic review

2. Original language title.

For reviews in languages other than English, this field should be used to enter the title in the language of the review. This will be displayed together with the English language title.

3. * Anticipated or actual start date.

Give the date when the systematic review commenced, or is expected to commence.

04/04/2019

4. * Anticipated completion date.

Give the date by which the review is expected to be completed.

20/12/2019

5. * Stage of review at time of this submission.

Indicate the stage of progress of the review by ticking the relevant Started and Completed boxes. Additional information may be added in the free text box provided.
Please note: Reviews that have progressed beyond the point of completing data extraction at the time of initial registration are not eligible for inclusion in PROSPERO. Should evidence of incorrect status and/or completion date being supplied at the time of submission come to light, the content of the PROSPERO record will be removed leaving only the title and named contact details and a statement that inaccuracies in the stage of the review date had been identified.
This field should be updated when any amendments are made to a published record and on completion and publication of the review. If this field was pre-populated from the initial screening questions then you are not able to edit it until the record is published.

The review has not yet started: No

PROSPERO
International prospective register of systematic reviews

NHS National Institute for Health Research

Review stage	Started	Completed
Preliminary searches	Yes	No
Piloting of the study selection process	Yes	Yes
Formal screening of search results against eligibility criteria	Yes	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

Provide any other relevant information about the stage of the review here (e.g. Funded proposal, protocol not yet finalised).

6. * Named contact.

The named contact acts as the guarantor for the accuracy of the information presented in the register record.

Verna Stavric

Email salutation (e.g. "Dr Smith" or "Joanne") for correspondence:

Ms Stavric

7. * Named contact email.

Give the electronic mail address of the named contact.

verna.stavric@aut.ac.nz

8. Named contact address

Give the full postal address for the named contact.

Private Bag 92006, Auckland 1142New Zealand

9. Named contact phone number.

Give the telephone number for the named contact, including international dialling code.

+64 9 921-9999 ext 7060

10. * Organisational affiliation of the review.

Full title of the organisational affiliations for this review and website address if available. This field may be completed as 'None' if the review is not affiliated to any organisation.

Auckland University of Technology

Organisation web address:

www.aut.ac.nz

11. * Review team members and their organisational affiliations.

Give the title, first name, last name and the organisational affiliations of each member of the review team. Affiliation refers to groups or organisations to which review team members belong.

Ms Verna Stavric. Auckland University of Technology
Dr Nicola Saywell. Auckland University of Technology
Assistant/Associate Professor Nicola Kayes. Centre for Person Centred Research, Auckland University of Technology

12. * Funding sources/sponsors.

Give details of the individuals, organizations, groups or other legal entities who take responsibility for initiating, managing, sponsoring and/or financing the review. Include any unique identification numbers assigned to the review by the individuals or bodies listed.

Auckland University of Technology

13. * Conflicts of interest.

List any conditions that could lead to actual or perceived undue influence on judgements concerning the main topic investigated in the review.

None

14. Collaborators.

Give the name and affiliation of any individuals or organisations who are working on the review but who are not listed as review team members.

15. * Review question.

State the question(s) to be addressed by the review, clearly and precisely. Review questions may be specific or broad. It may be appropriate to break very broad questions down into a series of related more specific questions. Questions may be framed or refined using PI(E)COS where relevant.

1. To determine effectiveness of web-based method of delivery in improving health outcomes for people living with chronic health conditions

2. To determine factors that facilitate engagement by extracting data on key characteristics of those interventions identified as effective

16. * Searches.

State the sources that will be searched. Give the search dates, and any restrictions (e.g. language or publication period). Do NOT enter the full search strategy (it may be provided as a link or attachment.)

Literature searches will be conducted in the following databases: Cumulated Index to Nursing and Allied Health Literature (CINAHL), MEDLINE, SPORTSDiscus through EBSCO Health Database, Allied and Complementary Medicine (AMED), Evidence Based Medicine (EBM) Reviews - Cochrane Methodology Register 3rd Quarter 2012, EBM Reviews - Health Technology Assessment 4th Quarter 2016 PsycINFO 1806 to July Week 2 2017, MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to present through OVID, in Scopus and in Web of Science. The Physiotherapy Evidence Database (PEDro) database will be searched (using simplified broad keyterms) [illegible] Population, Intervention, Comparison, Outcome (PICO) framework with a focus on key terms relevant to intervention (web-based exercise) and study design

(randomised control trial). The search will not be limited by population and outcome to keep the reach as broad as possible and ensure studies are not missed. Search strategies will also include Boolean, wildcard, truncation and proximity searching, tailored by database.

Peer reviewed studies that are published in full text and in English up until November 2019 will be included. The searches will be re-run just before the final analyses and further studies retrieved for inclusion.

17. URL to search strategy.

Give a link to a published pdf/word document detailing either the search strategy or an example of a search strategy for a specific database if available (including the keywords that will be used in the search strategies), or upload your search strategy.Do NOT provide links to your search results.

Alternatively, upload your search strategy to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

Do not make this file publicly available until the review is complete

18. * Condition or domain being studied.

Give a short description of the disease, condition or healthcare domain being studied. This could include health and wellbeing outcomes.

Health outcomes as a result of exercise in adults living with a chronic health condition

19. * Participants/population.

Give summary criteria for the participants or populations being studied by the review. The preferred format includes details of both inclusion and exclusion criteria.

Adults with an existing chronic health condition (having been diagnosed with a recognised health condition)

20. * Intervention(s), exposure(s).

Give full and clear descriptions or definitions of the nature of the interventions or the exposures to be reviewed.

The intervention needs to be app-based or web-based, following the definition by Barak et al (2009). It must have been designed for the use by people living with a chronic health condition and it must explicitly support progressive physical activity or exercise in a self-guided programme. The self-guided element of the intervention is defined as having minimal human contact comprising no more than initial contact for set up or orientation. Any ongoing contact that is generated is done so automatically.

21. * Comparator(s)/control.

Where relevant, give details of the alternatives against which the main subject/topic of the review will be compared (e.g. another intervention or a non-exposed control group). The preferred format includes details of both inclusion and exclusion criteria.

usual current 'face-to-face' interventions OR no intervention OR wait list OR paper-based versions OR

variations of intervention arms

22. * Types of study to be included.

Give details of the types of study (study designs) eligible for inclusion in the review. If there are no restrictions on the types of study design eligible for inclusion, or certain study types are excluded, this should be stated. The preferred format includes details of both inclusion and exclusion criteria.

Randomised controlled trials or pilot studies that contain data addressing effectiveness

23. Context.

Give summary details of the setting and other relevant characteristics which help define the inclusion or exclusion criteria.

24. * Main outcome(s).

Give the pre-specified main (most important) outcomes of the review, including details of how the outcome is defined and measured and when these measurement are made, if these are part of the review inclusion criteria.

Outcomes of interest will follow the International Classification of Functioning, Disability and Health (ICF) as a framework and look at primary outcomes of Functioning and Disability. For example, outcomes measuring the domains of Body Functions and Structures such as change in pain and aerobic capacity will be included. These may be measured with a Visual Analogue Scale and maximal oxygen uptake. As well, we will look at measures of change in Activity and Participation such as mobility and health related quality of life, where tools such as activity monitors (e.g. pedometers) and self-report questionnaires (e.g. SF-36) are used. Finally, we are interested in reported adverse events such as musculoskeletal injuries, falls or medical emergencies.

For studies which show intervention effectiveness, features of the intervention such as goal setting, prompts and feedback will be tabulated. These will be mapped onto the existing Behaviour Change Taxonomy as developed by Abraham & Michie (2008).

Timing and effect measures

None

25. * Additional outcome(s).

List the pre-specified additional outcomes of the review, with a similar level of detail to that required for main outcomes. Where there are no additional outcomes please state 'None' or 'Not applicable' as appropriate to the review

None

Timing and effect measures

Not applicable

26. * Data extraction (selection and coding).

Describe how studies will be selected for inclusion. State what data will be extracted or obtained. State how

this will be done and recorded.

All citations returned in the search will be downloaded and saved into EndNote X8. Duplicates will be removed and then titles screened by VS, according to the pre-defined inclusion criteria. Initially, a selection of titles will be independently screened by a second assessor (NS). Any disagreements will be reviewed and discussed to ensure consensus is reached. Should agreement not be reached, a third assessor (NK) will serve as arbitrator. The abstracts and then full texts of all those studies potentially meeting the inclusion criteria will be reviewed by VS before settling on a final set of included studies in consultation with NS.

Key details from each of the included studies will be recorded in data extraction tables. Details will include: author and country; study design; participant numbers and characteristics; treatment intervention (including features and components used); health outcome measures; and results.

27. * Risk of bias (quality) assessment.

Describe the method of assessing risk of bias or quality assessment. State which characteristics of the studies will be assessed and any formal risk of bias tools that will be used.

Risk of bias for each of the included studies will be assessed as low, high or unclear drawing on guidelines by The Cochrane Collaboration's tool for assessing risk of bias in randomised trials. Appraisal of the quality of included studies will follow the criteria outlined in the Critical Appraisal Skills Programme Randomised Controlled Trial Checklist.

28. * Strategy for data synthesis.

Provide details of the planned synthesis including a rationale for the methods selected. This **must not** be generic text but should be **specific to your review** and describe how the proposed analysis will be applied to your data.

We will provide a narrative synthesis focusing on the aggregated primary outcomes and key behaviour change features of the interventions being reported which show either a significant between group difference or equivalence in the case of non-inferiority trials. We will provide a summary of intervention effects for each study calculating standardised mean differences for continuous outcomes and median and range for ordinal outcomes and include 95% confidence intervals. Adverse events will require analysis by relative risk and 95% confidence intervals. We anticipate there will be limited scope for meta-analysis because of the range of different outcomes measured across the small number of existing trials. However, where possible and if appropriate, we will pool data for key outcomes of interest (e.g. physical activity) using a random-effects meta-analysis to account for between study heterogeneity. The extent of heterogeneity will be determined using the $?^2$ test and the I^2 test. High heterogeneity will be suspected when the $?^2$ result comes with a non-significant p value (p0.1) or if the I^2 result is over 50%. Forest plots will also be visually inspected for the presence or absence of overlapping confidence intervals to help suggest the presence or absence of heterogeneity. Heterogeneity will be determined before pooling data from more than one trial.

Data analysis will be carried out using the Comprehensive Meta-Analysis version 2 software.

Studies that meet the original inclusion criteria but do not contain sufficient data to calculate an effect size will be excluded from the meta-analysis.

The lead author will conduct the initial data synthesis and all authors will contribute to and confirm the synthesis of the extracted data. Discrepancies in data synthesis will be discussed amongst the authors until consensus is reached, with NK serving as arbitrator.

29. * Analysis of subgroups or subsets.

State any planned investigation of 'subgroups'. Be clear and specific about which type of study or participant will be included in each group or covariate investigated. State the planned analytic approach.

It is not possible to specify subgroups in advance.

30. * Type and method of review.

Select the type of review and the review method from the lists below. Select the health area(s) of interest for your review.

Type of review

Cost effectiveness
No

Diagnostic
No

Epidemiologic
No

Individual patient data (IPD) meta-analysis
No

Intervention
No

Meta-analysis
Yes

Methodology
No

Narrative synthesis
Yes

Network meta-analysis
No

Pre-clinical
No

Prevention
No

Prognostic
No

Prospective meta-analysis (PMA)
No

Review of reviews
No

Service delivery

No

Synthesis of qualitative studies
No

Systematic review
Yes

Other
No

Health area of the review

Alcohol/substance misuse/abuse
No

Blood and immune system
No

Cancer
No

Cardiovascular
No

Care of the elderly
No

Child health
No

Complementary therapies
No

Crime and justice
No

Dental
No

Digestive system
No

Ear, nose and throat
No

Education
No

Endocrine and metabolic disorders
No

Eye disorders
No

General interest
No

Genetics
No

Health inequalities/health equity
No

Infections and infestations
No

International development
No

Mental health and behavioural conditions
No

Musculoskeletal

No

Neurological
No

Nursing
No

Obstetrics and gynaecology
No

Oral health
No

Palliative care
No

Perioperative care
No

Physiotherapy
No

Pregnancy and childbirth
No

Public health (including social determinants of health)
No

Rehabilitation
Yes

Respiratory disorders
No

Service delivery
No

Skin disorders
No

Social care
No

Surgery
No

Tropical Medicine
No

Urological
No

Wounds, injuries and accidents
No

Violence and abuse
No

31. Language.

Select each language individually to add it to the list below, use the bin icon to remove any added in error.
English

There is not an English language summary

32. Country.

Select the country in which the review is being carried out from the drop down list. For multi-national collaborations select all the countries involved.

New Zealand

33. Other registration details.

Give the name of any organisation where the systematic review title or protocol is registered (such as with The Campbell Collaboration, or The Joanna Briggs Institute) together with any unique identification number assigned. (N.B. Registration details for Cochrane protocols will be automatically entered). If extracted data will be stored and made available through a repository such as the Systematic Review Data Repository (SRDR), details and a link should be included here. If none, leave blank.

34. Reference and/or URL for published protocol.

Give the citation and link for the published protocol, if there is one

Give the link to the published protocol.

Alternatively, upload your published protocol to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

No I do not make this file publicly available until the review is complete

Please note that the information required in the PROSPERO registration form must be completed in full even if access to a protocol is given.

35. Dissemination plans.

Give brief details of plans for communicating essential messages from the review to the appropriate audiences.

The results of the review will be published in a peer reviewed journal and presented at relevant national and international conferences. A summary of findings will be presented to key stakeholder groups. The findings will inform web-based intervention development.

Do you intend to publish the review on completion?

Yes

36. Keywords.

Give words or phrases that best describe the review. Separate keywords with a semicolon or new line. Keywords will help users find the review in the Register (the words do not appear in the public record but are included in searches). Be as specific and precise as possible. Avoid acronyms and abbreviations unless these are in wide use.

web-based; exercise; self-guided

37. Details of any existing review of the same topic by the same authors.

Give details of earlier versions of the systematic review if an update of an existing review is being registered, including full bibliographic reference if possible.

38. * Current review status.

Review status should be updated when the review is completed and when it is published. For newregistrations the review must be Ongoing.
Please provide anticipated publication date

Review_Ongoing

39. Any additional information.

Provide any other information the review team feel is relevant to the registration of the review.

40. Details of final report/publication(s).

This field should be left empty until details of the completed review are available.

Give the link to the published review.

Appendix G

Table of excluded randomised controlled trials from the systematic review and meta-analysis

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
Abadiyan et al., 2021	Non-specific neck pain	Smartphone app	Intervention more than just initial contact-ongoing intervention contact not generated automatically	The participants in each experimental group performed the intervention in a clinic and were supervised by physiotherapists and two corrective exercise trainers specialized at postural re-education exercises by the physiotherapists.
Allen et al., 2018	Knee osteoarthritis	Internet-based exercise training vs face-to-face physiotherapy vs wait list	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Participants could also communicate with study personnel via the internet program and request a reply if needed. Any questions pertaining to exercises or symptoms were handled by a healthcare professional associated with the study (i.e., physician or physical therapist).
Allen et al., 2021	Knee osteoarthritis	Progressively more supported exercise intervention for physical	Intervention more than just initial contact-ongoing intervention	Intervention did not compare minimal contact to control group. Intervention involved a combination of contact, depending on participant criteria.

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
		activity and exercise related to knee OA	contact not generated automatically	
An et al., 2021	Adhesive capsulitis	Deep learning-based smartphone application vs CPM	Intervention was not explicitly aimed at self-management of physical activity or exercise	Single session intervention comparing two intervention techniques.
An et al., 2021	Knee osteoarthritis awaiting total knee arthroplasty	Preoperative telerehabilitation (PT)	Intervention more than just initial contact-ongoing intervention contact not generated automatically	All interventions were performed at home using a smartphone or tablet via a two-way video call. The therapist provided supervision and intervention with real-time visual feedback and verbal cues.
Anan et al., 2021	Neck/Shoulder Pain/Stiffness	Artificial intelligence-assisted health program	Participants are not adults with a chronic condition	Not clear on if participants had acute or chronic conditions.
Antypass et al., 2014	Cardiovascular disease	Tailored internet and mobile based intervention for PA vs basic internet intervention with general info	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Discussion groups with moderation by research team/health professional.

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
				Participants could seek assistance by calling a physiotherapist during working hours.
Arbour-Nicitopolous et al., 2017	Spinal cord injury	SCI GetFit toolkit vs online Physical Activity Guidelines-SCI	Primary outcome is not physical activity or exercise related as per the ICF Framework	Outcomes include intentions to engage in PA; self-efficacy; outcome expectancies; action planning.
Asano et al., 2021	Stroke	Singapore Tele-technology Aided Rehabilitation in Stroke (STARS) trial	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Sessions involve Facetime video calls during a scheduled tele-consultation. Therapists also enter clinical notes and parameters into the application.
Asklund et al., 2015	Urinary incontinence	“Mobile app Tått” vs wait list control for pelvic floor muscle training	Not peer reviewed, conference proceeding or presentation	Abstract included in Clinical Trials registry but no other information provided.
Asklund et al., 2017	Urinary incontinence	“Mobile app Tått” vs wait list control for pelvic floor muscle training	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Non-respondents-were reminded twice by email after 2 and 4 weeks and once by telephone after 6 weeks.

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
Avila et al., 2019	Coronary arterial disease	Telemonitoring/rehab vs prolonged Cardiac rehabilitation vs Usual Care	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Once a week, participants received feedback by phone or e-mail.
Backer et al., 2021	Knee osteoarthritis – total knee arthroplasty	GenuSport app with knee trainer	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Both groups followed a standardized identical postoperative protocol and identical pain management.
Bae et al., 2021	Coronary heart disease	1-way SMS text messaging program	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Participants in the intervention group received 4 messages per week for 24 weeks in addition to standard care.
Ballin et al., 2020	Central obesity	Web-based exercise vs wait list control	Participants are not adults with a chronic condition	BMI included people below 30 kg/m2- Did not fit with inclusion criteria.

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
Bantum et al., 2014	Cancer	Self-management programme for cancer with content on web-based material focussing on healthy behaviour that was supported by facilitators	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Sessions were supported by facilitators who provided feedback and help.
Barnes et al., 2016	Chronic obstructive pulmonary disease	Web based pulmonary rehabilitation over 7 weeks	Conference proceeding or presentation	
Bateman et al., 2020	Obesity and Overweight	FunForWellness online intervention	Participants are not adults with a chronic condition	The BMI criterion in this study includes overweight (i.e., 25.00–29.99 kg/m2) and obese (i.e., ≥ 30.00 kg/m2) categories. BMI included people below 30 kg/m2- Did not fit with inclusion criteria.
Beerthuiszen et al., 2020	Asthma	Internet-based self-management of severe asthma vs usual care	Intervention more than just initial contact-ongoing intervention contact not generated automatically	The helpdesk was accessible for information and communication technology purposes.

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
Bentley et al., 2020	Chronic obstructive pulmonary disease	Smartphone app and activity tracker	Intervention more than just initial contact-ongoing intervention contact not generated automatically	The app was used initially in conjunction with the pulmonary rehab (PR) program, with continued use once the PR program had finished.
Berglind et al, 2020	Mobility disability	App-based intervention using commercially available apps vs supervised health programme	Intervention more than just initial contact-ongoing intervention contact not generated automatically AND Participants are not adults with a chronic condition	The intervention included three face-to-face consultations, in groups of approximately 20 participants, where information on how to use the apps (session one at baseline), goal settings (session two at six weeks), and motivation to continue exercise (session three at 12 weeks) were discussed.
Bettger et al., 2019	Total knee arthroplasty	Virtual exercise rehabilitation in-home therapy	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Telerehabilitation with remote clinician oversight by a physical therapist.

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
Bini et al., 2017	Total knee arthroplasty	Asynchronous video exercises between patient and physiotherapist vs traditional physiotherapy	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Ongoing contact with a supervising physiotherapist to progress the exercises, even though it was asynchronous.
Bonata et al., 2020	HIV	Exercise with app vs exercise with no app	Intervention more than just initial contact-ongoing intervention contact not generated automatically	During the study, participants received general dietary advice by nutritional biologists and through the app, participants received a weekly training plan, including date, duration, and distance of training, and a notification was sent before each training session to remind the exercise prescription. Online database daily monitored by the sport scientist.
Bosak et al., 2010	Metabolic syndrome	Web-based intervention to increase self-efficacy to overcome barriers.	Intervention more than just initial contact-ongoing intervention contact not generated automatically	The principal investigator provided standardized e-mail feedback to participants each week on the achievement of exercise goals.

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
Bourne et al., 2017			Intervention more than just initial contact-ongoing intervention contact not generated automatically	Contact details of the research team were provided so that participants had a point of reference for any queries they had regarding the technology or any health concerns.
Bozorgi et al., 2021	Hypertension	Mobile intervention	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Visits occurred for both groups throughout intervention period.
Buchan et al., 2020	Obesity and overweight	Wearable plus smartphone and tailored exercise programme	Participants are not adults with a chronic condition AND Intervention more than just initial contact-ongoing intervention contact not generated automatically	Participants could interact with each other or access researcher and/or technical advice if they had questions or concerns about the intervention.

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
Bughin et al. 2021	Obesity	Mobile telerehabilitation on metabolic and rehabilitation outcomes	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Intervention also included teleconsultations at 1 and 2 months. In addition, doctors also had access to a secure website with access to patient data.
Castellano-Tejedor et al., 2020	Obesity	PRECIOUS system app with biofeedback vs control vs app + biofeedback + motivational interviewin	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Research and clinical team interacted with participants regarding the use, problems, feelings, experiences, and everything arisen by the patient while using the system throughout the intervention period.
Chaplin et al., 2017	Chronic obstructive pulmonary disease	Web-based (SPACE for COPD) vs conventional PR programme	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Weekly contact between participants and team via email/phone for motivational interviewing, progression of exercise and answering queries.
Chiang et al., 2020	Cardiometabolic multimorbidity	Telerehab with heart rate sensing clothing-communicated to cloud for monitoring	Intervention more than just initial contact-ongoing intervention	Online communication was enabled using LINE software, which provided a platform for participants and researchers

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
			contact not generated automatically	to interact with each other through messaging. Exercise offered by a rehabilitation physician after the graded exercise testing and monitored by a physiotherapist and the nurse/researcher. Weekly reminders and support from nurse.
Choi et al., 2019	Frozen shoulder	Smartphone application vs conventional rehab	Intervention more than just initial contact-ongoing intervention contact not generated automatically	A clinical assistant contacted participants between scheduled visits to reduce the drop-out rate.
Chung et al., 2020	Breast cancer	WalkON walking and Distress Thermometer	Not an RCT powered to look at effectiveness-used data from previous study for control	
Claes et al., 2020	Cardiac	CR: PATHway	Intervention more than just initial contact-	Four orientations sessions as part of continuation of cardiac rehabilitation.

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
			ongoing intervention contact not generated automatically	
Clays et al., 2021	Congestive heart failure	HeartMan mobile personal health system for self-management	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Patients in the intervention group continued to receive usual care, and additionally used the HeartMan personal health system in their home setting.
Connelly et al., 2017	Type 2 diabetes living rurally	Interactive web group vs Info only web group vs leaflets containing web material	Intervention more than just initial contact-ongoing intervention contact not generated automatically	'ask the expert' web feature however this is not made explicit as there is not a clear section on the intervention details (after the development).
Cramer et al., 2019	Stroke	To increase arm therapy dose	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Participants in the intervention group also received therapist feedback on supervised days, based on the therapist's videoconference producing or presentation observations plus the therapist's review of electronic data (prior days' use, scores, and photographs

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
				during game play) and also received feedback on all days during game play.
Crawford et al., 2021a	Knee osteoarthritis-Total knee arthroplasty	Smartphone-based care platform vs traditional in-person physiotherapy rehabilitation	Intervention more than just initial contact-ongoing intervention contact not generated automatically	The smartphone-based care management system allowed messaging communication with the provider's office in a text messaging-like application.
Crawford et al., 2021b	Knee osteoarthritis-total knee arthroplasty	Smartphone-based care platform vs traditional in-person physiotherapy rehabilitation	Additional publication from same study	
Del Pozo et al., 2012	Low back pain	Web-based exercise and postural education vs usual care	Participants are not adults with a chronic condition	LPB was over 6 weeks but less than 12 weeks.
Dorion-Cadrin et al., 2020	Total knee and total hip arthroplasties	Tele-Prehabilitation vs usual prehabilitation	Intervention more than just initial contact-ongoing intervention contact not generated automatically	The tele-prehabilitation group performed the supervised exercise protocol at home. Only the first session was in person and the supervision of the home-based program was provided by a physiotherapist through

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
				telecommunication applications (two sessions per week).
Duan et al., 2018	Coronary heart disease	Web-based intervention to improve physical activity and fruit and vegetable consumption	Intervention more than just initial contact-ongoing intervention contact not generated automatically	To boost the engagement of patients, short message service (SMS) text messages were sent as reminders. Furthermore, the nurse contacted participants via phone calls once per week before each intervention session and at the 2 measurement points to remind the patients. Patients were also offered telephone cards as incentives for participation and data completion.
Duncan et al., 2020	Overweight and obese	Smartphone app with education/BCT, face to face, Fitbit, scales vs Enhanced vs Traditional	Participants are not adults with a chronic condition AND Intervention more than just initial contact-ongoing intervention contact not generated automatically	BMI between 25 and 40 kg/m2. BMI included people below 30 kg/m2-Did not fit with inclusion criteria.

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
Eichler et al., 2019	Total knee arthroplasty	3-month telerehabilitation as supplement and return to work using Kinect and synchronous or asynchronous communication with therapist	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Three ways to communicate with therapist: participant records message for therapist to get, therapist to record message for participant to get when exercising, real time video communication during pre-determined exercise.
Ellis et al., 2019	Parkinson's disease	MHealth (Wellpepper app) exercise programme and walking programme vs pedometer and exercise programme only	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Exercises adapted remotely and physiotherapist remotely monitored data, adherence, difficulty pain each week. Physiotherapist contacted participants via text message as needed.
Engelen et al., 2020	Cardiovascular disease	Vascular View containing 6 modules	Not an RCT powered to look at effectiveness or is a protocol	
Ferrante et al., 2017	Cancer	Web based intervention plus Fitbit plus support	Not an RCT powered to look at effectiveness or is a protocol	

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
Flachenecker et al., 2020	Multiple sclerosis	Home internet-based PA promotion vs no intervention	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Web- and telephone-based, behavior-oriented PA coaching with one individual and four group sessions, and individual exercise prescription in a one-to-one approach using a specialized, browser-based software solution.
Fleischman et al., 2019	Total knee arthroplasty	Home exercises web-based vs printed manual (vs conventional clinic based)	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Web-based intervention had interactive participant monitoring and communication portal.
Forbes et al., 2015	Cancer	Web-Based PA programme vs usual care	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Emails were developed to offer encouragement on PA-tailored if enough or not enough PA.
Frederix et a., 2015	Coronary artery disease	Internet-based telerehab	Conference proceeding or presentation	

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
Frensham et al., 2018	Cancer	Pedometer + Website vs pedometer only	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Researchers use inputs from participants to generate individually tailored target steps/day for the following week.
Frevel et al., 2015	Multiple sclerosis	Internet-based home training programme vs hippotherapy	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Therapist individually supervised every training session of each participant and adjusted the training schedules individually.
Ghadimi et al., 2021	Chronic obstructive pulmonary disease	Telerehabilitation	Full next not in English	
Ginis et al., 2016	Parkinson's disease	CuPiD gait training vs active control-personalised gait advice	Intervention more than just initial contact-ongoing intervention contact not generated automatically	CuPiD group participants received weekly home visits from the researcher during the six-week intervention.
Glasgow et al., 2010	Diabetes	CASM (self-administered Computer Assisted Self-Management using social	Intervention more than just initial contact-ongoing intervention	A moderated forum was used.

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
		ecological model and 5As self-management model) vs CASM + SS (CASM with enhanced Social Support with follow up phone calls, group visit.	contact not generated automatically	
Gohir et al., 2021	Knee osteoarthritis	iBEAT-OA internet-based treatment vs routine self-management	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Adherence was encouraged by daily emails or smartphone notifications, or by the physiotherapist via asynchronous chat or telephone during the study period.
Golsteijn et al., 2018	Prostate and colorectal cancer	OncoActive web-based intervention (PA advice tailored based on baseline info) vs usual care wait list	Intervention more than just initial contact-ongoing intervention contact not generated automatically	The option to consult a physical therapist for additional information is included.
Golsteijn et al., 2017	Prostate and colorectal cancer	OncoActive web-based intervention (PA advice tailored based on baseline info) vs usual care wait list	Additional publication from same study	

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
Gonzalez-Gerez et al., 2021	Acute Covid	Telerehabilitation Program	Participants are not adults with a chronic condition	Participants had acute COVID-19 within last 40 days and no chronic conditions.
Grau-Pellicer et al., 2019	Stroke	Multi-modal Rehab Program (MMRP) + mHealth app (Fitlab app)	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Physical therapist guided sessions and WhatsApp group for motivation and to provide feedback, etc.
Grey et al., 2019	Overweight and obese	Evolife website providing information about PA, healthy eating and behavioural changes using mismatch concept	Participants are not adults with a chronic condition AND Intervention more than just initial contact-ongoing intervention contact not generated automatically	Participants were a combination of overweight and obese. BMI included people below 30 kg/m2-Did not fit with inclusion criteria and they met with researchers to discuss goals, go over what plans may look like, shown how to use pedometer, daily routines, etc.
Grobe et al., 2020	Spinal cord injury	Internet-based exercise programme	Conference proceeding or presentation	

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
Hageman et al., 2018	Arthritis	Web-based weight loss intervention	Not an RCT powered to look at effectiveness or is a pilot paper without a control group	
Hajizadeh et al., 2020	Chronic obstructive pulmonary disease	TelePulmonary Rehab	Conference proceeding or presentation	
Hansel et al., 2017	Obesity and type 2 diabetes	ANODE intervention to help improve dietary habits and increase physical activity	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Human contact provided to support in cases of technical issues.
Hardt et al., 2018	Knee osteoarthritis – total knee arthroplasty	GenuSport app with knee trainer	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Both groups followed a standardized identical postoperative protocol and identical pain management.
Hassett et al., 2020	Mobility limitation	Digital device as appropriate vs usual care	Participants are not adults with a chronic condition AND	Face-to-face and remote sessions following a health coaching model using phone, email, video conferencing, or in person at the participant's discharge

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
			Intervention more than just initial contact-ongoing intervention contact not generated automatically	destination (home, transitional living unit, residential care).
Hemmes et al., 2021	Pulmonary arterial hypertension	Text-based mobile health intervention	Intervention more than just initial contact-ongoing intervention contact not generated automatically	All study participants, including those in the usual care arm, received daily reminders to sync their devices if more than 24 h had passed since the last syncing event. If no data were transmitted for more than 48 h, the study team received an alert and contacted the participant to encourage compliance.
Hidrus et al., 2020	Type 2 diabetes mellitus	WhatsApp exercise videos vs brochure on PA benefits	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Participants reminded regularly as researchers uploaded an exercise video every week.
Hilmarsdottir et al., 2021	Type 2 diabetes mellitus	Smartphone application (SidekickeHealth) vs control	Intervention more than just initial contact-	The first author sent short, individualized encouragement through the app, based

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
			ongoing intervention contact not generated automatically	on registered activity in the app. After the first 16 weeks, both types of messages were received every other week for two more months.
Hiremath et al., 2019	Spinal cord injury	PA promotion and PA with just in time prompts using smartwatch and wheel sensors	Not an RCT powered to look at effectiveness or is a pilot paper without a control group	
Hochsmann et al., 2019	Diabetes	Smartphone app with exergame using garden metaphor (+ consultation) vs one-time lifestyle counselling (+ consultation)	Intervention more than just initial contact-ongoing intervention contact not generated automatically	In both groups a sports medical expert provided a given number of personal exercise consultations on the telephone (weeks one and two). Consultations provided via telephone, including personal attention and instruction as well as technical support.
Hou et al., 2019	Low back pain	eHealth telehealth and website vs usual	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Participants could receive daily reports about exercise and alerts to prompt them to return to this system. They could also communicate with their doctors through this system. Through the Web-based interface, the doctors

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
				could adjust rehab plans for participants and view reports about the participants' daily exercise.
Houchen-Wolloff et al., 2018	Cardiac rehabilitation	Web-based cardiac rehabilitation	Not an RCT powered to look at effectiveness or is a pilot paper without a control group	
Ingram et al., 2019	Unsure	e-coacherER	Conference proceeding or presentation	
Isernia et al., 2019	Chronic neurologic conditions	Human Empowerment Aging Disability (HEAD) on Patient Reported Outcome Measures (PROM)	Not an RCT powered to look at effectiveness or is a pilot paper without a control group	
Jahangiry et al., 2017	Metabolic syndrome	My Healthy Heart website interactive website vs control waiting list	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Dietician sent tailored diet to participants' inbox. Email reminders sent. Participants could ask their questions at any time and received responses within 24h.

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
Jennings et al., 2014	Diabetes	Diabetes in Check website + pedometer vs control who received pedometer and limited website access	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Participants in the intervention group were also distributed a weekly email reminder and encouraged to join discussions with programme manager.
Jiang et al., 2020	Chronic obstructive pulmonary disease	WeChat PeR (pulmonary Internet Explorer Rehab)	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Interaction with health professionals ongoing during intervention.
Jimenez-Reguera et al., 2020	Chronic obstructive pulmonary disease	Happy Air mHealth Platform	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Lovexair team provided tele-care support + monitoring throughout trial period.
Kanera et al., 2016	Cancer	Kanker Nazorg Wijzer (Cancer Aftercare Guide, KNW) vs usual care	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Research team monitored the forum to control for advice contradicting the advice given in the modules.

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
Kanera et al., 2017	Cancer	Kanker Nazorg Wijzer (Cancer Aftercare Guide, KNW) vs usual care	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Research team monitored the forum to control for advice contradicting the advice given in the modules.
Kannan et al., 2017	Multiple sclerosis	Web-based fall prevention programme	Conference proceeding or presentation	
Kannan et al., 2018	Multiple sclerosis	Web-based fall prevention programme	Conference proceeding or presentation	
Kannan et al., 2019	Multiple sclerosis	Web-based fall prevention programme	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Participants received a daily email directing them to a survey and were contacted by phone or email if they failed to respond to the fall survey for seven consecutive days.
Kayser et al., 2019	Acute Coronary Syndrome	TAVIE en m@rche (videos delivered from virtual nurse based on profile determined from baseline online questionnaire) vs list	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Non-automated management of reminders to the experimental group. Ability to contact team regarding health concerns.

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
		of hyperlinks to increase daily steps		
Kelechi et al., 2020	Venous leg ulcers	FOOTFIT	Additional publication from same study	
Kenfield et al., 2018	Prostate cancer	Prostate 8 website + text messages vs control wait list	Conference proceeding or presentation	
Kenfield et al., 2019	Prostate cancer	Prostate 8 website + text messages vs control wait list	Intervention more than just initial contact- ongoing intervention contact not generated automatically	Every 2 weeks, participants were emailed by the principal investigator about blog topics and recipes added on the website.
Ki et al., 2020	Hemodialysis patients	Smartphone app exercises	Full next not in English AND Not an RCT powered to look at effectiveness or is a pilot paper without a control group	

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
Kim et al., 2016	Knee pain	SimpleTherapy web-video-based platform delivering progressive exercises based on user input vs web-based static exercises vs web-based video form	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Clinicians monitored pain levels and feedback but did not directly communicate with participants except to answer email questions.
Kim et al., 2019	Cardiovascular disease	mHeath using mobile app for 24 weeks for health behaviours	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Participants received weekly individualized services related to healthy lifestyles. These services were provided by professional health management teams comprising physicians, nurses, nutritionists, and physical activity experts who monitored health information online in real-time.
Kim et al., 2020	Hepatocellular cancer	mHealth Care App	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Each participant was given an individualized rehabilitation exercise program that was prescribed and adjusted at the 6-week mid-intervention period based on the assessment results. Participants' conditions, as a result of their exercise programs, were

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
				communicated through the app's real-time chat services.
Kloek et al., 2016	Osteoarthritis	Blended intervention e-Exercise	Conference proceeding or presentation	
Kloek et al., 2016	Osteoarthritis	Blended intervention e-Exercise	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Usual physical therapy sessions are integrated with a web-based program.
Knudsen et al., 2019	Ischemic heart disease or heart valve disease	Tele cardiac rehab	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Patients were supervised through weekly tele-consultations (phone, email or text message). The consultation was based on weekly multi-disciplinary team conferences in which the overall rehabilitation progress of each patient was evaluated.
Kolle et al., 2020	Patellofemoral pain	Online exercise therapy plan (Mawendo GmbH) with video exercises, information, tips	Intervention more than just initial contact-ongoing intervention	Clarification sought-No response from authors within required timeframe.

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
			contact not generated automatically	
Krein et al., 2013	Low back pain	Pedometer upload weekly and study website with automated feedback, targeted messages, e-community vs usual care pedometer upload monthly	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Research staff participated in and monitored the forum posts as well as used the forum to generate competitions to encourage meeting walking goals.
Lee et al., 2017	Chronic neck pain	App with Mckenzie neck exercises and self-feedback on exercise record and pain	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Both the app-based intervention group and the control group received text messages once a week to provide encouragement to the participants.
Lee et al., 2019	Colorectal polyps	Noom Coach app + pedometer vs control (diary and newsletter). Both received monthly telephone calls	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Both groups received monthly telephone calls for motivation.

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
Lee et al. 2021	Type 2 diabetes	Mobile application (LIBIT) for dietary and exercise management and Medilarm for medication adherence	Primary outcome is not physical activity or exercise related as per the ICF Framework	Outcomes of interest were changes in body weight, waist circumference, blood work values.
Levinger et al., 2017	Anterior cruciate ligament reconstruction	Internet interactive website vs usual post op care	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Participants in both groups received usual care.
Li et al., 2020	Inpatient rehab patients	Pt Pal app-based exercise prog + rehab vs usual rehab	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Intervention was in addition to ongoing in-person rehab.
Lim et al., 2016	Diabetes	U(ubiquitous) health care system and clinical decision support (CDSS) rule engine and PA monitoring device and dietary feedback vs	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Clarification sought-No response from authors within required timeframe.

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
		Routine self-monitoring of blood glucose		
Lison et al., 2020	Hypertension and obesity	Live Well website	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Researchers contacted participants if they stopped accessing the modules for more than two weeks after they were posted. In this case, a reminder email was sent. After three weeks without intervention access, a reminder telephone was made.
Liu et al., 2013	Chronic obstructive pulmonary disease	Dyspnoea breathing programme with video instruction vs control	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Participants who had not logging onto the online program regularly would receive a reminder by telephone from the respiratory nurse.
Loohuis et al., 2019	Urinary incontinence	App-based treatment	Conference proceeding or presentation	
Loohuis et al., 2021	Urinary incontinence	URinControl app-based treatment	Intervention more than just initial contact-ongoing intervention	The research team provided technical support only.

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
			contact not generated automatically	
Lozano Lozano et al., 2020	Breast Cancer	BENECA mobile app	Intervention more than just initial contact-ongoing intervention contact not generated automatically	The CUIDATE group will make the telephone calls and send messages of encouragement.
Lunde et al., 2020	Cardiac rehab	App vs usual care	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Supervisor monitored and provided tailored feedback through app and email. Participants could submit questions and receive answers.
Maresca et al., 2019	Aphasia	Virtual reality rehabilitation system (using a Tablet)	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Twice a week, the neuropsychologist performed a videoconference or presentation with patients to monitor the rehabilitation process carried out in their own home and discuss the feasibility and performance of the exercises.

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
Martin et al., 2015	At risk of cardiovascular disease	Automated smart texts vs no texts	Participants are not adults with a chronic condition	Outpatients at an academic prevention centre but participants don't all explicitly have a defined chronic health condition as part of the inclusion criteria.
Mayberry et al., 2021	Type 2 diabetes	REACH + FAMS vs REACH only	Intervention more than just initial contact-ongoing intervention contact not generated automatically	All participants—including those assigned to.the control condition—received access to a study helpline for questions about the study and their diabetes medications (a clinical pharmacist returned calls), text messages advising how to access study A1c results, and quarterly newsletters on healthy living with diabetes.
Mayer et al., 2018	Colon cancer	CHESS smartphone app + smartphone vs National Cancer Institute booklet, survival toolbox and pedometer.	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Staff facilitator and a personal trainer available for participants to ask questions about PA and to be involved in discussion group and to tailor messages to inactive participants.
McConnon et al., 2007	Obesity	Online advice, tools, information for behaviour	Intervention more than just initial contact-ongoing intervention	Clarification sought-No response from authors within required timeframe.

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
		change with personalised advice	contact not generated automatically	
McNeil et al., 2019	Breast cancer	Activity trackers	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Goals and barriers and strategies recorded to facilitate discussion by phone or email with study exercise physiologist to reinforce adherence, discuss problems barriers to achieve PA goals.
Morrison et al., 2016	Asthma	RAISIN (randomized trial of asthma internet self-management intervention) Living with Asthma website vs usual care	Intervention does not explicitly involve self-management of PA or exercise	Study aims do not include any PA or exercise related aims.
Moy et al., 2015	Chronic obstructive pulmonary disease	Taking Healthy Steps (internet mediated, pedometer-based walking programme) vs wait list control with pedometer only	Intervention more than just initial contact-ongoing intervention contact not generated automatically	All participants who were randomized to the intervention arm had access to the study staff for questions, which could be initiated by sending an email or directly on the website through a form. Participants could also call the staff on a

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
				toll-free number. Study staff usually responded with a phone call.
Muller et al., 2017	Diabetes	Healthy living with diabetes-web-based interactivity v web-based plain text	Primary outcome is not physical activity or exercise related as per the ICF Framework	Powered to assess change in outcomes of Usage, engagement, health literacy
Murphy et al., 2021	Cutaneous systemic sclerosis	Intensive and app-delivered occupational therapy	Intervention more than just initial contact-ongoing intervention contact not generated automatically	The therapist checked on progress via dashboard, communicated with the participant as needed, and uploaded other information (such as digital ulcer management and home paraffin wax treatment) weekly on the App for all participants.
Myers et al., 2020	Obesity and overweight	Fun For Wellness (FFW) vs Usual care	Participants are not adults with a chronic condition	The BMI criterion included people below 30 kg/m2-Did not fit with inclusion criteria.
Nelligan et al., 2021	Knee osteoarthritis	Self-directed web-based strengthening exercises and physical activity program	Intervention more than just initial contact-ongoing intervention	Certain text scenarios e.g., Response not supported:“Encourages contacting research team if needed. Inappropriate responses are monitored by the research

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
		supported by automated text messages	contact not generated automatically	team. Any that require action (e.g. safety concern) will be followed up by the research team.
Nyberg et al., 2019	Chronic obstructive pulmonary disease	COPD-web (with condition + professionals working with those with the condition) + usual care	Intervention more than just initial contact-ongoing intervention contact not generated automatically AND Participants are not adults with a chronic condition	Healthcare professional section of the website aimed at facilitating the *provision of support* for self-management strategies for people with COPD, thereby facilitating the implementation of such services and reinforcing the use of the COPD-web during follow-up visits.
Ormel et al., 2018	Cancer	Runkeeper app self-monitoring of PA with training reminder vs usual care of advice to be PA	Intervention more than just initial contact-ongoing intervention contact not generated automatically	One investigator was available for answering questions about the RunKeeper use by telephone or e-mail.
Ozen et al., 2021	Stroke	Computer game assisted task specific exercises (CGATSE) for arm function	Intervention more than just initial contact-ongoing intervention	Those allocated to the CGATSE group, received thirty minutes of CGATSE using the Rehabilitation Joystick for

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
		vs standard occupational therapy	contact not generated automatically	Computerized Exercise (Rejoyce) system five days per week under the supervision of the same occupational therapist in addition to one hour of therapy.
Pagliari et al., 2021	Multiple sclerosis	Integrated telerehabilitation using virtual reality vs home-based conventional rehabilitation	Intervention more than just initial contact-ongoing intervention contact not generated automatically	The exercises were performed at home by the patient using a dedicated virtual reality rehab system home-based kit in an asynchronous telerehab modality with digital contents and offline remote monitoring by the therapist.
Park et al., 2020	Chronic obstructive pulmonary disease	SASMP (smart app based self-management program) on self-care for COPD	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Participants were encouraged to communicate with other participants and research team by text messages in the smartphone app or call.
Passalent et al., 2016	Anxial spondyloarthritis	Interactive web-based e-Learning education module	Conference proceeding or presentation	
Passalent et al., 2017	Anxial spondyloarthritis	Interactive web-based e-Learning education module	Conference proceeding or presentation	

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
Petrozzi et al., 2019	Low back pain and chronic pain	Physiotherapy +/- MoodGYM	Intervention NOT explicitly directed to PA/ex AND Intervention more than just initial contact- ongoing intervention contact not generated automatically	MoodGYM CBT focussed intervention on mood NOT on changing behaviour of PA or exercise and participants were contacted weekly by research staff to increase adherence.
Pfaeffli Dale et al., 2015	Coronary heart disease	Text4Heart SMS and website 24-week intervention vs usual care	Intervention more than just initial contact- ongoing intervention contact not generated automatically	Individual questions were responded to personally by the research team within 48 hours.
Plow et al., 2017	Chronic health conditions	mHealth self-management via tablet and use of existing apps vs paper based self-management vs contact control	Intervention more than just initial contact- ongoing intervention contact not generated automatically	Participants received three follow-up phone calls at a frequency of one call placed every other week for six weeks after the in-person session.

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
Rafiq et al., 2021	Knee osteoarthritis	Lower limb rehabilitation with mobile health intervention	Intervention more than just initial contact-ongoing intervention contact not generated automatically	In addition, every patient was actively followed by phone at least once a week to ensure that they read the messages and performed the intervention.
Rees-Punia et al., 2021	Cancer	Health and Energy through Active Living Every Day (HEALED) web-based PA vs as usual wait-listed control	Intervention more than just initial contact-ongoing intervention contact not generated automatically	HEALED intervention group participants received monthly motivational e-mails announcing one new website feature to prompt return to the website
Reguera et al., 2017	Chronic obstructive pulmonary disease	Integrated internet programme after pulmonary rehab vs conventional	Conference proceeding or presentation	
Rigot et al., 2021	Wheelchair users	One off transfer skills training intervention delivered over the internet	Intervention does not explicitly support self-management of physical activity or exercise in an interactive self-	Intervention is skills training, not a physical activity or exercise programme.

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
			management programme	
Riva et al., 2014	Low back pain	ONESELF website containing static (library, first aid, FAQ) and interactive (Virtual gym, action plan, testimonials, commentaries, quiz) features	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Clarification sought-No response from authors within required timeframe.
Robinson et al., 2020	Chronic obstructive pulmonary disease	Internet-mediated walking programme with goal setting, feedback, motivation and education messages, and social support	Conference proceeding or presentation	
Robinson et al., 2021	Chronic obstructive pulmonary disease	Internet-mediated walking programme with goal setting, feedback, motivation and education messages, and social support	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Follow-up, in-person assessments occurred at 3 and 6 months for both groups. At each follow-up visit, study staff reminded participants not to disclose randomisation assignment and

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
				that they should be working to increase their walking and exercise.
Salaffi et al., 2015	Fibromyalgia	Multicomponent intervention and web-based evaluation	Intervention not web-based	
Salaffi et al., 2020	Fibromyalgia	Web-based intervention	Control data from previous work	
Salerno et al., 2021	Cancer	DVD delivered physical activity intervention	Intervention not web-based Intervention more than just initial contact-ongoing intervention contact not generated automatically	Both conditions received titrated support telephone calls from intervention staff over the course of the six months.
Schweier et al., 2014	Coronary heart disease and low back pain	Peer mentoring website containing clips on peoples' experiences on successfully modified behaviour vs usual care	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Participants encouraged to contact the project team in case of problems or questions and those who provided an email received email reminders.

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
Scorza et al., 2020	Parkinson's disease	Mhealth-supported exercise	Opinion article – not RCT	
Simpson et al., 2020	Obesity	HelpMeDoIt! Website and app providing evidence-based information on weight loss, goals, social support and methods on how to harness, set and monitor these using existing resources.	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Clarification sought-No response from authors within required timeframe.
Shang-Lin et al., 2020	Cardiometabolic multimorbidity	Home-based telehealth exercise training program	Intervention more than just initial contact-ongoing intervention contact not generated automatically	A weekly reminder for maintenance of exercise and providing patient support.
Short et al., 2017	Cancer	Web-based physical activity advice	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Participants were sent up to two email reminders (3 days apart) each time they had a module due. Participants were also

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
				sent up to two reminders to complete action plans when they became available
Smith et al., 2019	Pain	Reboot Online with graded exercises and narrated videos of three movement stations: flexibility, strength, stability; resources, relaxation stations.	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Participants were contacted via e-mail or telephone by the research technician after the first two lessons, then as requested by the participant.
Snoeck-Stroband et al., 2017	Asthma	Tailored web-based self-management support (SMS) in addition to standard care	Conference proceeding or presentation	
Streber et al., 2018	Multiple sclerosis	Internet-based after-care program	Conference proceeding or presentation	
Tallner et al., 2012	Multiple sclerosis	At home physical training (e-training) protocol focused on strength and endurance	Conference proceeding or presentation Intervention more than just initial contact-ongoing intervention	Training protocols were supervised and adjusted by sports therapists.

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
			contact not generated automatically	
Tarakci et al., 2021	Multiple sclerosis	12 week structured telerehabilitation program vs 12 week structured in person exercise program	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Patients in Group 2 were checked and controlled by means of telerehabilitation three times per week. Patients received telephone video calls to control their adherence to the exercise sessions and revise their exercises if needed
Taylor et al., 2020	Chronic conditions	ecoachER	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Participants in the intervention group continued to receive usual ERS input.
Taylor et al., 2020	Chronic conditions	ecoachER	Additional publication from same study	
Thielbar et al., 2020	Stroke	Virtual Reality	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Therapy involved Multi-User which involved therapist + participant (therapist in clinic + participant at home) in real time.

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
Thiengwittayaporn et al., 2021	Knee osteoarthritis	Mobile application	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Clarification sought-No response from authors within required timeframe.
Tomita et al., 2019	Heart failure	Information and exercise support with video	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Appraisal support was provided via email every month from appropriate health care professionals in dealing with subjects for the purpose of feedback for participants' records. This support was provided to encourage participant's ongoing actions for changing their health behaviors toward a maintenance stage (beyond six months). Emotional support was provided on an as needed basis via email.
Uhm et al., 2017	Breast cancer	Mhealth + pedometer vs usual care	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Clarification sought-No response from authors within required timeframe.

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
Ulcoq et al., 2019	Knee arthroscopy	Internet based physiotherapy	Conference proceeding or presentation	
Van de Wiel et al., 2021	Breast and prostate cancer survivors	Internet based physical activity support program	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Program involved physiotherapist telephone counselling.
Van den Berg et al., 2006	Rheumatoid arthritis	Internet-based PA interventions (individualised) vs generalised	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Every week the participants sent back a completed program schedule by e-mail, and subsequently a new schedule was put on the participant's personal web page. Participants received weekly, individual distant supervision by e-mail from 2 experienced physical therapists.
Van Dijk-Huisma et al., 2020	Post op total knee or hip arthroplasties	MOX sensor + Hospital Fit App to increase PA levels vs usual care	Intervention more than just initial contact-ongoing intervention contact not generated automatically	The extent of functional recovery was evaluated by the physiotherapist during every treatment.

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
Van Reijen et al., 2017	Ankle sprains	Strengthen your ankle app with videos and verbal instructions of 6 exercises with progressions to increase weekly over 8 weeks + balance board vs paper-based version + balance board	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Participants received a request by email to complete an online compliance questionnaire. After 3 days, a reminder was sent in case of non-response.
Vluggen et al., 2021	Type 2 Diabetes	Web-based computer tailored program	Intervention more than just initial contact-ongoing intervention contact not generated automatically	The program is self-guided and facilitated through periodic prompts and reminders to stimulate program engagement and completion.
Volders et al., 2020	Older adults with chronic illness	Active Plus intervention vs wait list control	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Participants in the intervention group received advice on three occasions, both online on a secured website and paper (via a letter by mail) that was based on their responses to questionnaires, participants' characteristics, psychosocial stance, current PA, and what local PA was possible.

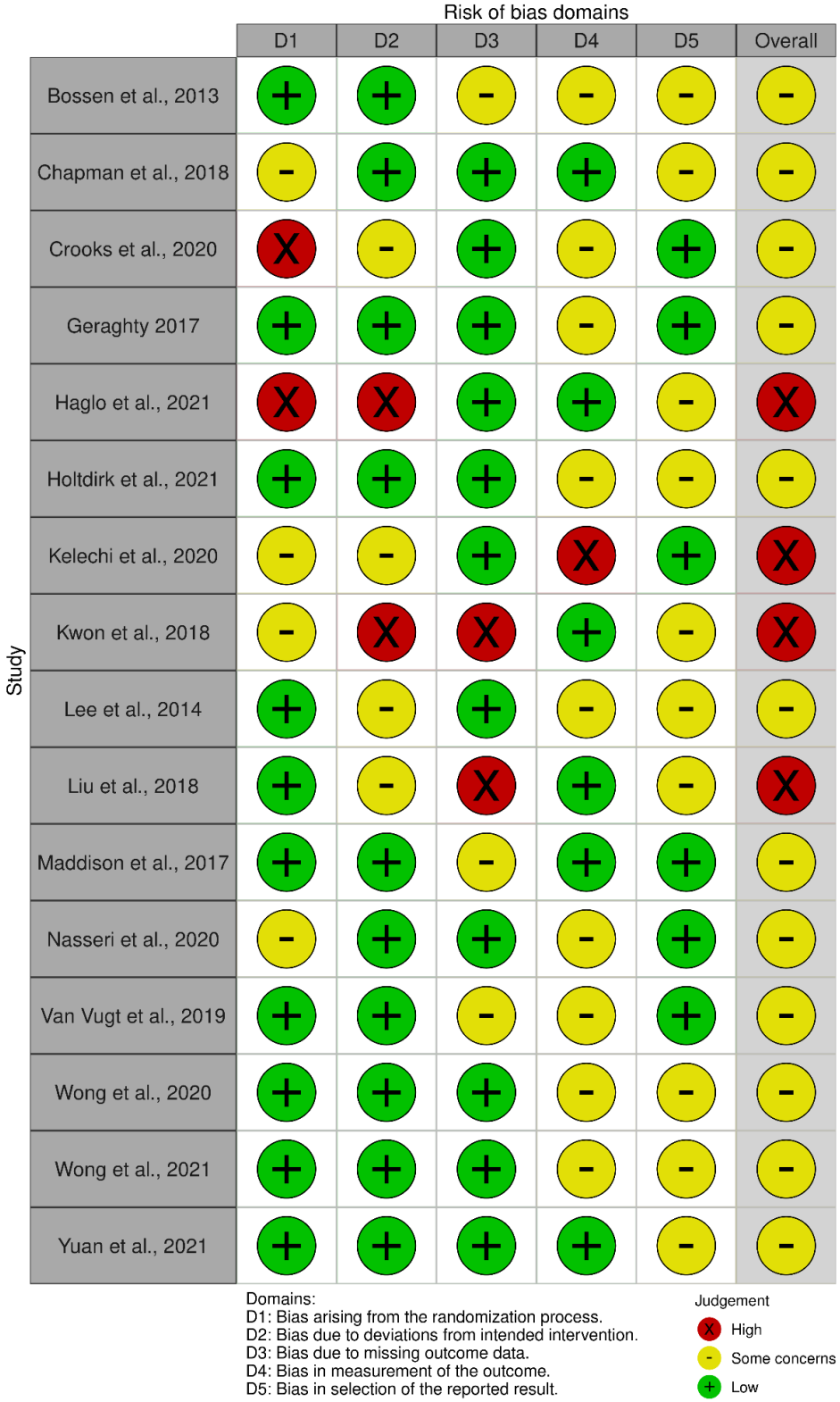
Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
Volders et al., 2021	Older adults with chronic illness	Active Plus intervention for older adults with chronic diseases	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Participants receive personal advice by email and by mail (from protocol Volders et al., 2019).
Wadensten et al., 2021	Urgency and mixed urinary incontinence in women	Mobile app for self-management of urgency and mixed urinary incontinence in women	Intervention more than just initial contact-ongoing intervention contact not generated automatically	If the app was not activated within 2 weeks, an email reminder was sent to the participant, and if it was not activated within another week, the participant was contacted via telephone and offered technical guidance.
Wan et al., 2017	Chronic obstructive pulmonary disease	Every step counts (ESC)	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Able to contact staff through website and participated in a minimum of two in-person clinic visits.
Wan et al., 2020	Chronic obstructive pulmonary disease	Every Step Counts (ESC)	Secondary data to previous study	

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
Wang, et al., 2020	Chronic obstructive pulmonary disease	Mobile health app vs routine care	Intervention more than just initial contact-ongoing intervention contact not generated automatically	One app module mainly provided motivational support to participants, which included peer support chat room and an expert support portal.
Wang, et al., 2021	Chronic obstructive pulmonary disease	Mobile application to support self-management	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Clarification sought-No response from authors within required timeframe
Wang, et al., 2020	Urinary stress incontinence	Audio guidance pelvic floor muscle training program app where participants are guided by audio to contract and relax pelvic floor muscles	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Significant input at baseline and researchers called the participants of the two groups once a month to answer their questions related to training or stress incontinence and encourage them to keep on training for at least three months.
Webb et al., 2019	Cancer	Move More Pack printed components and internet tools and e-newsletters	Inter more than just initial contact-ongoing	'Ask a physio' component on the internet component.

Author and date	Population	Intervention	Criteria used to exclude	Reason for exclusion
		drawing on theory vs waitlist control	intervention contact not generated automatically-	
Wu et al., 2020	Stroke	Telerehabilitation video conferencing twice a week	Intervention more than just initial contact-ongoing intervention contact not generated automatically	The collaborative care team developed rehab plans and once the patient was discharge home from in-patient care, the rehabilitation engineer and rehabilitation nurse performed personalized remote rehabilitation instruction twice a week.
Yun et al., 2020	Cancer	Health coaching through Smart Management Strategies for Health (SMASH) to improve health behaviors such as PA, weight control and distress management	Intervention more than just initial contact-ongoing intervention contact not generated automatically	Clarification sought-No response from authors within required timeframe.

Appendix H

Risk of bias table by domain: included studies for the systematic review and meta-analysis



Appendix I

Body functions and symptoms outcome measures across studies: included studies from the systematic review and meta-analysis

Author	Outcome measure		Assess point (weeks)	Mean group difference (Variance)	95% confidence intervals	SD	Hedge's g	95% confidence intervals
	Self-report	Instrument						
Physical activity								
Bossen et al. 2013 **OA**	**PASE (0-400)**		12	-1.6	-16.6 to 13.5	44	-0.03	-0.3 to 0.3
			52	21.2	3.6 to 38.9	54.1	0.4	0.1 to 0.7
		Physical activity (accelerometer min/day)	12	3	-26 to 32	11.1	0.1	-0.5 to 0.6
			52	24	0.5 to 46.8	43.1	0.6	0.001 to 1.1
Chapman et al. 2018 **Breast cancer**	**LSI-MSPA (calculated score)**		4	2.4	-2.2 to 7.1	11.1	0.2	-0.2 to 0.6
			24	7.2	2.3 to 12.1	11.1	0.6	0.2 to 1.1
Crooks et al. 2020 **COPD**		**7-day daily step count (number)**	12	-2252.9	-10433.8 to 5927.9	5577.9	-0.4	-1.5 to 0.7
Holtdirk et al. 2021 **Breast cancer**	**IPAQ-SF (MET-min/ week)**		12	243	NR	2593	0.1	-0.1 to 0.3
Lee et al. 2014 **Breast cancer**	**7-day exercise diary (reporting minutes per week ≥ 4 METs)**		12	3.4	1.2 to 10.2	Odds ratio	0.3	-0.2 to 0.8
Liu et al. 2018 **HTN**		**Daily step count (number)**	**expert driven**					
			16	2460	1137 to 3783	2980.7	0.8	0.4 to 1.3
			user driven					
			16	2459	NR	2403.2	1.0	0.6 to 1.5
Maddison et al. 2015 **IHD**	**IPAQ-LF (Median**		24	233.9	-146.5 to 614.2	1200.1	0.2	-0.1 to 0.5

Author	Outcome measure		Assess point (weeks)	Mean group difference (Variance)	95% confidence intervals	SD	Hedge's g	95% confidence intervals
	Self-report	Instrument						
	MET-min/ week)							
Nasseri et al. 2020 **MS**	**LSI-MSPA (calculated score)**		12	-3.0	-12.9 to 6.8	21.3	-0.1	-0.8 to 0.5
		mod-vigorous PA (accelero-meter %)	12	-2.9	-7.8 to -1.9	10.5	-0.3	-0.9 to 0.4
Wong et al. 2020 **CHD**	**GSLTPAS (calculated score)**		12	3.6	1.0 to 6.1	13	0.3	0.1 to 0.5
			24	2.3	-0.4 to 5.2	12.5	0.2	-0.02 to 0.4
Wong et al. 2021 **Metabolic Syndrome**	**GSLTPAS (calculated score)**		4	5.9	NR	16.3	0.4	-0.1 to 0.8
			12	8.6	NR	18	0.5	0.02 to 0.9
Body function and symptoms								
Bossen et al. 2013 **OA**	**KOOS / HOOS (0-100)**		12	6.5	1.8 to 11.2	15.4	0.4	0.1 to 0.7
			52	5.0	-1.0 to 11.0	18.6	0.3	-0.1 to 0.6
	Self-perceived effect (1-7)		12	10.7	4.3 to 26.4	Odds ratio	0.56	0.3 to 0.9
			52	1.2	0.6 to 2.4	Odds ratio	0.04	-0.4 to 0.5
Crooks et al. 2020 **COPD**	**CAT (0-40)**		12	-1.3	-4.47 to -1.92	12.4	0.1	-0.4 to 0.6
Kwon et al. 2018 **COPD**		**6MWT[a] (m)**	**Fixed-interactive**					
			6	-8.7	NR	94.54	-0.1	-0.6 to 0.4
			12	-6.6	NR	82	-0.1	-0.7 to 0.5
			Fixed					
			6	10.9	NR	70.5	0.15	-0.5 to 0.8
			12	10.3	NR	73.4	0.14	-0.5 to 0.8
	CAT[a] (0-40)		**Fixed-interactive**					
			6	-3.1	NR	8.6	0.4	-0.2 to 0.9
			12	-0.3	NR	9	0.03	-0.5 to 0.6
			Fixed					

Author	Outcome measure		Assess point (weeks)	Mean group difference (Variance)	95% confidence intervals	SD	Hedge's g	95% confidence intervals
	Self-report	Instrument						
			6	-4	NR	8.1	0.5	-0.1 to 1.1
			12	-1.4	NR	9.5	0.1	-0.5 to 0.8
	mMRC[a] (0-4)		**Fixed-interactive**					
			6	-0.01	NR	0.8	0.01	-0.5 to 0.6
			12	0.1	NR	0.8	-0.1	-0.7 to 0.5
			Fixed					
			6	-0.2	NR	0.8	0.2	-0.2 to 0.9
			12	-0.1	NR	0.7	0.2	-0.5 to 0.6
Geraghty et al. 2017 **Dizziness**	**VSS-SF (0-60)**		12	-2.8	-1.4 to -4.1	3.5	0.8	0.5 to 1
			24	-2.3	-0.3 to -4.1	7.23	0.31	0.1 to 0.6
Van Vugt et al. 2019 **Dizziness**	**VSS-SF (0-60)**		12	-4.3	-5.9 to -2.6	5.8	0.7	0.5 to 1.0
			24	-4.1	-5.8 to -2.5	5.8	0.7	0.4 to 1.0
Haglo et al. 2021 **Inflammatory rheumatic diseases**		**VO_2 max (ml/kg/ min)**	10	0.1	NR	6	0.02	-0.6 to 0.6
Yuan et al. 2021 **Fibromyalgia**	**WPI (0-19)**		6	0.2	-2.3 to 2.8	4.3	-0.05	-0.7 to 0.6
	VAS (0-10)		6	-0.4	-1.3 to 2.2	2.4	0.2	-0.4 to 0.8
	SS (0-12)		6	-0.2	-1.5 to 1.9	2.5	0.1	-0.5 to 0.7
Kelechi et al. 2020 **Venous leg ulcers**		**ROM (df) of right ankle (degrees)**	6	-3.1	NR	8.6	-0.35	-1.1 to 0.4
		ROM (df) of left ankle (degrees)	6	-6.3	NR	9.3	-0.65	-1.46 to 0.16
		Strength (pf) of right ankle (kg)	6	-4.4	NR	9	-0.5	-1.3 to 0.3
		Strength (pf) of left ankle (kg)	6	-1.8	NR	8.8	-0.2	-0.1 to 0.6

Author	Outcome measure		Assess point (weeks)	Mean group difference (Variance)	95% confidence intervals	SD	Hedge's g	95% confidence intervals
	Self-report	Instrument						
	FAAM (0-100)		6	-0.7	NR	30.8	-0.02	-0.8 to 0.8
		6MWT (m)	6	-18	NR	544.7	-0.03	-0.8 to 0.8
Maddison et al. 2015 **IHD**		**Peak VO_2 (ml/kg/ min)**	24	-0.2	-1.1 to 0.7	2.8	-0.1	-0.4 to 0.2
Wong et al. 2020 **CHD**	**SEE (0-90)**		12	0.3	-12 to 0.6	2.1	0.1	-0.1 to 0.3
			24	-0.03	-0.4 to 0.2	2.2	-0.02	-0.2 to 0.2
Wong et al. 2021 **Metabolic Syndrome**	**SEE (0-90)**		4	8.1	NR	15.6	0.5	0.1 to 1
			12	9.9	NR	15.9	0.6	0.2 to 1.2

Appendix J

Additional detail on coding and analysis in Interpretive Descriptive study

Data were analysed using conventional content analysis (Hsieh & Shannon, 2005). I initially read and reread the transcripts to allow for immersion in the data and to identify linkages and areas of potential interest. For context, I read them in conjunction with the researcher field notes taken at the time of the interviews. I then inductively coded the data, using exact words from the text, to capture key concepts and to maximise descriptive and interpretive validity (Sandelowski, 2000). All authors reviewed a purposeful selection of transcripts and initial key concepts and codes. We then met to discuss and explore consistent and conflicting interpretations. I analysed the data concurrently while continuing data collection which allowed me to challenge developing assumptions. I followed this process in an iterative cycle of returning to the original data to collate the codes and relevant data for re-coding and refinement. This process involved regular meetings of all authors to check for robustness of analysis. All authors examined and discussed initial codes and memos derived from the majority of transcripts (n=9) to identify meaningful clusters. Following this, I developed a coding framework with associated definitions, then analysed the remaining transcripts (n=3) by searching for statements that supported or challenged the proposed codes. This helped to refine the clusters and categorisation which were then discussed by all authors to identify themes. I entered all transcripts, memos and codes into NVivo 12 (QSR International Pty Ltd, 2018). I subsequently presented the findings to the stakeholder group to check for resonance (Lincoln & Guba, 1985) and inform final refinements.

Appendix K

Published manuscript: Interpretive Descriptive study

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Perceptions of a self-guided web-based exercise programme for shoulder pain after spinal cord injury: A qualitative study

Verna Stavric[1,2✉], Nicola L. Saywell[1] and Nicola M. Kayes[2]

STUDY DESIGN: Qualitative study.
OBJECTIVES: The benefits of exercise to reduce shoulder pain in people with spinal cord injury (SCI) are well documented. Digital health interventions offer a potential solution to overcome barriers to access rehabilitation support for exercise. The aim of this project was to gain people's perspectives to inform the development of a self-guided web-based exercise intervention. Shoulder Pain Intervention delivered over the interNet (SPIN) is a self-guided web-based intervention to prescribe, monitor, and progress evidence-based exercises for people living with SCI and shoulder pain.
SETTING: Community in Auckland, New Zealand.
METHODS: The Person-Based Approach was used as the framework. Using an Interpretive Descriptive methodology, data were collected in individual and focus group interviews, exploring participants' perceptions of this intervention idea. Data were analysed using conventional content analysis.
RESULTS: Sixteen participants took part and asked *Is it right for me?*. This had three main sub-themes. *Should I use it?*, whether I believe it will work for me right now; *Can I use it?*, whether I can operate the intervention competently and confidently and *Will I use it?*, whether it will be responsive to my unique needs, and keep me coming back.
CONCLUSIONS: Participants expressed their expectations and tipping points when considering using an intervention like this. These findings will inform and guide design and development of an acceptable technology-based intervention to increase the likelihood of engagement with a self-guided web-based exercise programme. The model developed from these themes could be used to inform future self-guided intervention development.

Spinal Cord; https://doi.org/10.1038/s41393-023-00877-3

INTRODUCTION

Management of shoulder pain in wheelchair users living with spinal cord impairment (SCI) often includes exercise-based rehabilitation. A programme of stretches and strengthening exercises has been shown to significantly reduce shoulder pain [1–4]. However, many people with SCI (pwSCI) who experience shoulder pain do not engage in these exercises [5]. They cite barriers to exercise and rehabilitation opportunities including limited access to knowledgeable health professionals, poor physical accessibility, and transportation difficulties [6]. Even when these barriers are addressed, persisting with exercises is difficult [5].

Self-guided web-based interventions could address these barriers and have been implemented successfully in other populations experiencing persistent pain [7]. However, existing web-based interventions [8–10] for pwSCI require ongoing input and monitoring from a clinician or do not provide structured exercise progression for shoulder pain.

Shoulder Pain Intervention delivered over the interNet (SPIN) is planned to be a self-guided web-based intervention using decision tree algorithms [11] to prescribe, monitor, and progress evidence-based exercises for pwSCI with shoulder pain [12]. The development of SPIN is supported by the Person-Based Approach (PBA) [12, 13]. The PBA approach seeks a deep understanding of the perspectives and psychosocial context of potential users through employing iterative qualitative research [13] and incorporating existing theories. Keeping users' needs and contexts in focus maximises engagement and effectiveness of an intervention [14, 15]. As such, understanding the psychosocial context of future users of SPIN is a critical component in this intervention development process. To that end, this study explored the experiences and perspectives of pwSCI regarding the possibility of a self-guided web-based exercise programme to inform the development of SPIN.

METHODS

Study design

This Interpretive Descriptive study [16] explored impressions and opinions of the possibility of a self-guided web-based exercise programme to treat shoulder pain. The project was approved by the Auckland University of Technology Ethics Committee (AUTEC) 18/263. A stakeholder group, formed as part of the larger project, was consulted to gauge how findings resonated with personal insights and experiences.

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Table 1. Interview guide.

Part 1 Sample of progressive interview questions
"What is your initial thought when you think of using a web-based exercise programme to treat your shoulder pain?"
"Now what if it is intended that you use this programme entirely independently?"
"What if the exercise programme will be set up and progressed without you seeing or being in contact with a health professional?"
Part 2 Probes and images of current web-based or app-based programme features are presented for feedback and comment
"What do you think of these features when thinking of a web-based exercise programme?"
"How would these features help with any of the concerns you raised earlier?"

Participants

People living with SCI were eligible for inclusion if they resided in New Zealand; were not engaged in a rehabilitation programme; were over 16 years old; had the capacity to give informed consent; were predominantly wheelchair users; and had experienced shoulder pain within the past 2 years. Participants were excluded if they were unable to communicate with the researcher for data collection.

Sampling and recruitment

Purposeful sampling was used for diversity in demography and to capture a breadth of perspectives and experiences. Advertisements were distributed within SCI community and rehabilitation providers (e.g. Spinal Support NZ, Neuro Rehab Results). Information was also circulated through social media sites and professional and personal networks. Our sample size was primarily determined by our goal to capture a breadth and diversity of experiences and we aimed to continue sampling until sufficient diversity was reached. We also drew on the concept of information power as a final check on sample sufficiency [17].

Data collection

Consent was obtained and recorded before data collection began. We collected data using individual and group semi-structured interviews (see Table 1 for interview guide) at participants' preferred location. We used probes to explore concepts of usability, safety, motivation, action planning, and progression. Participants were also asked about helpful features from websites or apps they currently used. We took notes and interviews were audio recorded, then transcribed verbatim.

Data analysis

We analysed the data using conventional content analysis [18], reading transcripts in conjunction with the field notes. VS inductively coded the data, using exact words from the text, to capture key concepts and maximise descriptive and interpretive validity [19]. A coding framework was derived from initial coding of the majority of transcripts ($n = 9$). VS exported all transcripts and the coding framework into NVivo 12 [20] and analysed the remaining transcripts, identifying meaningful clusters. All authors met regularly to discuss and contribute to theme construction. Preliminary themes were presented to the stakeholder group to check for resonance [21], and inform final refinements.

FINDINGS

Participant demographics

Sixteen pwSCI with shoulder pain took part in individual ($n = 8$) and focus group ($n = 8$, 4 groups) interviews (Table 2). In one focus group, a support worker also contributed. Participants' ages ranged from 30 to 67 years. We achieved diversity on the majority of key characteristics as reflected in Table 2, and the final sample has good information power in the context of the study aims, sample specificity, quality of dialogue, and analytical strategy.

Table 2. Participant demographics.

Demographic item	Category	Number of participants
Age (years)	30–44	4
	45–59	9
	60+	3
Ethnicity	NZ European	12
	Māori*	1
	Pasifika	3
Level of injury	Tetraplegia	7
	Paraplegia	9
Completeness of injury	Complete	11
	Incomplete	5
Time since injury (years)	0–10	2
	11–20	5
	20+	9
Living setting	Urban	12
	Rural	4
Wheelchair type	Manual	15
	Power	1
Interview type	Focus Group	8
	Individual Interview	8

*Indigenous population of New Zealand.

Main findings

Participants engaged in an evaluative process when considering the programme, asking *Is it right for me?*. Our findings suggest this was a nuanced and multi-layered process that consisted of supporting questions or themes to help inform the overarching question. These were: *Should I use it?*, *Can I use it?* and *Will I use it?*.

The relationship between these themes is presented in Fig. 1. *Should I use it?* reflects the first step in deciding to take up the programme. If participants determine that the programme has fit for them, they ask *Can I use it?* and *Will I use it?*. If their evaluation suggests that the programme is not responsive to their needs, they may cycle back to questioning *Should I use it?*. This in turn may make them reconsider *Is it right for me?*. The model reflects this cyclical process in deciding if the programme is right for them.

Theme 1: Should I use it?

Should I use it? represents the first step, deciding whether to start using the programme. Participants identified several factors that were important in their initial appraisal.

Credibility. Participants required their first impression to be of a credible programme which will meet their needs. Having the programme recommended by a trusted source was preferable to randomly finding it and having to evaluate it independently. Participants identified professional endorsement to be of value,

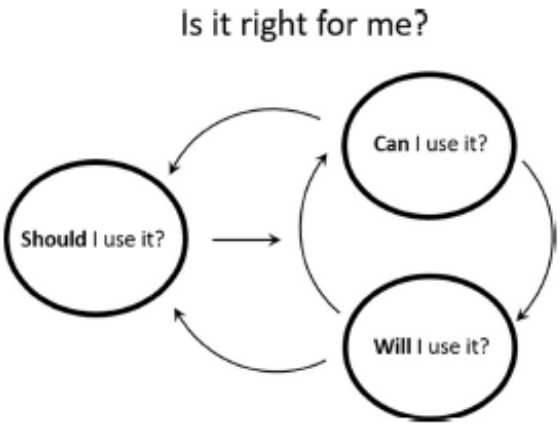

Fig. 1 Evaluative process when considering a self-guided web-based programme. Overview of key themes highlighting the evaluative process people with SCI work through when thinking about the possibility of a self-guided web-based exercise programme.

but highlighted that connection with and learning from peers with lived experience was even more powerful.

> […]if you've been set up for it by someone you know and trust, either the spinal unit or the physio you've been working with for a while, that would be different but […] if it's just something you stumbled across because you Googled for it […] somehow it wouldn't carry the same weight, or have the same authority. (Jeremy, C6 tetraplegic)

Safety. Safety of the programme was important. Clarity on how each user would be screened, without human oversight, helped to determine safety and engender trust. Despite an inherent assumption that exercise programmes delivered and monitored by humans would be safer and be able to be tailored to the unique needs of users, it was acknowledged that this was not always the case.

> Mind you, you can get that with human factor anyway. You might diagnose me wrong too so who cares. And one physio might recommend something different to another, doctors are exactly the same. (Tony, C6 tetraplegic)

Perceived value. Perceived value included the benefits of exercise generally, the extent to which exercise could address shoulder pain, and whether the proposed programme would address outcomes of value. Participants acknowledged that reduced access to other traditional or preferred treatments would increase the appeal and value of this programme.

> I have shoulder pain […] eventually it goes to the […case manager who…] makes a referral to the physio. Then there's a stand down period of time. Meanwhile I've just got to figure out my own kind of remedy. […] probably we're looking at maybe 4–6 months […] there's a loss of that whole period of time where I could have got some help. (Eleanor T12/L1 paraplegic)

Past experience with exercise shaped how the programme was perceived, influencing the value placed on exercise and a person's intention to exercise. While participants were overwhelmingly positive about the value of exercise for addressing shoulder pain, in some situations exercising was not always considered as important or achievable. There was a range of factors, including timing and competing demands, believed to influence uptake of an exercise programme.

> As you get older […] looking after your health is the most important thing. When you're younger […] it's on the list but it's not as high up the list. (Michael, T12/L1 paraplegic)

Theme 2: Can I use it?

Participants identified factors that would influence their interaction and ongoing engagement with the programme. *Can I use it?* captures the notion of using the programme and performing the exercises with confidence.

Feeling competent. Participants expected the programme to guide them to perform and progress the exercises correctly, for best effect. Support workers also wanted guidance from the programme to assist pwSCI to exercise accurately and effectively. Participants related concerns they experience in their daily life with respect to provision of support, including challenges with consistency, and confidence in how their care is delivered, which had the potential to affect programme uptake. This was considered particularly pertinent in the context of high support worker turnover or when therapy is provided by less experienced clinicians.

> You know when something didn't quite go right, they (support workers) didn't have the training and the knowledge to know which way to jump to sort it out, so we'd give up on it you know. (Jeremy, C6 tetraplegic)

Technological competence and usability of the programme also influenced participants' answer to *Can I use it?*. Recurrent techincal issues were factors that were believed to influence ongoing engagement with the programme. The usability and clarity of the programme must maximise the chance of successful use and effective exercise performance by users of all levels, with minimal support.

> I think that something you'd have to consider, is it's a lot easier not to ask for help and not do the exercise… Yeah just give up. (Robert, C5 tetraplegic)

Having control. Participants recognised the autonomy this programme could bring. They endorsed programme features which put them in charge, allowing them to personalise the programme and meet individual needs and preferences. Having agency to make decisions best suited to each individual, could reinforce engagement through a sense of ownership and control.

> Being able to tailor your own solutions, I think is a very important aspect. I hate the term that gets bandied around a lot, empowering you to do this thing or the other, but I mean that is precisely what that's doing, and I believe it's important. (Jeremy, C6 tetraplegic)

Practical considerations were important, like procuring and securing equipment, and the support they would need to carry out the exercises. Participants who relied on support from others expressed that the helper's capacity and beliefs influenced exercise completion, positively and negatively. The need to preserve the relationship has the potential to outweigh the drive to request help with an exercise routine, as it can become an additional demand to the usual list of cares.

> … and then, the exercises rely on having the TheraBand set up in such a way that you can do the exercises, now somebody has to set me up with that TheraBand, and that person has to be a willing participant. (Robert, C5 tetraplegic)

Theme 3: Will I use it?

Will I use it? reflects participants' views on the importance of being engaged by the programme to encourage them to keep coming back and complete the exercises.

Fostering positive experiences. Participants discussed how positive emotional experiences would be an important hook to encourage users and keep them interested. Participants suggested that early success and progression of exercise performance was one mechanism to achieve this. Being able to track performance and progress was seen as feedback that would encourage users.

The use of messages that give feedback on performance was also considered important. The tone, language and timing of this information were discussed. Some participants felt they would respond to a supportive tone whereas others felt a challenging and competitive tone was more motivating.

> You could have of fun with it, you know, and to engage and use it, they could customise it. So, I might have mine that says, 'you know, come on, you haven't done it for two days, 'the ** you doing?!' And it's kind of their own reminder so it's part of the whole orientation. Do you want to remind yourself? I do. (George, C6 tetraplegic)

The use of rewards to encourage return to the programme and focus on the goal was also discussed. Several participants suggested using gamification principles like awarding points for tasks to provide a positive experience and encourage regular use.

> It would give me my points for doing the exercises regularly, 3 days a week, 3 times a week, […], if I miss a day then I drop a few points, so that there's a desire to not miss a week you know, and I'm beating that guy so I'm doing better than he is […] The gaming aspect is to try and engage most people's inherent competitive nature, even if they're only competing against themselves. (Lawrence, T12/L1 paraplegic)

Seeing progress. Seeing progress in exercise performance or function, was important in promoting programme value. Participants spoke of their sense of success when they realised they could perform more exercises than they thought. This gave them the confidence to do more exercise and engage more in everyday activities. There was an understanding that progress can vary and the goal may be to increase daily activity or function, while keeping pain under control, rather than eliminate all pain. Ensuring meaningful progress is captured was considered formative to providing a personalised programme that accounts for user's needs and preferences. This was important to ensure ongoing engagement, when there is no clinician involvement.

> Yeah, I think the feedback that I would want to see, is a graph of my progress, so that I can see that I'm actually improving. (Robert, C5 tetraplegic)

Feeling connected. Participants spoke about how feeling connected helped them stay engaged and feel supported. While they felt this should come from their health professional, they valued support and encouragement from anybody who was interested and invested in their success. This support helped them stay on track and be accountable.

> I know from my previous life experience, that I always work better when I've got somebody to encourage me, or somebody that's interested, because they're interested in how I'm getting on. They don't want to see me suffering from sore shoulders. Yeah, so that connection might be really important. (Robert, C5 tetraplegic)

If accountability could be built into the system, participants were challenged to consider whether it mattered where it came from. Connection and accountability could come from nominated people, other users, and from the programme despite there not being a health professional involved. However, this was not universally endorsed.

> …if it was totally autonomous and there was no personal interaction whatsoever, they may not have all that interest in it, or they lose interest too quickly or whatever, it's just a soulless computer programme, nobody at the other end. (Robert, C5 tetraplegic)

DISCUSSION

We used the PBA to explore perceptions, of pwSCI, when considering using a self-guided web-based exercise programme to treat shoulder pain. The overarching question participants asked was *Is it right for me?*. Reinforcing this was a continuous process of revisiting the supporting questions of *Should I use it?*, *Can I use it?*, and *Will I use it?*.

Should I use it? highlighted the importance of credibility and safety when using a web-based intervention. PwSCI accessing web-based physical activity information have expressed a preference for knowing material came from a reliable source [22]. Features that promote credibility and guidance have been shown to increase trust in an intervention in other populations [23].

Can I use it? reflected participants' views about using the programme competently, confidently, and autonomously. The ability to tailor features, including prompts, has been employed by other self-management interventions after SCI [22, 24], increasing the programme's personal relevance. Our findings confirm those of Singh et al. [9] who reported that a self-management app for pwSCI would need to be intuitive and offer user flexibility and control.

Will I use it? related to ongoing engagement and motivation to keep returning to the programme and exercises. Strategies that were identified were consistent with findings from previous studies: being able to monitor progress to measure improvement and stay accountable [15, 22], and using peer connection [22, 24]. Perski et al. found that features which facilitated social support [24] positively influenced engagement [25].

In addition to the identified themes, three concepts were interwoven throughout the data: needing to feel connected, feel competent and have autonomy. These concepts align well with Self-Determination Theory (SDT), which proposes that three basic psychological needs have to be met to be self-determining and autonomously motivated; a need for competence, relatedness, and autonomy [26]. In the context of SPIN, users would need to feel competent using it, feel connected to it or others while using it, and have a sense of control or choice when using it. Development of SPIN will incorporate these concepts into its design.

SPIN development and roll-out implications

The design goal of SPIN is to incorporate features that can create experiences without a clinician being present. This requires intentional use of intervention features that engender confidence

that SPIN is a safe, effective, and personalised programme. This study's findings confirm previous findings that interventions need to be tailored, theory-based, multimodal, and incorporate behavioural strategies [15, 27]. Drawing on the PBA, our next step is to use what we have learned in this research, and from existing theory and evidence, to develop a set of guiding principles which articulate the intervention design objectives and the features needed to achieve these objectives [12]. Using the PBA in pwSCI with shoulder pain, has highlighted what they need from this self-guided exercise intervention. Our findings highlight that when SPIN is developed and ready for implementation, our roll out plan should include liaising with SCI clinicians and services to promote SPIN as an evidenced-based tool to augment current intervention options. Recommendations of SPIN from these credible sources would increase trust and uptake.

STRENGTHS AND LIMITATIONS

Strengths

The tiered process of questioning in this study allowed a depth of discussion and analysis in keeping with the PBA. The range of participants, coupled with the stakeholder group, ensured that findings have transferability to pwSCI. The robust methodological and analytic approach ensured that our findings went beyond a semantic level, to identify a deeper decision-making process, explaining a clinical phenomenon. This model could be applied when reflecting on the development of any self-guided intervention.

Limitations

Our findings may not be representative of the entire SCI community who live with shoulder pain. The perspectives of Māori, or indeed other indigenous and culturally diverse populations, and those who live rurally were not fully captured in this research. Future work will purposively work with these subgroups.

CONCLUSIONS

This study used the PBA to investigate the perceptions and experiences of pwSCI with shoulder pain to inform the development of a self-guided web-based exercise intervention. The involvement of participants in the early development phases has enabled us to identify key decision-making points when considering intervention uptake and ongoing use. This will inform the design of the SPIN programme and will act as a model which could inform the development of other self-guided interventions.

DATA AVAILABILITY

Data that was generated and analysed during this study can be found within the published article. Additional data are available from the corresponding author on reasonable request.

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AUTHOR CONTRIBUTIONS

All authors contributed to the study conception and design, and analysis. Material preparation, and data collection were performed by VS and analysis were performed by VS, NLS and NMK. The first draft of the manuscript was written by VS and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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COMPETING INTERESTS

The authors declare no competing interests.

ADDITIONAL INFORMATION

Supplementary information The online version contains supplementary material available at https://doi.org/10.1038/s41393-023-00877-3.

Correspondence and requests for materials should be addressed to Verna Stavric.

Appendix L

Ethics approval for the Interpretive Descriptive study

Auckland University of Technology Ethics Committee (AUTEC)

Auckland University of Technology
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T: +64 9 921 9999 ext. 8316
E: ethics@aut.ac.nz
www.aut.ac.nz/researchethics

8 August 2018

Nicola Saywell
Faculty of Health and Environmental Sciences

Dear Nicola

Re Ethics Application: **18/263 Shoulder Pain Intervention delivered over the Net (SPIN) after Spinal Cord Injury (SCI)**

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

Your ethics application has been approved for three years until 7 August 2021.

Standard Conditions of Approval

1. A progress report is due annually on the anniversary of the approval date, using form EA2, which is available online through http://www.aut.ac.nz/research/researchethics.
2. A final report is due at the expiration of the approval period, or, upon completion of project, using form EA3, which is available online through http://www.aut.ac.nz/research/researchethics.
3. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form: http://www.aut.ac.nz/research/researchethics.
4. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
5. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.

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

AUTEC grants ethical approval only. If you require management approval for access for your research from another institution or organisation then you are responsible for obtaining it. You are reminded that it is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard.

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

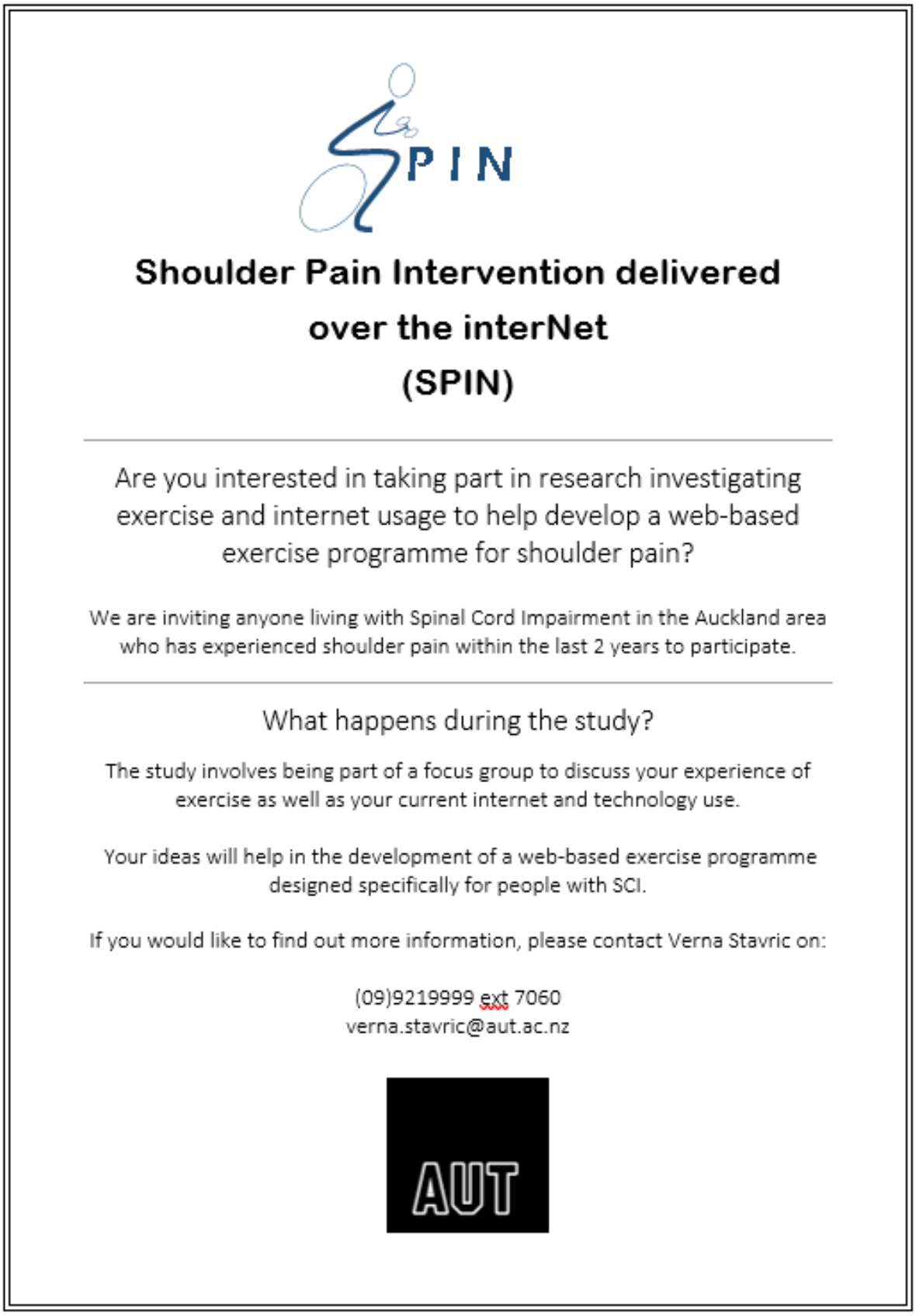
Yours sincerely,

Kate O'Connor
Executive Manager
Auckland University of Technology Ethics Committee

Cc: verna.stavric@aut.ac.nz; Nicola Kayes

Appendix M

Invitation to participants to be involved in SPIN (Interpretive Descriptive) study



Appendix N

Participant information sheet for the Interpretive Descriptive study

Participant Information Sheet

Appendix B Phase 1 Focus Group Interviews

Date Information Sheet Produced:

7 August 2018

Project Title

Shoulder Pain Intervention delivered over the Net (SPIN)
after
Spinal Cord Injury (SCI)

An Invitation

Kia ora, talofa lava and hello, you are invited to take part in a study aiming to understand how you currently manage your shoulder pain, how you access the internet and how an exercise programme may best be designed using the internet. This will help us to design an exercise programme that addresses shoulder pain for wheelchair users. This study is part of PhD project. Please remember that:

- Your participation in this study is entirely voluntary (your choice). You do not have to take part in this study.
- If you do agree to take part, you are free to withdraw up until we begin to review the transcripts, without having to give a reason. This will in no way affect your current or future health care.
- Participation in this study will be stopped should you appear to be uncomfortable or in any distress.
- If you like, you are encouraged to involve anyone to support you, such as your partner, carer and whanau at any stage of the study.

This information sheet will explain the research study. Please feel free to ask about anything you do not understand or if you have questions at any time.

What is the purpose of this research?

This study is exploring what makes it easy or hard for you to exercise and what makes it easy or hard to access and use the internet. This is being carried out through the Department of Physiotherapy at AUT University.

We want to:

a) Understand what you currently find easy or difficult in accessing or doing exercise.
b) Understand how you access the internet and digital devices and applications.
c) Ask your perceptions about what you would like to see in a web-based exercise programme.

The findings of this study will help us with the next phase of the study which will be to develop a prototype of a web-based exercise programme that has exercises to treat shoulder pain.

Being able to access and use a programme on your own that has been specifically designed for wheelchair users' shoulder pain would help increase your access to specialised care.

The results of this study may also be presented and published in professional settings to let health care professionals know of the work being done in this area and will help Verna work towards her PhD.

How was I identified and why am I being invited to participate in this research?

You have been invited to participate in the research because you are living with spinal cord impairment (SCI), are currently living in the Auckland area and have experienced shoulder pain in the last 2 years. You will have expressed an interest after seeing the advertisements or hearing about this study at a rehab clinic or through word of mouth and have either contacted me, or given permission for me to contact you.

I will need to ask you some questions about your characteristics such as your age, ethnicity, gender, level of SCI impairment and living situation and give you a chance to ask any questions before we plan the focus group interviews. We are limited in the number of people we are able to include in the focus groups. These focus groups provide the best information when they include people with a broad range of characteristics and perspectives.

After we talk, if you are still interested and the focus groups still require someone with your characteristics, you will be invited to one of the focus groups.

However, If the details you provide suggest that our focus groups already have similar representation, I will let you know. You will still be able to receive information of the findings from the study.

If you would like time to think about it this study, I will contact you again in 2 weeks. At that time, you can let me know if you are interested.

How do I agree to participate in this research?

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

If you agree to take part in the study, please make contact with Verna to indicate your willingness to be involved. She will arrange a time for the focus group interview. Before starting this session, you will be asked to complete a Consent Form, which Verna will provide, to record your willingness to take part in this study.

What will happen in this research?

We will be conducting focus group interviews, asking for your opinions and thoughts. The questions will focus on your experiences exercising, using internet devices and your impressions of what is important in a web-based exercise programme. We will also ask you for your views and thoughts on a prototype of an exercise programme. We will ask for your agreement to audio record the session. We will also ask about videoing any images and activities to help explain the audio recording. We will not be filming your face.

What are the discomforts and risks?

Taking part in the sessions will take some of your time (approximately 60-90 minutes). It is possible you may find talking about your experiences difficult or you may find it to be helpful. During the focus group or interview, you do not have to discuss any topic you find distressing and can stop at any point.

How will these discomforts and risks be alleviated?

If sensitive or distressing issues do arise during the focus group or interview, and you would like to discuss these with someone afterwards, please let us know so we can connect you with some support.

AUT Health Counselling and Wellbeing is able to offer three free sessions of confidential counselling support for adult participants in an AUT research project. These sessions are only available for issues that have arisen directly as a result of participation in the research, and are not for other general counselling needs. To access these services, you will need to:

- drop into our centres at WB219 or AS104 or phone 921 9992 City Campus or 921 9998 North Shore campus to make an appointment. Appointments for South Campus can be made by calling 921 9992
- let the receptionist know that you are a research participant, and provide the title of my research and my name and contact details as given in this Information Sheet

You can find out more information about AUT counsellors and counselling on http://www.aut.ac.nz/being-a-student/current-postgraduates/your-health-and-wellbeing/counselling.

What are the benefits?

For participants: You will be able to contribute to the development of a self-guided web-based exercise intervention to treat shoulder pain. You will have an opportunity to reflect on your experiences and you may benefit from hearing the experiences of other group members.

For the researcher: The benefits will be to better understand what factors have influenced your exercise, how you interact with the internet and how a self-guided, web-based exercise intervention to treat shoulder pain may be best developed to meet your needs. This will help inform further development of a self-guided web-based intervention and will help towards the Verna's PhD.

What compensation is available for injury or negligence?

In the unlikely event of a physical injury as a result of your participation in this study, rehabilitation and compensation for injury by accident may be available from the Accident Compensation Corporation, providing the incident details satisfy the requirements of the law and the Corporation's regulations.

How will my privacy be protected?

The focus group and interview recording and all other information that you provide will remain strictly confidential. No material that could personally identify you will be used in any reports from this study.

Upon completion of the study your records will be stored for at least 10 years in a secure, locked cabinet at Auckland University of Technology. All computer records will be password protected. All future use of the information collected will be strictly controlled in accordance with the Privacy Act.

What are the costs of participating in this research?

There will not be any cost to you except your time – about 1 to 1 ½ hours in total. If you need to travel to a focus group or interview, we will cover any travel costs that you incur with a $20 petrol voucher. This should also cover the cost of travel for a support person should you wish to bring one with you.

What opportunity do I have to consider this invitation?

You will be given at least 2 weeks to consider whether or not you would like to participate. You will be contacted at this point by Verna who will answer any further questions you may have. If you require, you will be given one more week to decide if you would like to participate.

Will I receive feedback on the results of this research?

If you would like to receive a summary of findings you can say so on the consent form and they will be sent to you at the end of the study.

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

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Nicola Saywell, nicola.saywell@aut.ac.nz, 09 921- 9502.

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC, Kate O'Connor, *ethics@aut.ac.nz*, 921 9999 ext 6038.

Whom do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

Researcher Contact Details:

Verna Stavric, verna.stavric@aut.ac.nz, 09 921-9999 ext 7060.

Project Supervisor Contact Details:

Nicola Saywell, nicola.saywell@aut.ac.nz, 09 921-9999 ext 9502.

Nicola Kayes, nicola.kayes@aut.ac.nz, 09 921-9999 ext 7309

Approved by the Auckland University of Technology Ethics Committee on *type the date final ethics approval was granted*, AUTEC Reference number *type the reference number*.

Appendix O

Consent forms for the Interpretive Descriptive study

Consent Form

Appendix D For use when focus groups are involved.

Project title: ***Shoulder Pain Intervention delivered over the interNet (SPIN)***

Project Supervisors: ***Nicola Saywell and Nicola Kayes***

Researcher: ***Verna Stavric***

- O I have read and understood the information provided about this research project in the Information Sheet dated 25 June 2018.
- O I have had an opportunity to ask questions and to have them answered.
- O I understand that identity of my fellow participants and our discussions in the focus group is confidential to the group and I agree to keep this information confidential.
- O I understand that notes will be taken during the focus group or interview and that it will also be audio-taped and transcribed.
- O I understand that there will also be video recording to help record what images and activities that were discussed.
- O 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.
- O I understand that if I withdraw from the study then, while it may not be possible to destroy all records of the focus group discussion of which I was part, I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.
- O I agree to take part in this research.
- O I agree to having the session video recorded: YesO NoO
- O I wish to receive a summary of the research findings (please tick one): YesO NoO

Participant's signature: .....

Participant's name: .....

Consent audio-recorded: .....

Participant's Contact Details (if appropriate):

.....

.....

.....

.....

Date:

Approved by the Auckland University of Technology Ethics Committee on 08 August 2018 AUTEC Reference number 18/263

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

Consent Form

Appendix E For use when interviews are involved.

Project title: ***Shoulder Pain Intervention delivered over the interNet (SPIN)***

Project Supervisor: ***Nicola Saywell and Nicola Kayes***

Researcher: ***Verna Stavric***

- O I have read and understood the information provided about this research project in the Information Sheet dated 25 June 2018.
- O I have had an opportunity to ask questions and to have them answered.
- O I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.
- O I understand that there will also be video recording to help record what images and activities that were discussed.
- O 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.
- O I understand that if I withdraw from the study then I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.
- O I agree to take part in this research.
- O I agree to having the session video recorded: YesO NoO
- O I wish to receive a summary of the research findings (please tick one): YesO NoO

Participant's signature: .....

Participant's name: .....

Consent audio-recorded: .....

Participant's Contact Details (if appropriate):

.....

.....

.....

.....

Date:

Approved by the Auckland University of Technology Ethics Committee on 08 August 2018 AUTEC Reference number 18/263

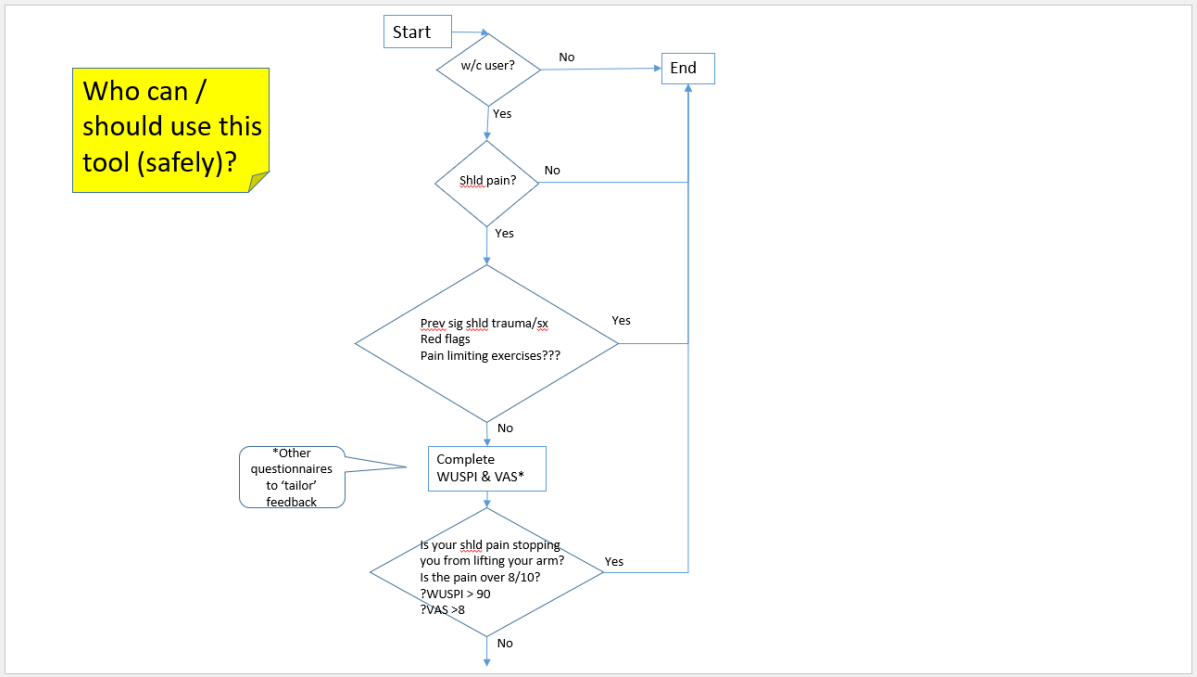
Note: The Participant should retain a copy of this form

Appendix R

Initial screening questions and decision trees

A significant consideration in the early design stages was to explore ways that a self-guided intervention could be used safely, in a way that would minimise harm to users' shoulders. Being clear that the intervention had this built-in would support *Should I use it?* and allows users to understand if the programme was right for them. The decision tree focused on suitabilty and the subsequent screening questionnaire was devised to be simple to use but indentify those for whom SPIN was not appropriate but be better suited to seek face-to-face input.

Decision tree:



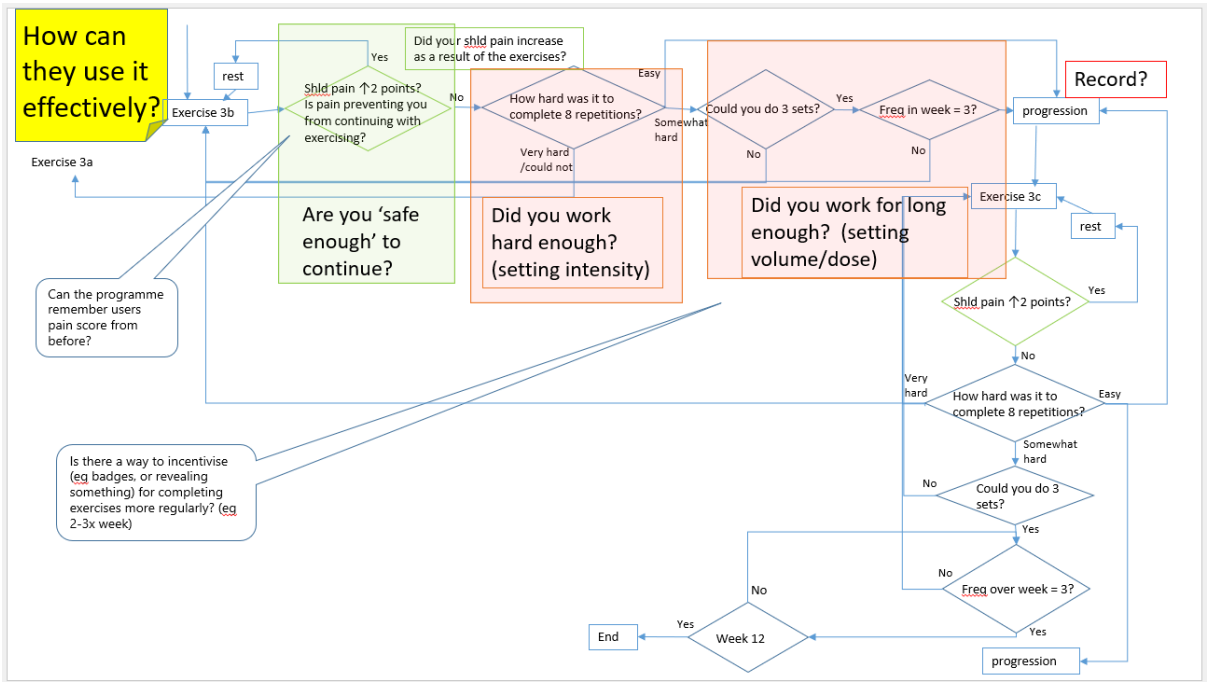
Through further consultation, it was later decided to remove several questions such as the Wheelchair Users Shoulder Pain Index (WUSPI) and asking if pain was stopping the performance of exercises.

During supervision meetings and meetings with physiotherapy academics, there was discussion about weighing up the added value of using the WUSPI compared to using Visual Analogue Scale (VAS) to screen for, monitor, and track pain while using SPIN. WUSPI has been used to measure shoulder pain outcome in observational and clinical

trials (Mulroy et al., 2011; Salisbury et al., 2006). Given that it is 15-item measure and it has a strong correlation (r=0.723) with VAS (Salisbury et al., 2006), a pragmatic decision was made to only include the VAS (NRS in SPIN). PwSCI were consulted on this decision during the development phase and fully supported it to improve their ease of use and flow through the wireframes.

During the development phase, pwSCI consistently misinterpreted the screening question "Is shoulder pain stopping you from lifting your arm" and ruled themselves out of SPIN. In consultation with pwSCI and physiotherapy clinicians, the decision was made to remove this question.

Below is an example of other intial decision tree concepts that were created when beginning to explore how exercises could be progressed in a self-guided intervention, using a pattern that follows clinical decision making parameters of safety and progressive loading based on user responses.



Screening questionnaire:

Screening Questionnaire:

Should you use this program?

Answer the following questions to find out if this program is right for you.

(to be displayed one at a time, and progressed, depending on the answer)

1. Are you a wheelchair user?

Yes **No** Yes-progress to 2
No- "Thank you for your interest in this program. This program is not suitable for you at this time."

2. Do you have shoulder pain?

Yes **No** Yes-progress to 3,
No- "Thank you for your interest in this program. This program is not suitable for you at this time."

3. Do any of these apply to you?

-Have you had any surgery on your shoulder for the pain?

-Is your shoulder pain because of significant trauma, a rheumatic condition (arthritis) or malignant disease (cancer)?

-Does your shoulder pain limit you from doing any sort of shoulder exercise?

No **Yes** No-progress to registration information
Yes- "Thank you for your interest in this program. Consider talking to a health professional about your shoulder pain."

Registration: To be able to keep track of your work and your progress, you will need to register now and then log in before each time you exercise in the future.

(Provide registration buttons and options and record registration and login details)

Registration
Username
Email address
Mobile phone (for text reminders)
Password
Login
Username
Password

(Once registration complete, show question below and with each login, show question below)

How painful is your shoulder now?

(a sliding scale would be good with a changing smiling face)

0_____**10**

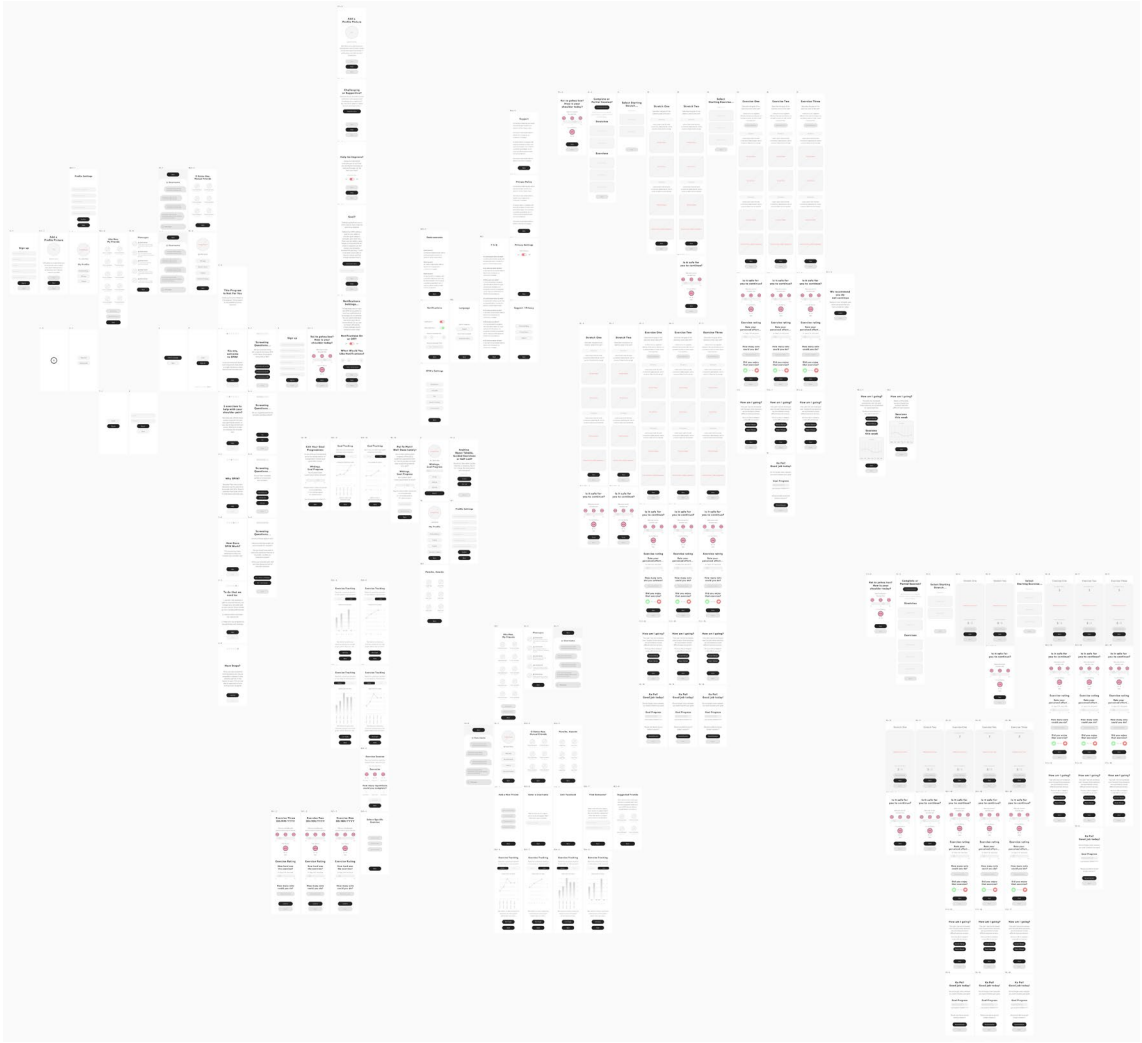

No pain **Very painful**

(record this number with the date and their login)

Appendix S

SPIN wireframe V.1

Below is a screenshot that contains an image of all the SPIN wireframes V.1 shown to pwSCI during the 'think aloud' sessions and demonstrates the relationship between them. Note this png file can be enlarged on screen for easier viewing.



Appendix T

Ethics approval for focus groups and 'think aloud' sessions

Auckland University of Technology Ethics Committee (AUTEC)

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

27 September 2021

Nicola Saywell
Faculty of Health and Environmental Sciences

Dear Nicola

Re: Ethics Application: **18/263 Shoulder Pain Intervention delivered over the Net (SPIN) after Spinal Cord Injury (SCI)**

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

The amendment to Phase 2 (exploring how usable the web-based programme prototype) for the option of interviews to be conducted online and an extension for one year has been approved.

Non-Standard Conditions of Approval

1. Remove the reference in the third bullet point of the Information Sheet about withdrawing until the review of the transcripts. The correct withdrawal statement is in the 'How do I agree ...

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

Standard Conditions of Approval.

1. The research is to be undertaken in accordance with the Auckland University of Technology Code of Conduct for Research and as approved by AUTEC in this application.
2. A progress report is due annually on the anniversary of the approval date, using the EA2 form.
3. A final report is due at the expiration of the approval period, or, upon completion of project, using the EA3 form.
4. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form.
5. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
6. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.
7. It is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard.
8. AUTEC grants ethical approval only. You are responsible for obtaining management approval for access for your research from any institution or organisation at which your research is being conducted. When the research is undertaken outside New Zealand, you need to meet all ethical, legal, and locality obligations or requirements for those jurisdictions.

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

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

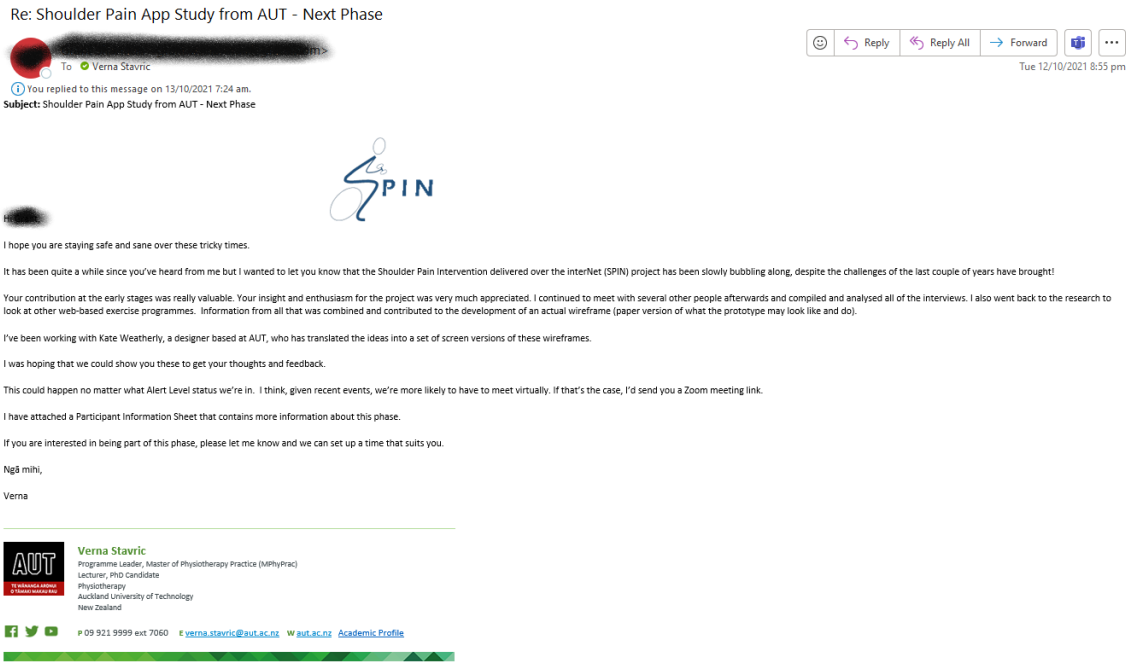
(This is a computer-generated letter for which no signature is required)

The AUTEC Secretariat
Auckland University of Technology Ethics Committee

Cc: _____,verna.stavric@aut.ac.nz; Nicola Kayes

Appendix U

Invitation to participate sent to pwSCI



Re: Shoulder Pain App Study from AUT - Next Phase

[redacted]
To Verna Stavric

Reply | Reply All | Forward

Tue 12/10/2021 8:55 pm

You replied to this message on 13/10/2021 7:24 am.

Subject: Shoulder Pain App Study from AUT - Next Phase

SPIN

[redacted]

I hope you are staying safe and sane over these tricky times.

It has been quite a while since you've heard from me but I wanted to let you know that the Shoulder Pain Intervention delivered over the interNet (SPIN) project has been slowly bubbling along, despite the challenges of the last couple of years have brought!

Your contribution at the early stages was really valuable. Your insight and enthusiasm for the project was very much appreciated. I continued to meet with several other people afterwards and compiled and analysed all of the interviews. I also went back to the research to look at other web-based exercise programmes. Information from all that was combined and contributed to the development of an actual wireframe (paper version of what the prototype may look like and do).

I've been working with Kate Weatherly, a designer based at AUT, who has translated the ideas into a set of screen versions of these wireframes.

I was hoping that we could show you these to get your thoughts and feedback.

This could happen no matter what Alert Level status we're in. I think, given recent events, we're more likely to have to meet virtually. If that's the case, I'd send you a Zoom meeting link.

I have attached a Participant Information Sheet that contains more information about this phase.

If you are interested in being part of this phase, please let me know and we can set up a time that suits you.

Ngā mihi,

Verna

AUT

Verna Stavric
Programme Leader, Master of Physiotherapy Practice (MPhyPrac)
Lecturer, PhD Candidate
Physiotherapy
Auckland University of Technology
New Zealand

P 09 921 9999 ext 7060 E verna.stavric@aut.ac.nz W aut.ac.nz Academic Profile

Appendix V

Participant information sheet for focus groups and 'think aloud' sessions

Participant Information Sheet

Appendix C Phase 2 Interviews

Date Information Sheet Produced:

27 September 2021

Project Title

Shoulder Pain Intervention delivered over the Net (SPIN)
after
Spinal Cord Injury (SCI)

An Invitation

Kia ora, talofa lava and hello, you are invited be part of a study aiming to understand how you currently manage your shoulder pain, how you access the internet and to design an exercise programme so that it can be delivered effectively and easily over the internet. This will help us to design an exercise programme that addresses shoulder pain for wheelchair users. This study is part of PhD project. Please remember that:

- We acknowledge how COVID has made life more complicated.
- Your participation in this study is entirely voluntary (your choice). You do not have to take part in this study.
- Participation in this study will be stopped should you appear to be uncomfortable or in any distress.
- If you like, you are encouraged to involve anyone to support you, such as your partner, carer and whanau at any stage of the study.

This information sheet will explain the research study. Please feel free to ask about anything you do not understand or if you have questions at any time.

What is the purpose of this research?

This phase of the study is exploring how usable the web-based programme prototype is for you. This is being carried out through the Department of Physiotherapy at AUT University.

We want to:

a) Ask about what you like and dislike about the web-based exercise programme prototype as you read through it.

b) Find out how easy it is to understand as you read through the web-based exercise programme prototype.

The findings of this study will help us further develop and test a web-based exercise programme that has exercises to treat shoulder pain.

Being able to access and use a programme on your own that has been designed to focus on shoulder pain in wheelchair users would be one way for you to get care for your specific needs.

The results of this study may also be presented and published in professional settings to let health care professionals know of the work being done in this area and will help Verna work towards her

PhD.

How was I identified and why am I being invited to participate in this research?

You have been invited to participate in the research because you are living with spinal cord impairment (SCI), are currently living in the Auckland area and have experienced shoulder pain in the last 2 years. You will have expressed an interest after seeing the advertisements or hearing about this study at a rehab clinic, or word of mouth and have either contacted me, or given permission for me to contact you.

You may have also already participated in the first phase of this research and heard about this next phase.

These sessions provide the best information when they include people with a broad range of characteristics and we are looking for participants who will represent a range of perspectives and characteristics. However, we are limited in the number of people we are able to include in this phase of the study.

After we talk, if you are still interested and the sessions still require someone with your characteristics, you will be invited to participate. However, If the details you provide suggest that these sessions already have similar representation, I will let you know. You will still be able to receive information of the findings from the study.

If you would like time to think about it this study, I will contact you again in 2 weeks. At that time, you can let me know if you are interested.

How do I agree to participate in this research?

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

If you agree to take part in the study, please make contact with Verna to indicate your willingness to be involved. She will arrange a time. Before starting this session, you will be asked to complete a Consent Form, which Verna will provide, to record your willingness to take part in this study.

What will happen in this research?

We will be conducting interviews, asking for your opinions and thoughts. We will meet in person or virtually (over Zoom), depending on Alert Levels and on your preference. The questions will focus on what you like and dislike about presentation of the sample web-based exercise programme prototype and what you find easy or difficult when reading through the sample web-based exercise programme prototype. Any video data used in reporting will be de-identified. We will always ask you before commencing any recording.

What are the discomforts and risks?

Taking part in the sessions will take some of your time (approximately 60 minutes). It is possible you may find talking about your experiences difficult or you may find it to be helpful. During the interview, you do not have to discuss any topic you find distressing and can stop at any point.

How will these discomforts and risks be alleviated?

If sensitive or distressing issues do arise during the interview, and you would like to discuss these with someone afterwards, please let us know so we can connect you with some support.

AUT Health Counselling and Wellbeing is able to offer three free sessions of confidential counselling support for adult participants in an AUT research project. These sessions are only available for issues that have arisen directly as a result of participation in the research, and are not for other general counselling needs. To access these services, you will need to:

- drop into our centres at WB219 or AS104 or phone 921 9992 City Campus or 921 9998 North Shore campus to make an appointment. Appointments for South Campus can be made by calling 921 9992
- let the receptionist know that you are a research participant, and provide the title of my research and my name and contact details as given in this Information Sheet

You can find out more information about AUT counsellors and counselling on http://www.aut.ac.nz/being-a-student/current-postgraduates/your-health-and-wellbeing/counselling.

What are the benefits?

For participants: You will be able to contribute to the development of a self-guided web-based exercise intervention to treat shoulder pain. You will have an opportunity to reflect on your experiences and to see how recommendations from the previous phase have been translated into a working prototype

For the researcher: The benefits will be to better understand what factors have are important in a web-based exercise programme and how to adjust it so that it is usable and meets your needs. This will help inform further development of a self-guided web-based intervention and will help towards the Verna's PhD.

How will my privacy be protected?

The focus group and interview recording and all other information that you provide will remain strictly confidential. No material that could personally identify you will be used in any reports from this study. This includes any video recordings that are made.

Upon completion of the study your records will be stored for at least 10 years in a secure, locked cabinet at Auckland University of Technology. All computer records will be password protected. All future use of the information collected will be strictly controlled in accordance with the Privacy Act.

What are the costs of participating in this research?

There will not be any cost to you except your time – about 1 hour in total. If you need to travel to an interview, we will cover any travel costs that you incur with a $20 petrol voucher. This should also cover the cost of travel for a support person should you wish to bring one with you.

What opportunity do I have to consider this invitation?

You will be given at least 2 weeks to consider whether or not you would like to participate. You will be contacted at this point by Verna who will answer any further questions you may have. If you require, you will be given one more week to decide if you would like to participate.

Will I receive feedback on the results of this research?

If you would like to receive a summary of findings you can say so on the consent form and they will be sent to you at the end of the study.

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

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Nicola Saywell, nicola.saywell@aut.ac.nz, 09 921- 9502.

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

Whom do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

Researcher Contact Details:

Verna Stavric, verna.stavric@aut.ac.nz, 09 921-9999 ext 7060.

Project Supervisor Contact Details:

Nicola Saywell, nicola.saywell@aut.ac.nz, 09 921-9999 ext 9502.

Nicola Kayes, nicola.kayes@aut.ac.nz, 09 921-9999 ext 7309

Approved by the Auckland University of Technology Ethics Committee on *27 November 2018*, AUTEC Reference number *18/263*.

Appendix Y

SPIN Wireframe (V.4) prototype overview

Below is the V.4 wireframe prototype demonstrating how each wireframe relates to the other. This png file can be enlarged for easier viewing.