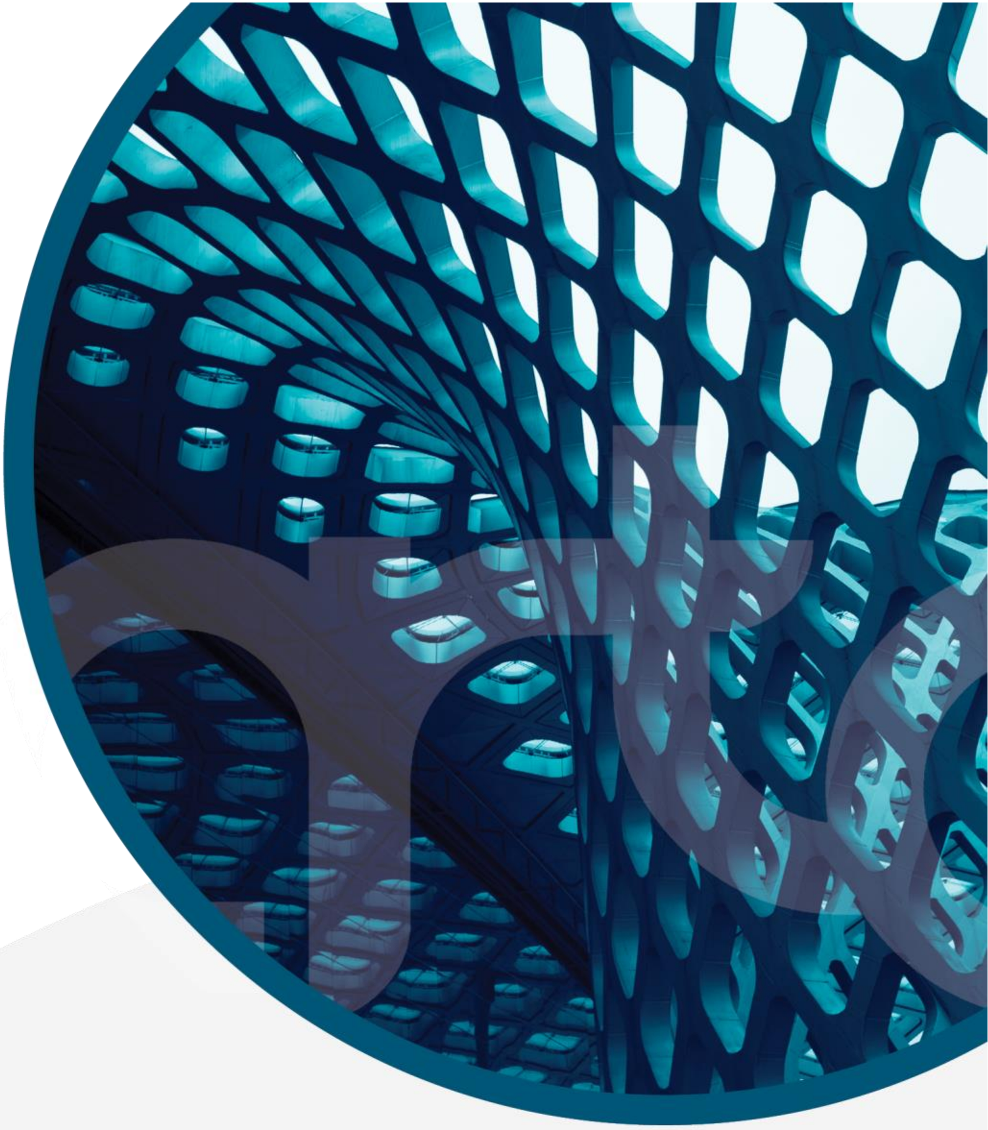
CONSULTANTS



DEVELOPING CLINICAL PRACTICE GUIDELINES FOR THE PHYSIOTHERAPY MANAGEMENT OF PEOPLE WITH SPINAL CORD INJURIES

QUALITATIVE RESEARCH REPORT

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ARTD consultancy team

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ACRONYMS AND ABBREVIATIONS

ACRONYMS

APA	Australian Physiotherapy Association
ASIA	American Spinal Injury Association
FES	Functional Electrical Stimulation
GP	General Practitioner
NDIS	National Disability Insurance Scheme
SCI	Spinal Cord Injury
JWCRR	John Walsh Centre for Rehabilitation Research

ABBREVIATIONS

Rehab	Rehabilitation

EXECUTIVE SUMMARY

PROJECT

This report presents the findings of a 2019 qualitative study in which ARTD Consultants interviewed 20 people with SCI (twelve inpatients and eight people with Spinal Cord Injury (SCI) living in the community), and 17 physiotherapists. Six stakeholders were also interviewed.

The results of this study are expected to inform the development of Clinical Practice Guidelines for the physiotherapy management of people with SCI.

KEY FINDINGS

The high-level common themes emerging from the research are shown below. These themes, and the broader range of views, are described in detail in the report.

Research focus	**Common themes**	
	Physiotherapists	**People with SCI**
Treatments valued	Improving upper body to enable quicker transfers, e.g. wheelchair to bed Mixed views on the value of robotic/ exoskeleton technologies Stretching is standard practice	Standing, assisted walking (e.g. gait training) Improving upper body strength for transfers, lifting Hydrotherapy Passive cycling (Functional Electrical Stimulation – FES) (inpatient)
Treatments provided where there is little evidence	Perception that there is limited evidence because of the diversity of presentation, individual responses to treatment and sample sizes in SCI research are generally too small to be scientifically valid or rigorous. Common treatments mentioned: Stretching exercises Passive cycling (FES) Tilt table for people with SCI with complete injuries Standing (particularly for people with complete injuries)	
Level of satisfaction with current treatment (people with SCI)		Positive about treatment provided by physiotherapists Value goal-oriented treatment Some people with SCI are frustrated with their progress

Research focus	Common themes	
	Physiotherapists	**People with SCI**
Influences on choice of treatment	The evidence behind the treatment Views of people with SCI What they have observed in their own practice The experience of other physiotherapists The feasibility of treatments (cost, practice models)	High level of reliance on advice from their physiotherapists What treatments have already worked for them Other sources of information
Common sources of information	Reputable academic journals and conference papers Other physiotherapists Professional learning	Their physiotherapist Advice from other people with SCI; family members; friends Media stories (particularly people with SCI living in the community) The internet (particularly people with SCI living in the community); both reputable and other websites
How much time and effort are people with SCI willing to devote to treatments		Very individual, depends on: • the observed benefits and the perceived value of the treatments to the person • the perceived motivation of staff to support them • the availability of desired equipment and facilities
Desired outcomes from treatment	Improving quality of life Maintaining function	Improving quality of life Increasing independence Walking (more so for inpatient) Maintaining function (more so for people with SCI living in the community)
Views on evidence-based Clinical Practice Guidelines	Welcomed – assist decision-making; support discussions with people with SCI about treatment; increase consistency and equity of treatment; and increase the credibility of clinical decisions Likely to follow, especially if they are compatible with their experience More important for graduate and generalist physiotherapists, and private practitioners	Welcomed – support discussions with physiotherapists about treatments Increase trust in recommended treatments Useful for themselves and particularly useful for generalist physiotherapists Likely to accept but want to retain a voice about their treatment Some said they may not read as they trust their physiotherapists advice
Enablers for adoption	Compatibility with own practice Supported by their workplace Better and more accessible information Credibility of authors and promoters Easy to access and use Able to see the benefits in their own practice Professional learning to support adoption Co-production is important	Accessible and user-friendly language Promoted widely

Research focus	Common themes	
	Physiotherapists	**People with SCI**
Barriers for adoption	Availability of resources to provide the recommended treatment/s Feasibility of implementation in the practice setting/ acceptance by people with SCI Response of people with SCI to recommended treatments Perception that the Guidelines may inhibit physiotherapists using their professional judgement Perception of a reduction in the range of treatment options because of limitations on the evidence available about effective practice	Perception of having less choice in treatment because of limitations on the evidence available about effective practice

1. INTRODUCTION

1.1 BACKGROUND

The John Walsh Centre for Rehabilitation Research (JWCRR) has been funded by iCare to develop Clinical Practice Guidelines for the Physiotherapy Management of People with Spinal Cord Injuries. iCare is a NSW government agency that delivers insurance and care services to the people of NSW. They provide treatment and care to people that have sustained severe injuries in the workplace or on NSW roads.

Physiotherapists from within NSW are interested in summarising the evidence base for physiotherapy management of people with spinal cord injury (SCI), including rehabilitation and life-long care. Presently, a range of treatments are provided, some of which are based on evidence and others for which there is no evidence, or the evidence is inconclusive.

The JWCRR in conjunction with physiotherapists across Australia and New Zealand are developing new Guidelines for Physiotherapy Management of people with SCI.

1.2 PURPOSE

The purpose of this research project was to explore the following.

- What are the facilitators and barriers to the roll-out of Clinical Practice Guidelines?
- What treatments are valued, and why, by people with SCI and physiotherapists?
- Where do people with SCI and physiotherapists source their information about treatments?

1.3 RESEARCH QUESTIONS

This project explored the following research questions. The full interview guides for each stakeholder group are in the Appendices.

PEOPLE WITH SCI

1. Why do people with SCI ask for certain types of therapies?
2. What sort of therapies do people with SCI want and why?
3. On what basis do people with SCI decide on the types of therapies they are happy to receive/ participate in?
4. How important is it to people with SCI to know that a therapy has a good evidence base?
5. How much time/ effort are people with SCI willing to devote to therapies?
6. What sorts of benefits do people with SCI expect/ want to see in return for spending time doing therapy?
7. How satisfied are people with SCI with the therapies they have received to date? If so why, and if not, why not?
8. Where do people with SCI get information about the types of therapies that are best for them?

9. How useful do people with SCI believe evidence-based guidelines for treatments would be?
10. How likely are people with SCI to accept evidence-based guidelines for treatments, and if not, why not (and vice versa)?

PHYSIOTHERAPISTS

1. Why do physiotherapists administer certain types of therapies, particularly if there is little evidence to support decisions?
2. How much are physiotherapists' decisions guided by what people with SCI want? And how important a consideration should this be?
3. How much benefit do physiotherapists need to see from a therapy to justify its use? (Note, there was no time to ask this question of physiotherapist in the consultations)
4. What sorts of therapies do physiotherapists currently provide that may not be justified on current evidence?
5. What sorts of therapies don't physiotherapists provide, that they believe they should provide?
6. How likely are physiotherapists to follow evidence-based guidelines for treatments, and if not, why not (and vice versa)?

Stakeholders from JWCRR, Agency for Clinical Innovation (ACI), NeuroMoves, Spinal Cord Injuries Australia and ParaQuad were also consulted for their views on the research questions.

1.4 METHODS

We consulted with 43 people—physiotherapists, inpatients with SCI, people with SCI living in the community, and other stakeholders. The consultations (focus groups and interviews) were conducted between September 2019 and December 2019.

We collected information in-person from physiotherapists that attended focus groups at two hospitals, Royal Rehab and Prince of Wales Hospital. We also held telephone interviews with physiotherapists, people with SCI living in the community, and stakeholders. All interviews were recorded, with the permission of participants, and transcribed. These were loaded onto an NVIVO, coded using a coding framework and a theme analysis done based on the research questions. See Appendix 1 for more detailed methods.

TABLE 1. INTERVIEWS AND INTERVIEWEES

Informants	Interview mode	Number
Physiotherapists	Focus group or teleconference	17
Inpatients	Face-to-face	12
People with SCI in the community	Phone interview	8
Stakeholders	Phone interview	6
Total		**43**

2. TREATMENTS FOR SCI: VIEWS OF PHYSIOTHERAPISTS AND STAKEHOLDERS

2.1 HOW DO PHYSIOTHERAPISTS CHOOSE WHICH THERAPIES TO ADMINISTER TO PEOPLE WITH SCI?

Physiotherapists reported that they choose treatments for people with SCI based on the evidence that is available and their professional experience. They will always consider the person's needs and wishes when administering treatments and may also seek advice from other clinicians.

Hospitals can vary in their timeframes for inpatient care, which impacts on the treatment options that physiotherapists can provide.

> *I'm in a setting where I don't get pressured to discharge people… We're very privileged in a way that we can try things and if that doesn't work, okay we're changing to something else.* [Physiotherapist]

Following discharge from hospital, where there is the opportunity for continuing improvements in function, physiotherapists will introduce new exercises and treatments, as appropriate. Where further changes are not expected, physiotherapists prescribe treatments that focus on maintaining current function. They take into consideration people's various commitments, such as jobs and family, that may impact on their capacity to maintain exercises once they leave hospital.

> *[People with SCI] need to do treatments that they can manage themselves. …. We try and only give the necessary things. We wouldn't give too many interventions to have at home. We would only give them the most important interventions.* [Physiotherapist]

2.2 WHY DO PHYSIOTHERAPISTS CHOOSE NOT TO ADMINISTER CERTAIN THERAPIES?

Physiotherapists explained why they would not provide some treatments to people with SCI. These reasons mainly included that:

- they **do not have the available resources** to provide certain treatments, including money, staff and/or equipment. For example, robotic solutions or treatments with high staff or time intensity
- certain treatments **do not have enough evidence of benefits** or have **too high a risk** to people with SCI and/or physiotherapists. Examples might include extended standing or vertical transfers (from chair to floor) for some people with SCI.
- certain treatments **are not appropriate to be offered by physiotherapists** and can be provided elsewhere.

Many treatments provided by physiotherapists are not supported by strong scientific evidence (see sections 2.3 and 2.3.1), but rather are supported by the physiotherapist's own clinical experience and/or that of their peers. There are no rules in place and no consensus among physiotherapists on the evidence required to support a decision about using or not using a treatment. More often, physiotherapists will look at the evidence of a treatment working against its costs, risks, complexity/ difficulty and its relevance to the person's specific needs.

Both hospital-based and community physiotherapists mentioned the provision of massage. One commented that they do not offer oedema massage (massage to reduce swelling) but may track the person's condition and refer them to a lymphoedema clinic if required. Physiotherapists preferred not to use massage on paralysed limbs, as they could not see any therapeutic benefit; but if people with SCI wanted massage, physiotherapists tended to suggest seeking that outside the clinical setting.

2.2.1 ARE THERE THERAPIES PHYSIOTHERAPISTS BELIEVE SHOULD BE ADMINISTERED THAT AREN'T?

Physiotherapists we spoke with did not believe there are any treatments they should be providing to people with SCI that they aren't currently providing, taking into consideration the resource constraints under which physiotherapists in the public health system work.

Sometimes physiotherapists do not provide certain treatments that have promising evidence to support their use, because they don't have the necessary equipment, for example with robotics/ exoskeleton-supported walking.

A few physiotherapists explained that sometimes it can take a while for new research with promising evidence of positive outcomes to be translated into hospital practice. Some treatments are not provided because of the timeframes for government to introduce legislation and for insurance companies to develop policies around their use.

> *You may have access to the new information by conferences or papers but for that to be translated into clinical practice takes a long time… Sometimes we may know about something new that's coming up, but the ability to actually apply that can be quite limited. It's not necessarily just a knowledge translation gap.* [Physiotherapist]

2.3 WHAT THERAPIES ARE BEING ADMINISTERED THAT ARE NOT BACKED BY MUCH EVIDENCE?

Spinal cord injuries are diverse and complex; every injury is different. Physiotherapists explained that, because so few people have an SCI, and each SCI is different, sample sizes in SCI research are generally too small to be scientifically valid or rigorous, which means evidence of treatments working holds less rigour.

The type of SCI the person presents with can make it difficult to evaluate the best course of action. In particular, there is limited evidence about effective treatments for incomplete injuries, which are highly varied.

Physiotherapists said that evidence on the benefits of stretching exercises is inconclusive, despite stretching being standard practice.

> *A lot of what we do is unsure with the evidence. Stretching is the perfect example. There's been a lot of studies done and it's a bit unclear, but we do a lot of stretching and positioning.* [Physiotherapist]

Other treatments mentioned by physiotherapists that do not currently have evidence that they believe to be effective, included:

- FES cycling
- tilt table for people with SCI with complete injuries
- standing (particularly for people with SCI with complete injuries)
- acupuncture for neural recovery.

2.3.1 WHY ARE THERAPIES NOT BACKED BY MUCH EVIDENCE BEING ADMINISTERED?

Although many treatments administered by physiotherapists working with people with SCI are not backed by strong scientific evidence, physiotherapists will provide the treatments based on their experiences and/or that of their peers that have some benefits. Physiotherapists also take into account that the treatments will not cause harm to the person they are treating.

A few physiotherapists said they will sometimes provide treatments suggested by people with SCI that lack scientific evidence of therapeutic benefits, because doing so may benefit the person's psychological wellbeing or keep them more engaged in treatments that aid their recovery. For example, passive cycling, where people with SCI can see their legs move. Physiotherapists said that they explain the available evidence on the treatment to the person they are treating.

> *Standing doesn't have great evidence for it, but....some people just really enjoy being upright... It's something that they're willing to do.* [Physiotherapist]

Other times physiotherapists said they may administer a treatment not backed by strong evidence, due to requests from people with SCI who feel strongly about that treatment and who want more control over their care.

2.3.2 HOW MUCH ARE PHYSIOTHERAPISTS' DECISIONS GUIDED BY WHAT PEOPLE WITH SCI WANT?

Most people with SCI leave decision-making about the treatments they receive to their physiotherapist, as they say their physiotherapist knows about the treatments. However, some will occasionally ask for specific treatments. If the physiotherapist thinks it is appropriate, they will provide the treatment, or give an explanation if they don't agree. If the person with SCI still wants the treatment and providing it won't cause any harm, then the physiotherapist will generally provide it.

Physiotherapists saw these requests as reasonable. They understood that it is the belief that a certain treatment will make a difference that drives people with SCI to ask for treatments.

> *It's their belief. Somewhere along the way someone at the sessions said it would be good for them. "I can't move my legs by myself, someone needs to move them for me." It's a pretty reasonable thought really… "My neck feels sore, why don't you give me some massage."* [Stakeholder]

Some physiotherapists talked about always providing a 'client-centred approach'; and the ethical dilemma they sometimes face, querying is it reasonable to take into account a person's preference for a certain treatment, knowing there are no real benefits for them, and given the treatment is funded by the public.

Physiotherapists also said that people with SCI will occasionally request treatments when they hear about them on the television, for example stories about new treatments provided in other countries. When this happens, physiotherapists search for evidence and use their professional judgment to decide if the treatment is suitable for the person who requested it. However, a few physiotherapists said that people with SCI can become misguided when they see treatments on television or on websites, as these sources can misrepresent the timeframes, costs, risks and benefits.

> *Like sensationalist sort of media presentations and things……It can actually be quite counterproductive, because it means that people don't see the real gains that they're making, those emotional gains and all the effort that they're putting in, and the outcomes that they're getting, it's not as good as what I saw on television. It's not that miracle.* [Physiotherapist]

Physiotherapists said that sometimes people with SCI have different expectations to physiotherapists about the benefits or outcomes of a treatment. For example, sometimes those with more complete injuries will believe treatments will work for them, when there is only evidence that the treatment will be effective for people with incomplete injuries.

Physiotherapists said it can be hard to deny people with SCI treatments they really want, but that often it is funding restraints that place the limitations on treatments.

> *A majority of the work is through funding bodies. All of it I have to get pre-approval for, and that's a really good thing because you have to say to [people with SCI], "Look, I've got to justify why they've got to pay me all this money." Therefore, [treatments] have got to have goals and it's got to be a measurable type of thing… It means you're always objective, you're always like, "Is this reasonable? Is this necessary? Does it have that kind of cost benefit ratio?"* [Physiotherapist]

> *They are tough conversations to have with clients when they're so focused on a certain thing they want done… They've got good reason to feel upset if they hold strong beliefs about something… They don't understand why you won't give it to them. "You've got the equipment, why don't you do it?"* [Physiotherapist]

If a person with SCI feels strongly about wanting to do a certain treatment that the physiotherapist sees as having no benefit, physiotherapists will often act as 'decision tools' for their client. This involves hearing the person’s request, coming back to them with other treatments that they may see as more appropriate and beneficial, explaining the differences between treatments in terms of their benefits, and then letting the person with SCI decide what they want to pursue.

> *Our role is to provide them* [person with SCI] *with education and what we know about that intervention, and then it’s up to them to make a choice of whether they want to pursue it or if they want to leave it.* [Physiotherapist]

There can be a range of reasons why physiotherapists accept the requests of people with SCI. Physiotherapists stressed that as long as the requested treatment is safe and there is time and available resources (funding and/or equipment) they will likely adhere to the person’s requests. If a requested treatment is likely to have similar benefits as the treatment they planned to do and will not take too much time away from other, more beneficial treatments, physiotherapists are generally willing to compromise and accept the person’s request.

Some physiotherapists said they will provide a treatment that, although it will not provide the outcome the person expects from it, will have other benefits. In these situations, the physiotherapist will explain this to the person with SCI.

Some physiotherapists argued that it is worth providing requested treatments that they believe have no evidence to support them, so the person with SCI can see that it has limited or no benefits. A few hospital-based physiotherapists said they will trial requested treatments because it is safer for the person that they do it in a safe and supported hospital environment, than seeking the treatment elsewhere.

Physiotherapists observed that people with SCI generally accept their physiotherapist’s advice, but there are times when people get frustrated if their physiotherapist will not provide a requested treatment. Some commented further that, despite them explaining the requested treatment has no benefit, some people with SCI will likely seek the treatment from another provider.

> *They agree with you at the time, but I don’t think you’ve changed their beliefs about it… and they end up engaging a different service to do it.* [Physiotherapist]

3. TREATMENTS FOR SCI: VIEWS OF PEOPLE WITH SPINAL CORD INJURIES

3.1 TREATMENTS THAT ARE VALUED BY PEOPLE WITH SCI

Treatments provided to people with SCI, and the intensity of treatment required, change as they progress through their rehabilitation following a SCI. There can be changes to the goals and expectations of people with SCI throughout this time period also, as the extent of the injury becomes better understood. To reflect this experience, the findings from inpatients and people with SCI living in the community are presented separately in this chapter.

INPATIENTS

The treatments that inpatients mentioned they receive in hospital include the following.

- Strength training (trunk, arms, legs) for example moving from a sitting position to standing
- the tilt table
- trunk control
- using an exercise ball or TheraBand
- Balance training
- Stretching: also provides pain relief
- Hydrotherapy: fitness training; balance
- Meeting functional goals for everyday life: transfers; standing; walking; climbing stairs.

One inpatient described the range of treatments they are receiving as like a jigsaw puzzle, with each treatment needing to be worked on individually and then all treatments fitting together to bring progress towards achieving specific functional goals. Seeing their own progress towards achieving their goals was encouraging for people with SCI. Visualisation, working with a mirror, or using digital imagery showing the muscle movement on a screen was highly engaging for some people. One person videoed their progress, which was motivating for them.

> *They [physiotherapists] had the machine where they would move my legs, they stuck on some electrodes and I was watching a guy on the screen, and I was acting like the guy. It moved my legs and I could see my quads and hamis tense. That was really awesome. It was really amazing, just to see that. It's a mental thing as well, to be able to see it happen.* [Person with SCI]

Some people with SCI noted specific treatments that were most important for them in achieving their goals. For example, one said that learning about '*leg positions, hand positions and the aids available*' (in this case '*little handles*') to do transfers can make '*all the difference*' in mastering the new skills needed for independent living.

A few noted the social aspect in accessing some treatments in hospital. One inpatient said that the recreation program they participated in, which included lawn bowls, basketball and archery, *'was really good for your mental health and wellbeing*.' Some people with SCI formed friendships while in hospital that continued after discharge.

PEOPLE WITH SCI LIVING IN THE COMMUNITY

People with SCI living in the community talked about a range of treatments they are engaged in, through seeing a physiotherapist in hospital out-patient departments or other facilities, home visits from a physiotherapist and/or pursuing their own exercise regimens. Treatments they spoke of included the following.

- Gravity work, stretches
- Strength building exercises: cardio, for example modified rowing trainer; upper body work, hand strengthening exercises; core strengthening
- Focus on technique, for example manual wheelchair skills
- (FES) cycling
- Treatments that focus on balance; coordination; standing; walking; practising transfers; climbing steps
- Hydrotherapy, swimming
- Inspiratory Muscle Training (IMT)
- Massage
- Hand stimulation for improved hand function.

A small number of people said it can be challenging to maintain motivation and commitment without the input of a physiotherapist/ coach. One person commented on the need for physiotherapists to encourage people to learn the benefits of the exercises that they're doing—to learn the health benefits associated with certain exercises and rehabilitation. For example, improving lung capacity through using the IMT, which can prevent respiratory disease and complications—*'it's a small thing to do that makes a big difference.'* Some explained that there is a need to pay attention to your mental state, and not lose motivation, as you move on and process things following discharge from hospital and then later as you transition from out-patient treatments.

3.1.1 SATISFACTION WITH TREATMENTS RECEIVED

INPATIENTS

Inpatients were all satisfied with the treatments they were receiving in hospital and were satisfied that physiotherapists were assessing their abilities and creating treatment plans that worked towards achieving goals.

Physiotherapists often challenged people with SCI to extend their abilities and persevere in their treatments in the face of pain and difficulty, so that they could become as independent as possible. One inpatient talked about enjoying being pushed to go beyond what they thought were their limits, to achieve outcomes they didn't think were possible. Introducing teamwork and some competition helped to heighten the motivation and effort for some people with SCI.

There were only a very small number of inpatients who expressed some dissatisfaction with some of their treatments. One felt their physiotherapist had an over-emphasis on safety, which prevented people with SCI from using the gym unsupervised (i.e. on evenings and weekends). Another commented that some hospital gym facilities were designed to cater for people in wheelchairs, or people recovering from stroke or brain injury, and were limited in scope for more able people with SCI. These people were highly motivated and wanted to make progress at a fast rate and felt their progress was being hampered by their limited access to suitable equipment.

PEOPLE WITH SCI LIVING IN THE COMMUNITY

Many people with SCI living in the community expressed their satisfaction and appreciation for the dedicated work of their medical teams, including physiotherapists.

> *We say that we are unlucky to be in the situation we're in but very lucky to have the people who are working with us to try and get us back on our feet again. They're so dedicated in what they do, they really go out of their way to try and help you.* [Person with SCI]

The main reasons people with SCI living in the community liked the treatments they received were that:

- they keep their body supple
- they support ongoing improvement in their movements
- they can be integrated with other things they are doing in their life.

People with SCI assessed their level of satisfaction with a treatment in terms of their progress over the long-term, rather than the short-term. They also understood there are subtle improvements they may not observe but that have occurred.

> *My transfers into bed are a lot quicker, like it used to take up to an hour and now I can probably do it in 15 minutes, which makes it much less of an ordeal going to bed. And I can go to bed later.* [Person with SCI]

People with SCI acknowledged that some treatments they do may not be goal-oriented, but they choose to continue doing them as they are enjoyable, for example leg lifting, and standing.

Some people with SCI living in the community gave reasons for feeling less satisfied with their treatment/s. They may have very specific goals and be frustrated at not attaining them, for example getting their feet onto the bed in a different way; doing transfers in a different way.

A small number of people with SCI talked about the challenge in finding a suitable gym, with regular gyms described as *'too gung-ho'* and others, while more suitable, were geared for people in wheelchairs, which could be challenging if the person is able to walk and other gym users (in wheelchairs) question why they are there.

They talked about the challenges and tough times since their SCI, *'lots of crying, lots of tears, lots of anger.'* And also, that there may be arguments and discussions with their physiotherapist about the suitability of their treatments, goals, expectations of what is possible and pace of progress. These do not necessarily reflect a lack of satisfaction with their treatments but are part of the process.

3.1.2 WHAT SORTS OF THERAPIES DO PEOPLE WITH SCI WANT AND WHY?

The main goals and purpose of treatments is to attain the greatest level of independence as possible and freedom from pain. Most people we spoke with wanted to walk or at least stand again, if possible. For more on the benefits that people with SCI expected from their treatments, see section 3.2.1.

Many people were not explicit about the sorts of treatments they wanted, explaining that they were satisfied with what they were receiving and could not think of anything they had missed out on.

> *Anything that I've asked for that is specific to my recovery they go out of their way to make sure I get it. [Person with SCI]*

Several people commented on enjoying hydrotherapy, with many saying it felt good to be weightless. Those who had enjoyed swimming, surfing or fishing before their injury wanted to return to their previous activities, as far as this was possible, and be able to stay safe in the water. Physiotherapists also commented that hydrotherapy is a common request from people with SCI.

Two people with SCI wanted to try gait training because they liked the idea of getting their legs moving. Some physiotherapists explained that offering this treatment within the public health system can be problematic as it is staff intensive.

> *Just the feeling of being able to get up and swing your legs in like a walking pattern is pretty cool. It's really the idea of it.* [Person with SCI]

Physiotherapists commented that massage is often requested, but usually declined as there is no evidence for its benefit. One person with SCI spoke of wanting massage for pain management.

3.2 HOW MUCH TIME/ EFFORT ARE PEOPLE WITH SCI WILLING TO DEVOTE TO TREATMENTS?

There are many variables affecting how much time and effort people with SCI are willing to devote to treatments. External factors may include access to facilities, their relationship and rapport with their physiotherapist, and the ability of their physiotherapist to motivate them. The mental attitude of the person with SCI plays a big role also and can be influenced by the progress they are making, the goals they are working towards and the transitions they are going through, for example leaving hospital or tapering off from out-patient treatments.

Inpatients we spoke to had been in hospital from three weeks to up to five months; and, some people with SCI living in the community we spoke to had left hospital fairly recently, while others had left hospital up to seven years ago.

Four inpatients mentioned doing daily treatment sessions, with some sessions occurring twice daily. These sessions typically went for 1-2 hours, and often involved strength and movement training using weights or bikes in the gym, and/or practising transfers.

Treatments such as hydrotherapy, using a standing frame and using a FES bicycle were mentioned as occurring less frequently, for example 1-3 times a week. Group training sessions also occurred weekly.

People with SCI are motivated to spend time on treatments that will improve their life skills and help cope with physical challenges arising from their injury, for example spending time in hydrotherapy to maintain fitness levels. If they can see how one exercise contributes to a skill they want to master, they are motivated to persist with it, for example spending time on balance or stretching or exercises that improve upper body strength to assist with transfers.

Nearly all of the people with SCI living in the community were doing stretches and other daily exercises at home. Commonly, these individuals spent half-an-hour to two hours per day doing these exercises. One person with SCI said that their carers help them with their daily exercises, and two others mentioned that a physiotherapist comes to their home to provide treatment—some of these were long-term, ranging from several months to several years.

People with SCI in the community varied in how often they saw a physiotherapist, from three days a week to once every six weeks, to once every six months, and they saw a physiotherapist less often the longer they had been out of hospital. These sessions commonly involved exercise physiology, but some also mentioned massage, needle massage, acupuncture or water aerobics.

3.2.1 WHAT SORTS OF BENEFITS DO PEOPLE WITH SCI EXPECT/ WANT TO SEE IN RETURN FOR SPENDING TIME DOING TREATMENT?

People with SCI said their treatments help them regain or retain strength, balance and/or coordination, which contributes to increasing their independence. Independence was described in terms of increased capacity to perform self-care activities; increased movement capability, particularly being able to transfer independently, for example from wheelchair to bed, or from wheelchair to car; and being able to re-enter the workforce.

Some, more commonly people with SCI living in the community, spoke about the benefits of their treatment in enabling them to stand, even if they were supported by a frame, as they liked the feeling of standing: "*It just feels nice for the body to be standing.*"

Some inpatients had an expectation that their treatments would support them to walk again.

> *I've achieved what I've got to do on my spinal rehab so that's the bladder, bowel and skin care. So now it's more a case of just getting my legs back to some semblance of being able to walk.* [Inpatient]

People with SCI in the community were generally less focused on walking and more focussed on other health benefits such as improved core strength, muscle strength, bone density and bowel health.

> *I'm doing swimming sessions which are so helpful in terms of everything actually, I can stand in the water. It feels good, also it helps me to release some pressure from my back and it also helps me internally in bowel care.* [Person with SCI]

Their goals included quicker transfers or improved hand function, managing their weight, reducing or managing their pain, and avoiding secondary health complications.

> *I think keeping my body in a decent condition so I avoid secondary health complications, [and] so that if there are treatments made available, I will be able to benefit from them … From an emotional and mental perspective, exercise is beneficial, it helps.* [Person with SCI]

They commonly saw the mental health benefits of ongoing treatments and regular exercise. They spoke of the value of keeping a positive mindset in incrementally achieving goals. Having regular treatments helps them feel that they are working towards something.

This disparity of expectations between inpatients and people living in the community was corroborated by what some physiotherapists said in the focus groups.

4. SOURCES OF INFORMATION ABOUT TREATMENTS FOR PEOPLE WITH SCI

People with SCI have multiple sources of information about treatments, with the most frequently mentioned sources (from highest to lowest) being clinicians (specialists, GPs, physiotherapists), the internet, friends and family and other people with SCI (in person only). Other sources mentioned by just a few people included nurses, television, newspaper articles, and outreach and advisory services. People with SCI used these various sources not only for information on treatments, but also for advice on how to adjust their lifestyles post-injury and to become more independent in their daily life.

Responses reflect what physiotherapists have observed; that inpatients are more likely to rely on their clinical teams for information, while people with SCI living in the community rely more on the internet and advice from other people with SCI.

> *There is a lot of information when they are in hospital, it is more coming from the medical staff. Once [people with SCI] start to get on their own it comes from lots of other people with SCI, talking about things. But also, just Googling, I think.* [Stakeholder]

4.1 HOW CREDIBLE ARE THE SOURCES OF INFORMATION?

Physiotherapists and stakeholders we spoke with valued journal articles and conference papers as credible, evidence-based sources of information, and they accessed these sources through the internet and by attending conferences. Physiotherapists would also confer and seek advice from other physiotherapists about people with SCI, their injuries and treatments.

Stakeholders that provide advice and support to people with SCI said they source their information through research papers, conferences, Google scholar, professional development opportunities and from peak bodies/ foundations (e.g. Christopher Reeves Foundation). If peak bodies support a therapy, then that gives some credibility to the treatment.

4.1.1 PHYSIOTHERAPISTS

People with SCI respected the training of their physiotherapists and trusted their expertise. They also liked how physiotherapists worked with each other and shared ideas.

One person with SCI commented that in retrospect, they wished that they had trusted their own instincts more and been more assertive in arguing for a difference in one of their treatments: "*I trusted the professional, which was not the best thing. I think [you must also] learn to trust yourself*."

4.1.2 THE INTERNET

People with SCI commonly used the Internet as a source of information about their treatments and other treatment options, as well as adjusting to life post-injury. As noted by physiotherapists, while some of the information is highly credible, some is misleading, inaccurate or irrelevant.

People with SCI talked about accessing specific sites, which were useful for learning about certain exercises and about their recovery, including muscle growth and nerve regeneration. These websites were deemed highly credible by people with SCI as they were affiliated with a university and/or new research or had extensive resource libraries. Some of these websites included Spinal Cord Injuries Australia; the Mayo Clinic; Project Edge.

However, the most common type of online resource accessed by people with SCI were social media sites, such as chat forums or closed Facebook groups, that are run by or heavily feature people with SCI. These are easily accessible, have a community feeling and provide useful information about life post-injury.

> *Well I would look online and see YouTube videos of how to do things. Most of the time it will be practical things, like getting on an airplane.* [Person with SCI]

Physiotherapists commented that chat forums and the like were very useful for learning about specific adjustments, but also noted that there was credible and less credible information in these forums.

A few people with SCI made '*random searches*' about '*anything related to the spine*,' or searched online after hearing about a treatment on television while others made more targeted searches on specific treatments, doctors they had heard of or health complications related to their SCI.

Physiotherapists were apprehensive about generic Google searches or social media success stories because such sources:

- can write about anything they want to and aren't held to standards of accuracy
- oftentimes only highlight instances where treatments have worked, and do not report on treatments failing to work
- rarely mention related health complications, long timeframes or the financial costs of successful treatments
- rarely mention the nature of the person's injury, whether it is complete or incomplete, or how extensive it is
- can contain biases, such as trying to sell equipment or a product, which people with SCI may not recognise.

Many people with SCI were also dubious about online sources of information. Two people commented that they used the Internet to look for treatments but were not satisfied by what they had found.

> *I just kind of try laying off that stuff [searching for information online] because you fill your head with, like, false information and then we'll go down the rabbit hole – a rabbit hole that will never end.* [Person with SCI]

4.1.3 FRIENDS AND FAMILY

Just over half of all people with SCI interviewed used friends and family as a source of information about their treatments and adjusting to life post-injury**Error! Reference source not found.**. There were similar responses from inpatients and people living in the community in terms of how much they used friends and family as sources of information.

People with SCI assessed information from friends and family members in various ways, including whether they had academic credentials, worked in the field of SCI or had a SCI themselves, or had previously recommended useful treatments/ life adjustments including things they had not heard about from clinicians.

4.1.4 OTHER PEOPLE WITH SCI

People with SCI commonly valued the information given to them by other people with SCI, as they felt they could relate to at least some of their experiences. People with SCI viewed the stories and tips of peers with SCI as highly credible and relevant to their recovery, especially in coping with such a dramatic change to their lives. People with SCI also saw seeking information from peers with SCI as opportunities to indirectly get advice from a broader range of physiotherapists.

Physiotherapists agreed that sharing information on day-to-day practical adjustments was helpful though they had reservations about people not recognising the complex differences between individual injuries when other people with SCI recommended treatments to them.

Visitor/ mentor programs for inpatients, where a person with SCI, e.g. a Paralympian, speaks about their experiences and gives information on coping mechanisms and how to manage rehabilitation, were also seen as helpful.

4.1.5 OTHER SOURCES OF INFORMATION

Other sources of information about treatments included nurses, television, newspaper articles, and outreach services. One person with SCI spoke about their resource folder that was compiled by clinicians while they were in hospital, containing contacts and information that they can take home with them. "*Sometimes when there's a lot of information it's hard to take all in at once. I'm glad to have the resource folder.*"

Physiotherapists commented that people with SCI who come to them with '*miracle cures*' often saw them on television. Stakeholders also recognised the tension between managing expectations and beliefs driven by media or personal stories and the efficacy of treatment. They pointed out that sometimes therapies can cause harm, and some are very expensive for little or no benefit.

Physiotherapists and other stakeholders expressed reservations about stories that attribute a successful outcome to having a good mindset and perseverance, when the most important factor is the type of injury a person has. They see this rhetoric as potentially damaging to people with SCI who will never be able to walk again due to their injuries: "*the subtext is they haven't tried hard enough*."

4.2 ON WHAT BASIS DO PEOPLE WITH SCI DECIDE ON THE TYPES OF THERAPIES THEY RECEIVE?

People with SCI said that their physiotherapist made most of the treatment decisions at the start of their recovery because they were still trying to come to terms with their injury and were often overwhelmed: "*Everything is so different to you and your life has changed so much so suddenly.*"

People with SCI described the decision process as a negotiation or compromise in some instances, in which physiotherapists would explain treatment options and then they would have the final say. They mostly went along with their physiotherapists' recommendations, and particularly paid attention when advised to not use a certain treatment: "*There'd have to be a reason for them not to want to do something, you know?*" Another person said that they like to know that their treatments are proven effective before they decide to go ahead with the treatment: "*It's important for me to see what's happening and that I can rely on something that has been approved.*"

People with SCI observed that their physiotherapists were good at picking up on any issues their bodies were having during treatments, such as a sore neck or congested chest, and deciding on or altering treatments to remedy or account for these issues. They felt their treatment sessions worked well when they told their physiotherapist what they were having issues with, which would then inform the types of treatments they received.

People with SCI spoke about setting short-, medium- and long-term goals alongside their physiotherapist while in hospital, which helped determine their treatments. This collaborative effort helped them align their personal goals with more practical ones and was seen as a strength by people with SCI. Goals were reassessed further into recovery.

As inpatients progressed in their recovery and were capable of expanding the range of treatments, or intensity of treatments they undertook, they were given more choices, described to them by their physiotherapist in terms of risks and benefits. Some commented that it was good to speak up and ask for what they want, whether deciding which treatments to pursue, or in the level of intensity of the treatment.

A small number of people with SCI spoke about questioning their physiotherapist's recommendations or pushing for particular treatments. One mentioned having arguments with their clinical team about receiving a treatment they wanted, which they eventually received. Another commented that their family member is active in questioning treatment decisions.

5. EVIDENCE-BASED CLINICAL PRACTICE GUIDELINES: VIEWS OF PHYSIOTHERAPISTS AND STAKEHOLDERS

This chapter presents the views of physiotherapists and other stakeholders on the perceived usefulness of guidelines for the provision of treatment for people with SCI and the enablers and barriers to use.

5.1 HOW USEFUL DO PHYSIOTHERAPISTS AND STAKEHOLDERS BELIEVE EVIDENCE-BASED CLINICAL PRACTICE GUIDELINES WOULD BE?

Overall, the production of the Guidelines has been welcomed by physiotherapists and stakeholders because there is the potential to capture the research about what works in one place, that is readily accessible. As such, the Guidelines would provide a very useful tool in supporting discussions between physiotherapists and people with SCI about the best treatments for them to follow.

> *They're your first 'go to' point as to how to adapt the treatment to the context. Whether it's community, whether it's out-patients, whether it's inpatient, acute rehab – it gives us something to guide best practice in the relevant context.* [Physiotherapist]

Physiotherapists and stakeholders believed that having Clinical Practice Guidelines would:

- increase the credibility of physiotherapists amongst peers and people with SCI and engender a greater trust in decisions about the treatment being recommended. This is especially important in a context where people with SCI are exposed to potential sources of misinformation about effective treatments through the Internet and traditional media and are open to wasting time and money on treatments that provide no benefits.
- increase an individual clinician's confidence that the treatment being provided is beneficial to people with SCI.
- support productive discussions between clinicians and people with SCI and families about what treatments are effective and what are not and the reasons why clinicians might choose one treatment over another. Some physiotherapists cited people with complete SCI seeking treatment that involves standing on a treadmill and indicated that having the Guidelines may support a change in practice in this instance.
- ensure a greater consistency of information about treatment across different units or hospitals and in the community
- reduce clinical variation amongst physiotherapists, ensuring care is more equitable.
- provide management with a tool to compare service practice against, and justification about use of resources (time and funding)
- support physiotherapists' funding applications for equipment.
- make the research and practice-based knowledge about effectiveness of treatments readily accessible, saving clinician's time in seeking out the research individually
- assist support organisations to provide advice and appropriate referrals.

> *The advantage would be that [the Guidelines] would be a more comprehensive approach to what we are doing now. It would give a framework that doesn't currently exist. When you have that framework, I think you can be more secure in your decision-making processes.* [Stakeholder]

The Guidelines were perceived to be most useful for student physiotherapists; less experienced physiotherapists and/or physiotherapists who see few people with SCI or are new to units where people with SCI are treated. Examples included inexperienced clinicians working in small rural hospitals or private physiotherapists registered under the NDIS but without much experience treating people with SCI.

One stakeholder suggested that the Guidelines could be useful when making referral for accommodation and felt these would support consumers to make their own decisions for independent living.

> *I would find [the Guidelines] useful because, across the state, people ring to find out where they could find information and I would definitely refer people on to these Guidelines … It's good for consumers so they know what is good for them and can advocate for themselves.* [Stakeholder]

The Guidelines were perceived to be less useful if they:

- do not cover the diversity of injury types and presentation.
- do not identify treatments for which there is strong evidence. Some physiotherapists suspect that there are many treatments for which there is insufficient evidence, and this could limit treatment options and the usefulness of the Guidelines.
- hinder or restrict the application of professional judgement and experience in decision-making about treatments, especially where there is insufficient research evidence, but physiotherapists have seen benefits for people with SCI they have treated.

5.2 HOW LIKELY ARE PHYSIOTHERAPISTS TO FOLLOW CLINICAL PRACTICE GUIDELINES FOR TREATMENTS?

Even though physiotherapists welcomed the Guidelines, they expressed different views about their readiness to adopt them, typically based on their level of experience in working with SCI. Physiotherapists with greater experienced were more likely to rely on their own professional judgement when making decisions about treatments. While they commonly expected that the Guidelines will reflect their views about suitable treatments, if their views are contradicted, they may find the Guidelines difficult to adopt. Many hoped that the Guidelines will not be imposed on them, but that physiotherapists will still have professional agency to make their own clinical judgments.

Personal predilections towards changing practices were also an important factor. Some physiotherapists described themselves as early adopters, eager to adopt the latest approaches as soon as possible, while others prefer to wait longer (and have more certainty) before using new approaches even if these were to appear in the Guidelines.

Some physiotherapists expressed doubts about adopting the Guidelines because they wanted to be confident in their ability to implement a new approach before adopting it, or they wanted to confirm the evidence themselves. Having confidence in the rigour of the approach used to develop the Guidelines will help address these concerns. Ensuring professional learning is available to increase skills in practising unfamiliar recommended treatments will also be important. The earlier this can happen, the quicker physiotherapists said they would incorporate new treatments routinely in their practice.

> *If I feel like I've got a relatively decent grasp and am confident enough that I could implement it appropriately and correctly, then I'd probably take it up early.*
> [Physiotherapist]

5.3 ENABLERS FOR CLINICAL PRACTICE GUIDELINES

Physiotherapists and stakeholders raised several factors that they believe will enable the use of Clinical Practice Guidelines. To a large extent these reflect the conditions that enable adoption of innovation to be faster and more likely, as shown in the literature on diffusion of innovation[1].

1. Confers **relative advantage** on what is in place – physiotherapists commonly said that the Guidelines will be advantageous should these provide more information about best practice treatments for people with SCI than is currently available. Currently individuals must do their own research about suitable treatments.
2. **Compatibility** – the Guidelines should recommend treatments that are compatible with current practice wisdom and with rehabilitation systems. Stakeholders commented that Guidelines must consider community settings, not just hospital settings. Some physiotherapists and stakeholders indicated that they are unlikely to make drastic changes based on Guidelines but would adopt some new practices while also maintaining their current practices.
3. **Complexity** – are the Guidelines difficult to learn or read? Physiotherapists recommended that Guidelines be accessible in different formats and places (for example, online resource, hard copy, course material), and are easy to navigate so that information can be found quickly.
4. **Trialability** – the literature says that people are more likely to adopt guidelines if users can test out what is being recommended and see the benefits themselves. This is reflected in some physiotherapists' comments about wanting to test out any unfamiliar treatments recommended in the Guidelines before adopting these in their practice. For some it is important that the Guidelines are not imposed on them but are voluntary.
5. **Potential for reinvention** – can the Guidelines be updated or reviewed? Physiotherapists commented that co-design is important, with the Guidelines developed and reviewed with physiotherapists who work with people with SCI. In addition, the Guidelines need to be regularly updated to maintain their usefulness.

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[1] Green, L.W., Ottoson, J.M., García, C., Hiatt, R.A., Roditis, M.L. "Diffusion theory and knowledge dissemination, utilization and integration." *Frontiers in public health services & systems research*. 2014;3(1): page 5. Knowledge Utilisation Theory also emphasises the importance of building relationships between those producing the knowledge and potential users of the information, and early and sustained involvement in the knowledge production process by users.

Stakeholders commented that the highly variable nature of spinal cord injuries means that Guidelines should incorporate new evidence as soon as it is available.

6. **Opinion leaders** – the Guidelines are more likely to be used if written or recommended by people who are well respected by physiotherapists. Some physiotherapists said that experts in managing SCI need to be involved in the formulation of the Guidelines to encourage other physiotherapists to use them[2].

In addition, some physiotherapists said that training on how to access and use the Guidelines might be necessary to facilitate translation to clinical practice. Some suggested an interactive scenario, as part of training, to increase awareness and adoption of the Guidelines.

Some physiotherapists emphasized that experienced clinicians need to be consulted during the development of the Guidelines to ensure their usefulness in a clinical setting and take-up by clinicians. Stakeholders agreed that an inclusive strategy would be needed for implementing, using and auditing the Guidelines.

5.4 PROMOTING AND DISTRIBUTING THE GUIDELINES

To achieve widespread adoption, physiotherapists and stakeholders generally agreed that the Guidelines need to be promoted through a range of avenues, for example conference presentations and by the Australian Physiotherapy Association. Some recommended the Guidelines be embedded across university curricula to encourage more early-career physiotherapists to use them. This would involve working together with key academics to design and develop approaches to embed the Guidelines. Some physiotherapists saw value in making the Guidelines free and/or putting them on highly reputable, academic sites.

Physiotherapists highlighted a need to carefully consider the types of media used to distribute the Guidelines. They mentioned a range of different media as avenues for distribution, which included:

- an easily navigable website
- an App
- a PDF version
- a hard-copy textbook version
- visual aids to supplement text, including videos or cards.

> *Something that you could print off and provide as a written piece of information is still really important to back your verbal conversations. [Physiotherapist]*

Easy navigation was considered crucial for Guideline use. Many wanted to be able to search for key words or have key phrases be easily recognisable, which would direct them to information on specific injuries or treatments with good evidence behind them.

Stakeholders would like to see the Guidelines promoted through funding organisations, mentors for physiotherapists in rural communities and support coordinators.

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[2] Translation research suggests that the credibility of the knowledge producer is an important facilitator of use. See Grimshaw, Jeremy M., Eccles, Martin P., Lavis, John N., Hill, Sophie J., and Squires, Janet E. (2012), "Knowledge translation of research findings". *Implementation Science* 127:50.

5.5 BARRIERS FOR CLINICAL PRACTICE GUIDELINES

The barriers raised related to the practicality and feasibility of following the Guidelines within physiotherapy practice settings, and to the acceptance of and responses to the treatments by people with SCI.

Some physiotherapists believed there might be financial and practical barriers to adopting the Guidelines about suitable treatments, particularly where a treatment may involve expensive equipment or be very resource intensive.

Another barrier commented on was the perceived tension between having more standardised practice and tailoring care to the needs of an individual. One noted that there will always be exceptional cases, and "*physiotherapists can never give up on that exception*."

Physiotherapists highlighted that spinal cord injuries are highly complex and can also be accompanied by other health issues, so Guidelines will not be able to cover all varieties of presentation that need to be addressed in practice.

6. EVIDENCE-BASED CLINICAL PRACTICE GUIDELINES: VIEWS OF PEOPLE WITH SPINAL CORD INJURIES

This chapter presents the views of people with SCI on the perceived usefulness to them of the Guidelines and the enablers and barriers to use.

6.1 HOW USEFUL DO PEOPLE WITH SCI BELIEVE EVIDENCE-BASED GUIDELINES FOR TREATMENTS WOULD BE?

Both inpatients and people with SCI living in the community mostly perceived evidence-based guidelines as being useful, especially in guiding generalist physiotherapists who may not be specifically trained in SCI. Some people with SCI also saw Guidelines as a form of accountability for physiotherapists, ensuring people with SCI received best practice, safe treatment and conversely, avoiding risky or costly treatments.

Inpatients thought the Guidelines could be useful for people at the beginning of their treatment, to reassure them about how the injury might be managed and what benefits they might expect. One person commented that the Guidelines would be particularly useful for people with SCI living in regional or rural areas, and physiotherapists who may not have access to the latest clinical supports and resources. More generally, people with SCI anticipated that the Guidelines would help them clarify what treatments may or may not be suitable for them and enable them to have more informed discussions about treatments with their physiotherapist.

> *I think you kind of want to drive decisions yourself a bit, but you want to make sure that you are making ones that make sense through using the Guidelines and talking to your therapist about it. I think that's the way to go.* [Person with SCI]

Many felt the Guidelines could be a useful discussion tool when discussing treatments and/or requesting or pushing back against certain suggested treatments. Once any issues are clarified, people with SCI felt they would be satisfied with following through with a recommended treatment. People with SCI place a high value on having a say in their treatment, especially because spinal cord injuries vary extensively between people, making it difficult to generalise approaches.

> *If the Guideline said something, and I didn't want to spend time to do that, then I would ask the physiotherapist to justify it and convince me. If I saw that it could help me then I would do it, but if I couldn't be convinced then I would spend the time doing what I want to do.* [Inpatient]

Others wanted the Guidelines to cover issues of self-management of SCI at home, such as enemas and bowel and bladder care. In a related point, one inpatient said that the Guidelines would be useful if there was a possibility to follow the treatments suggested when they returned home, which the person believed has the potential to save money.

> *Just to know what works, and to know if my physiotherapist is doing the right thing and doing what works. Then maybe I can apply some of those things at home or day to day… If I can do that at home, and that's proven to help me, and that cost me $10—that's a huge help to the consumer I would say.* [Inpatient]

However, people with SCI also anticipated that it may be difficult for the Guidelines to cover all types of SCI and the various comorbid complexities that can impact recovery times. They believed this could make the Guidelines less useful for physiotherapists and people with SCI.

> *I think it would be difficult to come up with a very concise set of guidelines, just due to the nature of spinal cord injuries being so different from one patient to another. … [T]here are people with SCI here with very similar injuries to me and we have widely different abilities.* [Person with SCI]

6.2 HOW IMPORTANT IS IT TO PEOPLE WITH SCI TO KNOW THAT A THERAPY HAS A GOOD EVIDENCE BASE?

Almost all of the people with SCI that we spoke with felt that it was important that a treatment had a good evidence base and were not '*not ideology-based.*'

People with SCI wanted to be sure that they were not wasting time with treatments that wouldn't benefit them or help them reach their goals, and they felt that good evidence would show which treatments were and were not worthwhile: "*To me, it means there's concrete proof that something is achievable*." They felt that having a strong evidence base would help physiotherapists and other medical professionals prescribe relevant and beneficial treatments.

A couple of people with SCI also felt that a good evidence base would mean that physiotherapists could provide more accurate recovery timeframes and better manage expectations, letting people with SCI know with more certainty what is and is not achievable.

People with SCI wanted to be sure that a treatment would not cause them or others harm or reverse any of the progress they had made in their recovery. They felt a good evidence base would protect them from these issues.

One person had some concerns that evidence-based guidelines may be used to reinforce the classification of injuries, for example using the ASIA scale. They argued that classifications are horizon-limiting for people during recovery and that people with the same ASIA classification can have different recovery outcomes—sometimes unexpected ones.

> *Because of my initial experience with my physiotherapist when I was in rehab—she was saying that the evidence says I could not ever transfer, which I eventually did do. So, I am sceptical about evidence… I prefer my physiotherapist to be goal orientated rather than based on my level of injury.* [Person with SCI]

A small number argued for the value of anecdotal evidence and the benefits of a positive mindset to treatment outcomes. Two people with SCI did not want to be limited by current 'evidence', stating that they '*will try anything if it will help them stand one day.*'

6.3 HOW LIKELY ARE PEOPLE WITH SCI TO ACCEPT EVIDENCE-BASED CLINICAL PRACTICE GUIDELINES FOR TREATMENTS?

Overall, people with SCI were open to accepting evidence-based guidelines informing their treatment. They felt that referencing a rigorous and considered resource could help physiotherapists choose the best treatments; and would give people with SCI trust in the advice they receive about treatments. Some people with SCI also mentioned that there might be an array of other conditions a person could experience, and they felt that having Guidelines would give physiotherapists more direction and confidence managing such conditions.

> *If it's a good source of balanced viewpoints and information that can help you make a decision on what rehab activities you take part in and decide on why that would be important… A lot of times you are left guessing to some extent as to what's important for you and why you should be doing certain things.* [Person with SCI]

The likelihood of accepting the Guidelines was also linked to the rigour of the process of developing them. Some people expected there would be consultation amongst different health professionals in the creation of the Guidelines.

Having some say in the choice of treatment was a common theme, with some people with SCI very strongly saying the final decision about treatment should be theirs.

> *Because I've always, regardless of the doctor or the qualification, made the final decision on my personal treatment. That's the sort of person I am, except when I was unconscious at the doctors because I was in coma.* [Person with SCI]

A few mentioned that they listen to their body more than anything and may not readily follow the Guidelines if they contradicted their own intuition: "*I trust my body. I trust myself*."

6.4 PROMOTING AND DISTRIBUTING CONSUMER GUIDELINES

People with SCI would like to see a consumer version of the Guidelines written in plain English, and where needed versions using a person's own language, to maximise accessibility and usefulness.

The presentation of information was the most important enabler discussed by people with SCI. Some suggested using illustrations showing the exercises to make it more accessible. Others thought that testimonies from people with SCI would also be of interest to readers.

APPENDIX 1. METHODS

PHYSIOTHERAPIST INTERVIEWS

We spoke with 17 physiotherapists, two more than we had initially planned. We interviewed 15 physiotherapists face-to-face – 12 at Royal Rehab, over two focus groups (six physiotherapists in each group); and three in a focus group held at Prince of Wales Hospital. Each focus group ran for approximately 90 minutes. These physiotherapists worked across a variety of settings (inpatient/community; public/private; hospital/University). We also conducted a teleconference with two physiotherapists based in the Hunter region; this interview ran for around an hour. In consultation with the client, the interview guide we used with physiotherapists was adapted from the initial guide developed, with some questions not asked due to concerns about not being able to cover all the original questions in the time allotted for the consultations.

Physiotherapists were approached by the JWCRR to express interest in participating in the research; and the JWCRR managed the consent process.

PEOPLE WITH SCI INTERVIEWS

We interviewed 20 people with SCI, which is the number we planned. The JWCRR informed us of each person’s injury type to better inform the interview.

We spoke with 12 inpatients across the two hospitals, six at each hospital. Inpatients were approached by a key contact within each hospital to seek interest in participating in an interview. Each inpatient was interviewed one-on-one, and the interview was conducted either in the inpatient’s room or in a common area of the hospital. Upon arrival at each hospital, we were introduced to the inpatient prior to their interview so they would know who we were. The interviews ranged in length from 20 minutes to an hour.

We interviewed eight people with SCI living in the community. The JWCRR sought interest from people with SCI known to physiotherapists, with outpatient departments or the Spinal Outreach Service to be involved in the research. Once they agreed to be interviewed the JWCRR introduced us to them via email and we then contacted the person to organise a suitable time for the phone interview. Each interview ran for approximately an hour.

STAKEHOLDER INTERVIEWS

We interviewed six stakeholders by phone, including two JWCRR representatives. The other four stakeholders were from the Agency for Clinical Innovation; NeuroMoves; Spinal Cord Injuries Australia and ParaQuad. The JWCRR approached the organisations to seek interest in participating in a telephone interview and managed the consent process.

This report focuses on the views of physiotherapists and people with SCI. We have only referenced stakeholders’ views specifically, where these differ from the views of physiotherapists and people with SCI.

DATA ANALYSIS AND SYNTHESIS

Focus groups and interviews were recorded, with the participant's permission, and transcribed. Transcripts were loaded into an NVIVO database and categorised according to stakeholder type. A coding framework was developed based on the research questions and all transcripts were coded using this framework and also by interview guide and question. This allowed responses to be extracted according to their coding and also in full by question.

Four people contributed to the coding, although most was completed by one person. The main coder provided guidance to the others and discussed ambiguities to help ensure similar decisions were made.

Two analysts, who had been involved in the coding of the transcripts, wrote a first draft theme analysis for each of the research questions, and extracted illustrative quotes. These drafts were refined and shaped by three senior members of the team, using further NVIVO queries to explore the data.

Project approved on 22nd August 2019 by the Northern Sydney Local Health District Human Research Ethics Committee (2019/ETH00589).

APPENDIX 2. CODING FRAME FOR THEMES

TABLE 2. CODING FRAME

Level 1	Level 2	Level 3
Treatments (People with SCI)	Viewed positively	Reasons
	Viewed negatively	Reasons
	Basis for decision	Research evidence
	Time devoted to therapies	Daily Weekly Other
	Expected benefits	
	Satisfaction	High (reasons) Moderate (reasons) Low (reasons)
Choosing treatments	Clinician role	Strengths Weaknesses Challenges
	Person with SCI role	Strengths Weaknesses Challenges
Information sources about treatment	Physiotherapist Friends/family Other spinal cord patients Internet GPs Specialist doctors Other	Highly credible (reasons) Moderately credible (reasons) Low credibility (reasons)
Treatments (clinicians)	Treatments provided	Research evidence Has seen benefits Person with SCI wishes Little or no current evidence
	Treatments not provided	Believe they should
Evidence based guidelines	Perceived usefulness	Positive Neutral Negative
	Likely to accept/ follow	Yes (reasons) Unsure (reasons) No (reasons)

APPENDIX 3. INTERVIEW GUIDES

TABLE 3. PEOPLE WITH SPINAL CORD INJURIES: INPATIENT

Q Number	Question
1	About yourself and your injury
2	Kinds of physiotherapy treatment in hospital
3	Have you had the type of physiotherapy you wanted/expected
4	Which physiotherapy treatments have been most important to you and why?
5	What problems are these treatments helping you with?
6	Are there physiotherapy treatments that you haven't received that you wanted to try?
7	Are there physiotherapy treatments that you have received that you would prefer not to continue with and why?
8	How do you and your physiotherapist decide on what treatment will be helpful for you?
9	Did you or your physio always agree on what was the best physio for you?
10	Where else do you get information on what physiotherapy treatments might work for you?
11	Which of these information sources are you listening to most and why?
12	Have you heard of the term evidence-based practice and if so what does it mean to you?
13	How important is it for you that there is good scientific evidence that a physiotherapy treatment will help you? Why/why not?
14	Have you heard of Clinical Practice Guidelines for consumers?
15	Would you consider using Clinical Practice Guidelines to help decide what physiotherapy treatments would benefit you most?
16	How much do you think the Guidelines are needed by physiotherapists?
17	How much do you think the Guidelines are needed by people with spinal cord injuries?
18	What if the Clinical Practice Guidelines recommended a treatment that you didn't think was worthwhile? Would you change how you view the Guidelines?
19	What if the Clinical Practice Guidelines did not recommend a treatment that you think is worthwhile? Would you change how you view the Guidelines?
20	Scenario – would you be willing for physiotherapists to follow the Guidelines?

TABLE 4. PEOPLE WITH SPINAL CORD INJURIES IN THE COMMUNITY

Q Number	Question
1	About yourself and your injury
2	Kinds of physiotherapy treatment in hospital
3	Were you given the type of physiotherapy that you wanted and/or expected?
4	What kinds of physiotherapy treatments have you received after discharge from hospital?
5	How long have you been getting these kinds of physiotherapy treatments?
6	How much time per week do you spend in physiotherapy and what kinds of treatment do you spend your time on?
7	Are there physiotherapy treatments that you got when you went home from hospital that you didn't want to continue with? Reasons.
8	Are you getting the physiotherapy that you want? Right amount? Right type?
9	Which physiotherapy treatments do you find most helpful/ were most important to you? Why?
10	Are there kinds of physiotherapy that you haven't received since going home that you would like to try? Why these treatments?
11	How do you and your physio decide on what therapies will be most helpful for you?
12	Did you receive physiotherapy for long enough after return home?
13	What do you see as benefits of ongoing physiotherapy for next 5 years? 10 years? 20 years?
14	Where else do you get information on what physiotherapy treatments might work for you?
15	Which of these information sources are you listening to most and why?
16	Have you heard of the term evidence-based practice and if so what does it mean to you?
17	How important is it for you that there is good scientific evidence that a physiotherapy treatment will help you? Why/why not?
18	Have you heard of Clinical Practice Guidelines for consumers?
19	Would you consider using Clinical Practice Guidelines to help decide what physiotherapy treatments would benefit you most?
20	How much do you think the Guidelines are needed by physiotherapists?
21	How much do you think the Guidelines are needed by people with spinal cord injuries?
22	What if the Clinical Practice Guidelines recommended a treatment that you didn't think was worthwhile? Would you change how you view the Guidelines?

23	What if the Clinical Practice Guidelines did not recommend a treatment that you think is worthwhile? Would you change how you view the Guidelines?
24	Scenario – would you be willing for physiotherapist to follow the Guidelines?

TABLE 5. PHYSIOTHERAPISTS: HOSPITAL BASED

Q Number	Question
1	About you and the work you do
2	Do people with spinal cord injuries or their families ever ask for physiotherapy during their stay in hospital that you are not willing to provide even if you had the equipment and resources?
3	Do people with spinal cord injuries or their families ever ask for physiotherapy treatments that have no evidence base?
4	What kind of advice do you give people about what physiotherapy treatments will help them once they go home from hospital?
5	How much of a say do people with spinal cord injuries/families have about the physiotherapy they get while in hospital?
6	Where do you usually seek information about what physiotherapy treatments are most effective for people with spinal cord injuries? Why those?
7	Where do people tell you they get information about physiotherapy treatments? How credible and reliable are these sources?
8	Which are the best sources of information about new treatments? Why these? Example and rationale.
9	If there is no research evidence about the efficacy of a treatment how do you decide about whether or not you are going to use it?
10	What sorts of therapies do you currently provide that may not be justified by current evidence?
11	How does having Clinical Practice Guidelines for people with spinal cord injuries compare to how you access information now? What are pros and cons for you?
12	Do you believe the Guidelines would be useful for your practice?
13	How much do you think the Guidelines are needed by other physiotherapists?
14	How much do you think the Guidelines are needed by people with spinal cord injuries?
15	Are you the sort of person who takes up new things early, or would you normally wait a while before changing how you do things?
16	What do you suggest the Guidelines authors do to support physiotherapists like you to use the new Guidelines?
17	What might make it difficult for physiotherapists to use Guidelines in their practice?

TABLE 6. PHYSIOTHERAPISTS: COMMUNITY BASED

Q Number	Question
1	About you and the work you do
2	Do people with spinal cord injuries/families ever ask for physiotherapy treatments that have no evidence base? What kinds of therapies? What is driving these requests?
3	What kind of advice do you give people about physiotherapy treatments will help them once they go home from hospital?
4	What keeps people with spinal cord injuries continuing with their physiotherapy once they are home?
5	How much are your decisions about treatment guided by what people want? How important a consideration should this be?
6	Where do you usually seek information about what physiotherapy treatments are most effective for people with spinal cord injuries? Why those sources?
7	Where do people with spinal cord injuries tell you they get information about physiotherapy treatments? In your opinion, how credible and reliable are these sources?
8	Which are the best sources of information about new treatments? Why those sources? Please give me an example of when you have taken up a new treatment and the rationale for doing so.
9	If there is no research evidence about the efficacy of a treatment how do you decide about whether you are or are not going to use it?
10	What sorts of therapies do you currently provide that may not be justified by current evidence?
11	How does having Clinical Practice Guidelines for people with spinal cord injuries compare to how you access information now? What are the pros and cons for you?
12	Do you believe the Guidelines would be useful for your practice?
13	How much do you think the Guidelines are needed by other physiotherapists?
14	How much do you think the Guidelines are needed by people with spinal cord injuries?
15	Are you the sort of person who takes up new things early, or would you normally wait a while before changing how you do things?
16	What do you suggest the Guideline authors do to support physiotherapists like you to use the new Guidelines?
17	What might make it difficult for physiotherapists to use Guidelines in their practice?

TABLE 7. STAKEHOLDERS

Q Number	Question
1	About you and the work you do
2	Is your role as an academic, consumer organisation, government agency or other?
3	Where do people with spinal cord injuries tell you they get information about physiotherapy treatments? In your opinion, how credible and reliable are these sources?
4	Where do you usually seek information about what physiotherapy treatments are most effective for people with spinal cord injuries? Why those sources?
5	Where else do you get information about what physiotherapy treatments might be important to people with spinal cord injuries?
6	Which of these information sources are you listening to most and why?
7	How important is it to you that there is good scientific evidence for physiotherapy treatments used by people with spinal cord injuries? Tell me a little bit about this.
8	Which are the best sources of information about new treatments for people with spinal cord injuries? Why those sources?
9	Have you heard of Clinical Practice Guidelines?
10	Would physiotherapy Clinical Practice Guidelines be useful to you in the work that you do? Why or why not?
11	What if the Clinical Practice Guidelines recommended a treatment that you didn’t think was worthwhile for people with spinal cord injuries? Would that change how you view the Guidelines?
12	What if the Clinical Practice Guidelines did not recommend a treatment you think is worthwhile? Would that change how you view the Guidelines?
13	How does having Clinical Practice Guidelines for people with spinal cord injuries compare to how you access information now? What are the pros and cons for you?
14	Do you believe the Guidelines would be useful for your current work?
15	How much do you think the Guidelines are needed by physiotherapists?
16	How much do you think the Guidelines are needed by people with spinal cord injuries?
17	What do you suggest the Guideline authors do to support use of the new Guidelines?
18	What might make it difficult for users to implement the Guidelines in their practice?