

# Physical Activity Promotion in the Thalidomide Population

Final Report  
March 2021  
Loughborough  
University

Dr Han Newman  
Dr Christof Leicht  
Dr Anthony Papathomas (PI)

# Executive summary

## Introduction

This Executive summary provides an overview of the methods and key findings associated with the Promotion of Physical Activity in Thalidomide Survivors research project. The research was conducted by Loughborough University researchers between January 2020 and February 2021.

## Thalidomide survivors and physical activity

Thalidomide survivors, born circa 1960 with often severe birth defects, are currently experiencing premature ageing and high prevalence of disability induced health issues such as arthritis and obesity. The Thalidomide Trust has identified physical activity as a potential strategy to improve age-related health issues and support patrons to age successfully. A survey of Thalidomide survivors' perceived health needs has also identified an interest in physical activity and exercise but a lack of knowledge on how to achieve this.

## Aims and objectives

The overarching aims of this project were to develop an understanding of Thalidomide survivors' experiences of physical activity and use this understanding to promote an increase in physical activity motivation and behaviour.

## Approach to research

The research took the form of a participatory action research (PAR) project; an approach to research that prioritises collaboration with the people the research focuses on (Wallerstein & Duran, 2010). In PAR, the goal is knowledge but also social change that benefits beneficiaries, and it aligns with the disability activist mantra:

### **"nothing about us, without us"**

This research project therefore involved Thalidomide survivors as co-producers at every stage of the research process. Beneficiaries' experiences of physical activity informed the design of a pilot intervention aiming to increase physical activity motivation and behaviour, and an intervention Design Team was formed so that the content of this intervention was decided in collaboration with Thalidomide survivors.

## Methodology

The research project took a three phase format (see Figure 1 below). The first phase aimed to better understand Thalidomide survivors' varied experiences of physical activity. The second phase aimed to use these experiences to design a pilot intervention aiming to increase physical activity motivation and behaviour. The third phase involved running the pilot intervention and subsequent evaluation.

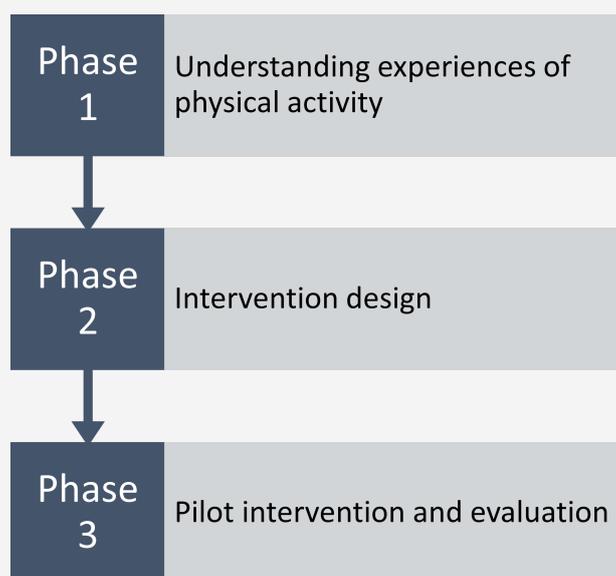


Figure 1: Research overview

### Phase One: Understanding physical activity experiences

The aim of Phase One was to explore Thalidomide survivors' experiences of physical activity. This focus on experience involved an exploration of the perceived benefits, barriers, and facilitators to physical activity. It also explored how physical activity is subjectively valued, for example, is it a "necessary burden" or something that is "enjoyed".

Two focus groups and 28 one-to-one interviews were conducted with Thalidomide survivors. Overall, 31 Thalidomide survivors took part in Phase One (18 women and 13 men).

Audio recordings from both the focus groups and the interviews were fully transcribed and analysed using thematic analysis, which is a method for identifying, analysing, and reporting patterns (themes) within data (Braun & Clarke, 2017). We identified two core themes that describe Thalidomide survivors' physical activity experiences (see Table 1).

Themes	Subthemes
<b>Balancing cost versus benefits</b>	Striving for independence: risk vs. reward Impact on mental health
<b>Barriers and facilitators to physical activity</b>	Pain vs. pain management Access to knowledge & expertise The importance of social support Motivation and mindset

*Table 1: Themes and subthemes*

## Phase Two: Intervention design

The aim of Phase Two was to design a real-world, viable intervention to support Thalidomide survivors to increase physical activity motivation and behaviour, informed by the findings from Phase One.

A group of 12 Thalidomide survivors (all who identified as inactive and/or struggling to make physical activity a regular part of their life) were recruited to form an intervention Design Team and work in collaboration with the researchers.

The intervention design process consisted of a series of video call discussions between the lead researcher and the 12 Thalidomide survivors in the Design Team – a combination of whole team meetings, small group discussions, and individual one-to-one interviews.

By the end of Phase Two, a final pilot intervention plan was agreed between the Design Team and the researchers. This intervention aimed to empower Thalidomide survivors to make their own choices regarding physical activity and focused on addressing three key elements:

- **Mindset** (Me)  
What are my goals? What is my motivation? How can I improve my relationship with physical activity?
- **Social** (Us)  
How can we support each other? What ideas or experiences can we share?
- **Knowledge** (Others)  
What do I need from others to achieve my goals? How do I find the right people to help me? Where can I access this information?

## Phase Three: Pilot intervention and evaluation

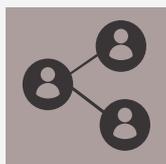
The aim of Phase Three was to pilot the intervention with beneficiaries and evaluate it using follow-up process evaluation interviews. Seven beneficiaries – 5 women and 2 men – (who all identified as inactive and/or struggling to make physical activity a regular part of their life) completed the pilot intervention.

The intervention ran across a five-week period, and consisted of the following elements:



### Mindset

Bitesize video series  
Individual support



### Social

'Buddy' system  
Sharing of ideas platform



### Knowledge

Toolkit resources  
General resource pool

Within the mindset component, beneficiaries were offered individual support sessions with the lead researcher in week 1, week 3, and week 5. Within the social component, beneficiaries were matched with a virtual physical activity 'buddy', who they committed to 'meeting' with once per week during the intervention period. The resources that formed the knowledge component of the intervention were available to beneficiaries throughout the intervention period.

## Outcome measures

For those who took part in the pilot intervention, measures of **self-reported physical activity, motivation, physical activity self-confidence, and mental health** were taken pre-intervention, immediately post-intervention, and two-months post-intervention.

Mean levels of **self-reported physical activity** and **physical activity self-confidence** increased from pre- to post-intervention. Increases were maintained at 2 month follow-up. Mean scores for symptoms of **depression and anxiety** reduced from pre- to post-intervention and remained lower than pre-test scores at 2 month follow-up.

'Physical condition' was the most important form of **motivation** at all three time points, and there were also decreases in the mean scores for extrinsic forms of motivation, such as the expectations of others, and increases in the mean for intrinsic forms of motivation, such as enjoyment. Intrinsic motivation remained stronger than extrinsic motivation at 2 month follow-up.

Although no statistical analysis was conducted due to small sample size, the analysis of means demonstrates strong proof of concept regarding intervention ingredients.

## **Process evaluation**

Following the intervention period we conducted six process evaluation interviews – five with beneficiaries who completed the pilot intervention, and one with a beneficiary who withdrew from the process. These interviews explored beneficiaries' personal experiences of participation and were used to evaluate the pilot intervention. To analyse the evaluation interview data we took a flexible, deductive approach, basing our analysis on the three key features of the intervention. Strengths and weaknesses were scrutinised according to these three components and general participation experiences.

Beneficiaries who completed the intervention described positive experiences of taking part, and resultant benefits to their relationship with physical activity. Individual mindset support was highly valued, helping beneficiaries to establish physical activity goals and to fulfil them. Beneficiaries enjoyed the 'buddy' system and experienced benefit from the connection to others that the social component of the intervention enabled. The knowledge component empowered beneficiaries to explore a variety of types of activity and/or exercise equipment that suited their physical activity preferences and needs. Although some beneficiaries would prefer more prescriptive intervention – such as provision of exercise opportunities and/or instructions of what to do and when – this did not interfere with the overwhelming positivity for the process and intervention components.

## **Conclusions**

In conclusion, this research project demonstrates that Thalidomide Trust beneficiaries are receptive to a physical activity promotion intervention. There was a smooth recruitment process, sound engagement in collaborative interviews, and timely completion of outcome measures. Dropout was minimal. The intervention tools developed hold proof of concept and warrant further study. A larger-scale roll-out of this work, incorporating lessons learned and targeting the entire UK Thalidomide community, represents a viable research initiative with the potential for great benefits to physical and mental health. The participatory action research approach, which integrated beneficiaries into every element of the research process including intervention design, was also successful. This project has remained faithful to the "nothing about us, without us" mantra and all subsequent projects should aspire for this too.

## **The Research Team**

**Dr Anthony Papathomas (Principal Investigator)**

**Dr Han Newman (Lead Researcher)**

**Dr Christof Leicht (Co-investigator)**

Please direct all correspondence related to this report to Anthony Papathomas (a.papathomas@lboro.ac.uk)

This Final Research Report provides a detailed account of the project entitled Physical Activity Promotion in the Thalidomide Population. We summarise the research aims and methods, present the key findings, and offer recommendations for future practice.

2 Executive summary

8 Research aims & objectives

9 Research overview

10 Phase One

21 Phase Two

29 Phase Three

35 Intervention evaluation

45 Recommendations for practice

48 References & Appendices

## Table of Contents

# Research aims & objectives

The overarching objective of this research was to develop an understanding of Thalidomide survivors' experiences of physical activity and use this understanding to increase physical activity motivation and behaviour. The following research questions were addressed:

- **What are Thalidomide survivors' experiences of physical activity and exercise?**
- **What are the main barriers and facilitators to engaging with regular physical activity?**
- **What are the perceived benefits of physical activity?**
- **How can the Thalidomide community be empowered to engage in more physical activity?**

The research took the form of a participatory action research (PAR) project; an approach to research that prioritises collaboration with the people the research focuses on (Wallerstein & Duran, 2010). In PAR, the goal is knowledge but also social change that benefits beneficiaries, and it aligns with the disability activist mantra:

**"nothing about us, without us"**

This research project therefore involved Thalidomide survivors as co-producers at every stage of the research process. Beneficiaries' experiences of physical activity informed the design of a pilot intervention aiming to increase physical activity motivation and behaviour, and an intervention Design Team was formed so that the content of this intervention was decided in collaboration with Thalidomide survivors.

# Research overview

The research project took a three phase format (as shown in Figure 1). The first phase aimed to better understand Thalidomide survivors' varied experiences of physical activity. The second phase aimed to use these experiences to design a pilot intervention aiming to increase physical activity motivation and behaviour. The third phase involved running the pilot intervention and subsequent evaluation. Further details of each stage are provided later in this report.

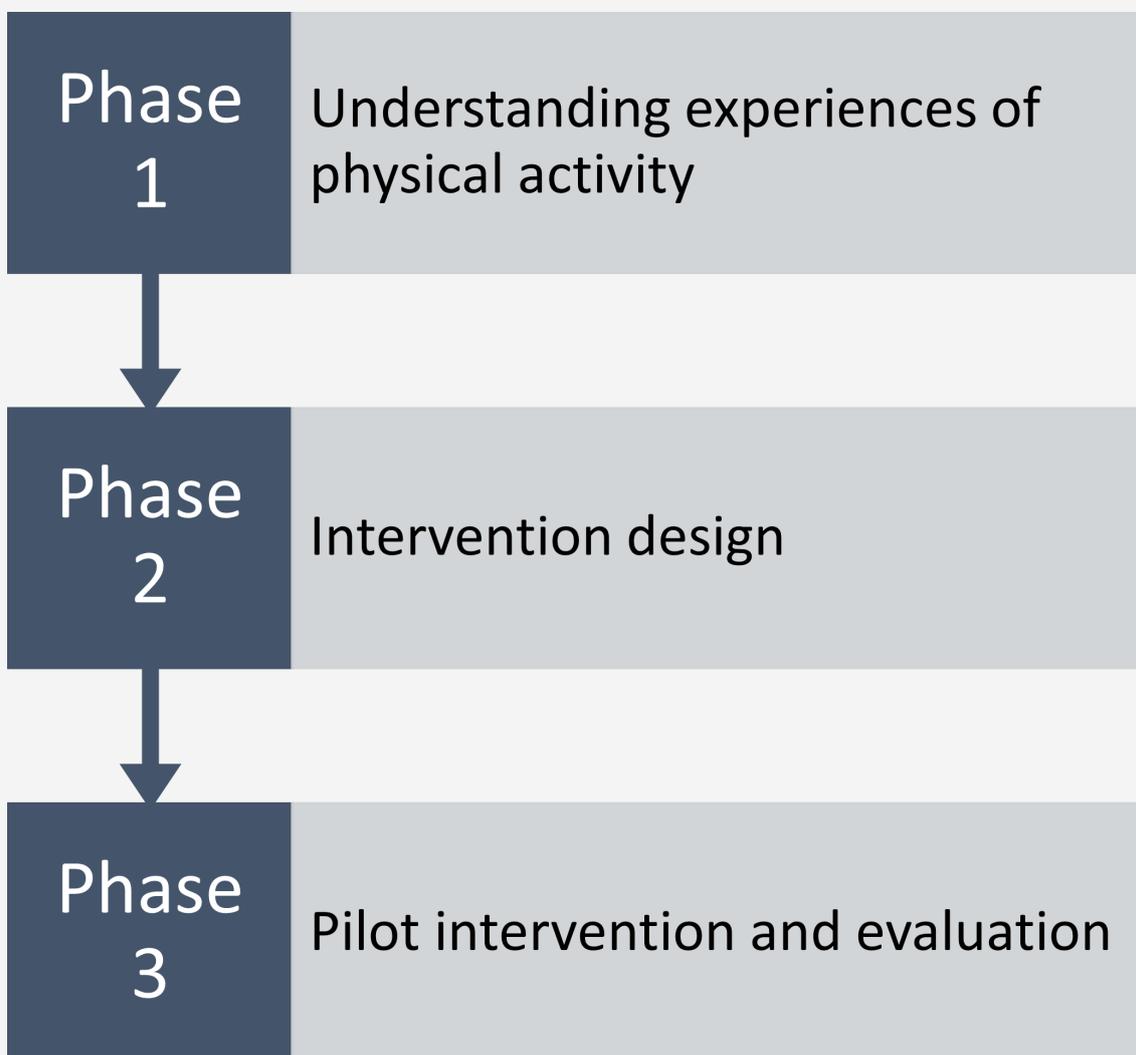


Figure 1: Research overview

# Phase One

## Understanding physical activity experiences

### Aims

The aim of Phase One was to explore Thalidomide survivors' experiences of physical activity. This focus on experience involved an exploration of the perceived benefits, barriers, and facilitators to physical activity. It also explored how physical activity is subjectively valued, for example, is it a "necessary burden" or something that is "enjoyed".

### Methodology

A range of amendments were made to the original research proposal to ensure this research was conducted in line with Loughborough University COVID-19 safe protocol. Two in-person focus groups with Thalidomide survivors took place prior to the introduction of COVID-19 restrictions (Newport, March 2nd, 2020 and Newbury, March 6th 2020). After these, all research participation was amended to take place remotely via video or telephone call.

Focus groups are a form of group interview that use group interaction to generate data (Kitzinger, 1995). The focus groups were facilitated by the

lead researcher, Han Newman. The role of the focus group facilitator is to create an environment in which participants feel relaxed and comfortable to share their experiences and views (Krueger, 1994), to use guiding questions that prompt interaction and discussion between group members, and to periodically refocus the direction of the discussion (Sparkes & Smith, 2014). There were three beneficiaries in the first group, and five in the second (five women and three men). Recruitment for this phase of the research invited any Thalidomide survivor to take part, regardless of current physical activity engagement. This ensured representation of varied physical activity experiences between the beneficiaries in both focus groups.

Subsequent to research participation being moved online, 28 one-to-one interviews were conducted with Thalidomide survivors between May 4th and June 16th, 2020. 15 via video conferencing software, and the remaining 13 by telephone, as was most convenient and viable for each beneficiary. Five of those beneficiaries interviewed had also attended one of

the two focus groups, the remaining 23 had not. As per the focus groups, participation in the one-to-one interviews was open to any Thalidomide survivor with an interest in talking to us about their physical activity experiences. A qualitative interview is described as a 'conversation with a purpose' (Holloway, 1997, p. 94) in which the interviewer aims to explore the experiences, perspectives, attitudes, and opinions of those being interviewed. The use of one-to-one interviews as well as focus groups meant the interaction and discussion generated between beneficiaries was complemented by the exploration of individual experiences in greater depth. All interviews were conducted by the lead researcher, Han Newman, and were semi-structured,

meaning a pre-planned but flexible interview guide was used to direct the interaction (Sparkes & Smith, 2014).

Overall, 31 Thalidomide survivors participated in Phase One (18 women and 13 men). The focus groups and interviews yielded approximately 1095 minutes / 18.25 hours of data. The age of beneficiaries ranged from 55 to 61, with a mean age of 58. One third of beneficiaries described themselves as "active", with the remainder identifying as "inactive" or "lightly active". There was variation in disability amongst beneficiaries. Using the 'classification of original Thalidomide damage', disability range included hand damage, upper limb damage, lower limb damage or both upper and lower limb damage.

## Findings

Audio recordings from both the focus groups and the interviews were fully transcribed and analysed using thematic analysis, which is a method for identifying, analysing, and reporting patterns (themes) within data (Braun & Clarke, 2017). The aim of thematic analysis is not to summarise data content, but to identify and interpret key features of the data, guided by the research question. To achieve this, Braun and Clarke's (2006) six-step process for conducting thematic analysis was followed. We identified two core themes that describe Thalidomide survivors' physical activity experiences (see Table 1). In this section of the report we use quotes taken from the focus group and interview data to demonstrate these themes. Pseudonyms have been used to protect the anonymity of the beneficiaries.

Themes	Subthemes
<b>Balancing cost versus benefits</b>	Striving for independence: risk vs. reward Impact on mental health
<b>Barriers and facilitators to physical activity</b>	Pain vs. pain management Access to knowledge & expertise The importance of social support Motivation and mindset

*Table 1: Themes and subthemes*

## Balancing cost versus benefits

All beneficiaries recognised the importance and benefits of being physically active for their physical health, and many discussed its importance for their mental health. However, these benefits were also often set against potential costs of being active. The costs and benefits described by beneficiaries comprised of these core areas: striving for independence: risk versus reward, and mental health.

### *Striving for independence: risk vs. reward*

“

**I need to give myself the best possible chance to be in my own home without care for as long as possible.**

”

A key perceived benefit of physical activity was its potential to help maintain independence as survivors get older. For example, Jane, 55, said:

**"It's also about the fear of care for me, I don't want to be cared for, I need to be as fit and as healthy, and it takes the littlest thing for me that causes issue... it's like oh can you even wash? Can you even dress? Can you even cook yourself food? So the main thing for me is I need to stay fit and healthy, that means I need to stay flexible and I need to give myself the best possible chance to be in my own home without care for as long as possible."**

Some beneficiaries also commented on the specific impact that the loss of mobility could have on their everyday function. For example, Diane, 59, said:

**"Using your feet when you don't have any arms, they need to be in tip top condition if you can do that. I use them for everything. I was just thinking about it before, I hang upside down practically, I sit on units in the kitchen and then hang upside down to reach the highest shelf I can reach so it also involves pulling on the core muscles and so I need to be able to reach... I need to have fit, strong legs to be able to do all of those things so it's important I look after them."**

Although beneficiaries mostly spoke positively about the potential benefits of physical activity for independence, some expressed concerns. Barry, 57, argued exercise might jeopardise his independence:

**"I think two of those (injuries) have made me more nervous now about some of the activities that I used to do because I can't bear to lose my independence... I think the number one challenge for me now is fear of injury... And my road bike now, I'm kind of thinking to myself I could take it out on a cycle path... but I'm thinking I want to be a bit fitter first and more confident because I don't want to fall off it and hurt myself again. So I think there's a fear of impairment and knowing how long it takes to recover."**

Fred, 59, offered similar concerns:

**"If you knew it was just about exercise, you could go out and just do the exercise. But you've got to be tempered with other things as well. Still going to have to be able to move around, to transfer into cars, so if you go out and pull a muscle in your neck because you've been doing weights and then you can't move yourself into the car that's you fucked. But you should have thought about that before you started lifting weights. So yeah, it's difficult."**

Weight management was also identified by some beneficiaries as an important physical activity benefit that has an impact on everyday function and independence. For example, Phoebe, 57, explained:

**"Before I lost the weight I couldn't even stand long enough to fill my car up with diesel. I probably could have stood long enough to do that but then I'd have to walk and stand in a queue to pay. And I would feel myself getting quite anxious because at some point I'm going to kind of run out of steam and my back starts to hurt and oh my god I'm going to need to sit down."**

The value of effective weight management was echoed by Victoria:

**"If I go past the dreaded weight it's nothing about looking good, it's all about physical movement."**

Weight management was therefore perceived as a benefit of physical activity, and this perception was largely focused on its potential impact for independence and everyday function. Beneficiaries hence demonstrated an awareness of the benefits that physical activity could or does have for their independence, whilst also expressing concern that it could have the reverse impact by inducing further pain or injury.

### ***Impact on mental health***

“

**I love it. I absolutely love it. It's the thing that keeps my head straight.**

”

Some of the beneficiaries perceived there to be mental health benefits of physical activity. For example:

**"I love it. I absolutely love it. It is the thing that keeps my head straight. If I've got something that is going around in my head... either I will sort it out in my head while I'm walking, or I'll keep walking until I'm too tired to think about it. And then when I come back inside it's either sorted or I'm too tired to think about it and it doesn't do the hamster wheel thing in my head."**

Similarly, Terry, 59, described benefits to his mood from being physically active:

**"Well, you definitely get the sense that going for a little walk does give you a sense of wellbeing that's better, doesn't it, it lifts your spirits, and it does help, it just helps to get out and do something rather than just... so it does, you know it often proves that you feel better for a good walk."**

The impact of physical activity on mental health has been experienced in other disabled populations (e.g.,

Williams, Smith, & Papatomas, 2014) and in other older populations (Middleton, Moxham, & Parish, 2018). Mental health benefits of physical activity were not perceived universally by beneficiaries in this research though. Some of the beneficiaries who identified as inactive were more sceptical of the mental health benefits. For example, Brian, 57, stated:

**"I'd have more, well allegedly have more energy but as I say it's always exhausted me and not, I mean I wish I could experience this endorphin rush that people talk about you know, it's just exhaustion for me."**

Overall, the potential for being active to help beneficiaries maintain their independence was the most prominent benefit of physical activity. Weight management was also important to many, and was often linked to the impact of being overweight on the physical ability and mobility that would help them to remain independent. Potential mental health benefits of being physically active were recognised by many beneficiaries, although for some these were not as prevalent.

## Barriers and facilitators to physical activity

### *Pain vs. pain management*

“

**knowing that I'm going to pay for it pain wise for an unknown quantity of time afterwards makes it very difficult to motivate myself to do it.**

”

For many beneficiaries, their experiences of pain acted as a barrier to physical activity, either because of the pain they experienced during activity, or because of the potential pain after being active. For example, John, 61, said:

**"so both my knees, my right ankle, and my shoulders are just like, the pain is just unbearable. I do have steroid injections in my shoulders every now and again when they get really bad and they're going to think about doing it to my knees now as well. I can't get out to do proper exercising... If I've been for a walk at the woods, and I get to the woods a mile away and my knee goes or my hip goes, how do I get back?"**

Johnnie, 59, spoke about the potential pain after physical activity:

**"I need to build back up but doing that there's a pain cost at the end of it... Part of it is that you know if you go and exercise, there's going to be all these benefits, but possibly for a day or two days after it you're going to feel like Mike Tyson's had a go at you... knowing that I'm going to pay for it pain wise for an unknown quantity of time afterwards makes it very difficult to motivate myself to do it."**

For other beneficiaries though, physical activity was deemed an important way of managing their pain, as exemplified by Phoebe, 57, here:

**"I think a good part of my exercise routine is stretching. About half an hour, 40 minutes, is just stretches, for my neck, my back, my shoulders, you know all sections of my back, my lower back, my neck... and realising that if I do those I don't get the same pain that I used to."**

Jane, 55, also spoke about the benefits of physical activity for pain management:

**"It keeps me off painkillers... before, when I started doing the walking at the beginning I was taking tablets like you wouldn't believe and over a 5-year period I got off all that with massage and fitness and ultrasound. But I was still taking the anti-inflammatories right up until I was about 6 months into the yoga. I now don't take anything. For two and a half years I haven't taken anything at all, but I'd taken tablets for 25 years."**

For those who described physical activity as beneficial for their pain, this was often linked to activities such as yoga and pilates, or other stretching and strengthening based activity. There is a substantial body of existing research showing that exercise can be beneficial in managing pain in other disability groups, older age groups, and those with arthritis (e.g., Callahan, 2009; Koltyn, 2002). The importance of knowledge of appropriate forms of exercise to manage pain was apparent and is explored in the next sub-theme.

### ***Access to knowledge & expertise***

“

**therapists have actually caused a lot of pain and possibly damage, because they don't have the experience or knowledge to do an odd body like mine.**

”

Knowledge featured prominently as either a barrier or facilitator to physical activity: having access to knowledge, access to knowledgeable health and fitness professionals, having the knowledge to know what activity to be doing, and knowing how to adapt exercise equipment for their own needs were all deemed as facilitators to physical activity. Not having access to this knowledge, or access being difficult, was a barrier to physical activity for many.

Many beneficiaries spoke of the difficulties they had faced in finding health and fitness professionals (e.g., personal trainers, physiotherapists, and yoga or pilates instructors) with the right skills, knowledge, and experience of working with 'different' bodies. For example, Lynn, 59, stated:

**"In fact, I actually have to travel for hours to get to a massage therapist who will do me well. Some of the local massage therapists have actually caused a lot of pain and possibly damage, because they don't have the experience or knowledge to do an odd body like mine."**

Those who had found a professional who had the right skills and knowledge to adapt to their individual needs described many benefits of this.

Some saw these health professionals regularly in person, others gained the knowledge they needed from them and then chose to implement this on their own, for example, Phoebe, 57, said:

**"I had a free session with a personal trainer at the physio clinic that I was attending... he spoke to my physio, so had an understanding about my difficulties. We tried out different things and it soon became apparent that equipment didn't work for me... But trying things basically just inspired me to think well that worked, and that worked, so I bought a few bits of home gym equipment... I went back a couple of times to the personal trainer but I didn't actually need them, I was doing it on my own and I was quite driven and happy."**

As it was for Phoebe, appropriate support from exercise instructors and healthcare providers has been found to be a facilitator to physical activity, including in other disabled populations and those with long-term health conditions (e.g., Veldhuijzen van Zanten, Rouse, Hale, et al., 2015).

Several beneficiaries expressed the benefits of finding ways to be active either at home, or in other settings away from formal exercise facilities, such as gyms or swimming pools. This included the use of adapted equipment or having equipment adapted for their needs when possible. Barriers to using exercise and leisure facilities were discussed, such as inaccessible facilities and challenges to getting changed. This will be discussed further in the next sub-theme.

### ***The importance of social support***

“

**Just going for a walk... my friend's with me and if I do stagger I can take her arm or whatever.**

”

Social support for physical activity can take many forms. It can be instrumental and direct support (e.g., transportation to an exercise facility); emotional and motivational support (e.g., encouragement, praise); or observational support (e.g., modelling of healthy behaviours) (Springer, Helder, & Hoelscher, 2006).

The support of other people was a crucial facilitator to being physically active for many beneficiaries, and conversely the lack of support acted as a barrier. For some, this support was referring to help and support from a knowledgeable exercise professional, as described previously. For others though, this was referring to having somebody to do physical activity with. For example, Lucy, 59, stated:

**"when my husband was alive we did used to use a local gym... Part of my problem with exercise is changing and getting dressed and undressed. Of course, having my husband there to do all of that for me it didn't then pose a problem... He wouldn't mind doing showering and blow drying my hair... I feel now my sons are having to help me... they're my sons, I didn't have them to be carers.... I don't want to be a burden to them."**

In describing the impact the loss of her husband has had on her physical activity, this quote from Lucy also demonstrates the challenges for some in finding appropriate social support. Not wanting to burden other family members, Lucy appears at a loss here as to who she can turn to for this type of direct support.

Challenges to changing, and the need for someone else to be there to help with changing either at a gym or swimming pool, was one key reason why the direct support of another person was integral to some beneficiaries' experiences of physical activity. This challenge was compounded for some by problems with inaccessible facilities, for example, Greg, 58, said:

**"It's time, availability of other staff to come with me, and if I'm honest, because they don't have family or unisex changing facilities there, because all of my staff are female I can't have anybody to assist me with undressing and dressing and changing into my swimming things. And I find that difficult as well."**

Another reason why the support of another person was crucial to some was the fear of falling, expressed by Doreen, 57:

**"The last fall was two years ago and I landed up in hospital for six days... So since then I've become very, I wouldn't say reluctant, reluctant is the wrong word, but I'm worried about it in case I do it again. Even just going for a walk I'm like... So in this time of lockdown, we would normally go out and about, my friend's with me and then if I do stagger, you know I can take her arm or whatever. But we can't do that right now."**

Aside from the necessity for having the direct support of others to help them be physically active in the ways discussed above, emotional and motivational support was also mentioned by many beneficiaries as being potentially helpful. For some this was because of the added encouragement this could bring. For example, Greg, 58, said:

**"I think having an exercise buddy helps. You know, you pair up with somebody else, and that way you kind of encourage each other... if you just once a fortnight have a chat about how has it been for you... what have you been able to do, what haven't you been able to do, I think that kind of peer support is good."**

Other potential benefits of social support mentioned included a form of accountability that could aid motivation, an added social side to physical activity, and the sharing of ideas. Greg mentions specifically here the benefits of peer support. Peer support is provided by bringing together people with shared experiences. These people use their own experience to provide knowledge, emotional, social, or practical help to each other (Mead, Hilton, & Curtis, 2010). It was also noted by many that this peer support did not necessarily have to be in person, but that virtual forms of support could also be helpful. The potential benefits of social support, particularly from peers, as described by beneficiaries here, have been found in previous research to increase physical activity retention and adherence in older adults (Crozier, Porcellato, Buckley, et al., 2020).

## Motivation and mindset

“

**I'm really fed up with being overweight... but that is not motivating me to want to go out and do an hour's exercise.**

”

Some of those who struggled to be physically active also mentioned difficulties in having the right mindset and/or finding the motivation either to do some form of physical activity, or to find ways to overcome the logistical and physical barriers that they faced. For example, Lucy, 59, said:

**"I would love to know what I could use as motivation, I really don't know. I know I'm stuck in a rut at the moment and my mood is not very good, it's quite a low mood. So it's like looking through a forest at the moment... I have no idea what motivation I could get. I'm really fed up with being overweight and that causes me problems physically doing things... But that is not motivating me to want to go out and do an hour's exercise every day. Even though I know it's a problem, and I know I'm sitting on my backside a lot of the time eating, but I don't know how I get over that bit."**

Lucy's account highlights the challenges that can come with an over-reliance on extrinsic motivators (Kilpatrick, Hebert, & Jacobsen, 2002), in this case weight loss, which is hard to achieve through exercise alone and often takes considerable time.

Some beneficiaries also described self-consciousness around their body and

their disability as another barrier to being physically active in public spaces, for example Viv said:

**"It's walking into a pool with a lot of people when you've got a very obvious disability. That was a huge issue to start with... it involved climbing in with help, other people sitting around, and you're very close in a spa... psychologically that was a huge issue to overcome.... I found it very daunting and upsetting to start with."**

For Lucy, 59, this self-consciousness and discomfort in being active in public facilities was compounded by negative interactions and discriminatory behaviour from others:

**"people look, stare and well we've had some horrendous comments about not touching equipment because I've touched it and all that sort of thing. Some of it is just so hard believe. I had a comment when I was a little girl and I'll never forget it... Two ladies came walking towards us and both me and my mum overheard them comment about should have been put down at birth... Those things stay with you, and they do scar you, they leave their mental scars. So all that adds to my anxiety of not going anywhere alone. I need a bit of back up in place."**

The connection Lucy makes between these discriminatory interactions and the difficulties she experiences in going out to do physical activity alone again emphasises the importance of social support. Other beneficiaries also expressed similar concerns, including concerns around self-consciousness in exercise facilities such as gyms, but also in group exercise settings and classes. Previous negative experiences with physical activity have had a lasting impact on their confidence in being active. In previous research, self-consciousness has been found to be a common barrier to physical activity in a range of populations (e.g., Dergance, Calmbach, Dhandra et al., 2003).

## Summary of barriers and facilitators to physical activity

Barriers	Facilitators
Lack of/inaccessibility of knowledge or knowledgeable professionals.	Access to knowledge/knowledgeable health professionals.
Physical pain/fear of pain.	Having the support of someone else to do physical activity with.
Lack of motivation/difficulties with mindset.	Peer support – in person or virtually.
Inaccessible facilities and challenges of changing.	Sharing of ideas for physical activity.
Having no one to help with logistical challenges.	Motivation or mindset to overcome other barriers or find other ways to be active.
Self-consciousness.	Adapted equipment.
Cost or inaccessibility of adapted equipment.	

*Table 2: A summary of barriers and facilitators to physical activity*

# Phase Two

## Intervention design

### Aims

The aim of Phase Two was to design a real-world, viable intervention to support Thalidomide survivors to increase physical activity motivation and behaviour, informed by the findings from Phase One.

### Methodology

#### Participatory action research

The design process adopted in this phase was guided by the principles of participatory-action research (PAR) and collaborative social change. Community-based participatory action research is a research paradigm that can bridge the gap between science and practice through community engagement and social action to increase health equity (Wallerstein & Duran, 2010). It strives to give marginalised groups a collaborative role in intervention-based research, thereby improving the ultimate success of the intervention. Participatory action research holds two parallel goals: 1) increasing conceptual knowledge through rigorous academic research and 2) effecting positive social change in collaboration with the target population. This methodological approach expands the potential to develop, implement, and disseminate

effective interventions across diverse communities by redressing power imbalances and facilitating mutual benefit among community members and academic partners.

#### Design team recruitment

A group of 12 Thalidomide survivors were recruited to form an intervention Design Team. The role of the Design Team was to work in collaboration with the researchers in the design and evaluation of the intervention process. It was agreed by the research team and the Thalidomide Trust that the intervention was best aimed at those it could help the most: Thalidomide survivors who identified as inactive and/or struggling to make physical activity a regular part of their life. Members of the intervention Design Team were purposively recruited in line with this decision. Beneficiaries from Phase One who met these criteria were therefore invited to be a part of the intervention Design Team. A recruitment email was also sent out to beneficiaries not involved in Phase One who met the relevant criteria. As a result, the team of 12 (6 women and 6 men) was formed of 11 beneficiaries who had taken part in Phase One, and one participant who was new to the project in Phase Two.

Separately from the intervention Design Team, a second group of Thalidomide survivors were invited to be a part of an Advisory Group that, where appropriate, would later be asked to review materials produced throughout the research process, and share their thoughts and feedback at different stages of the project. Those invited to be a part of this group were beneficiaries from Phase One who did not meet the criteria for the target audience of the pilot intervention (i.e., they were already regularly active and had an existing physical activity routine that worked for them). The Advisory Group was formed of 13 beneficiaries (8 women and 5 men).

## **Intervention design process**

The intervention design process consisted of a series of video call discussions between the lead researcher (Han) and the 12 Thalidomide survivors in the Design Team – these were a combination of whole team meetings, small group discussions, and individual one-to-one interviews. The lead researcher worked with the group to ensure that key psychological principles were embedded within the final intervention design.

When working with the intervention team's ideas, the research team ensured self-determined motivation – exercising because you value and enjoy it – was encouraged ahead of controlling motivations (e.g., exercising because you feel you have to). Promoting more self-determined motivation involves developing an intervention that encourages **autonomy** (personal choice), **relatedness** (feeling connected to others in some way) and **competence** (feeling a sense of mastery and success) (Ryan & Deci, 2017). Hence, the research team ensured these principles remained a focus of the intervention design when working with the Design Team's ideas. The research team also worked to ensure that the intervention design emphasised activities that are enjoyable (Ladwig, Hartman, & Ekkekakis, 2017). Here we detail the collaborative process involved in developing the final intervention design (see Figure 2 overleaf for a summary).

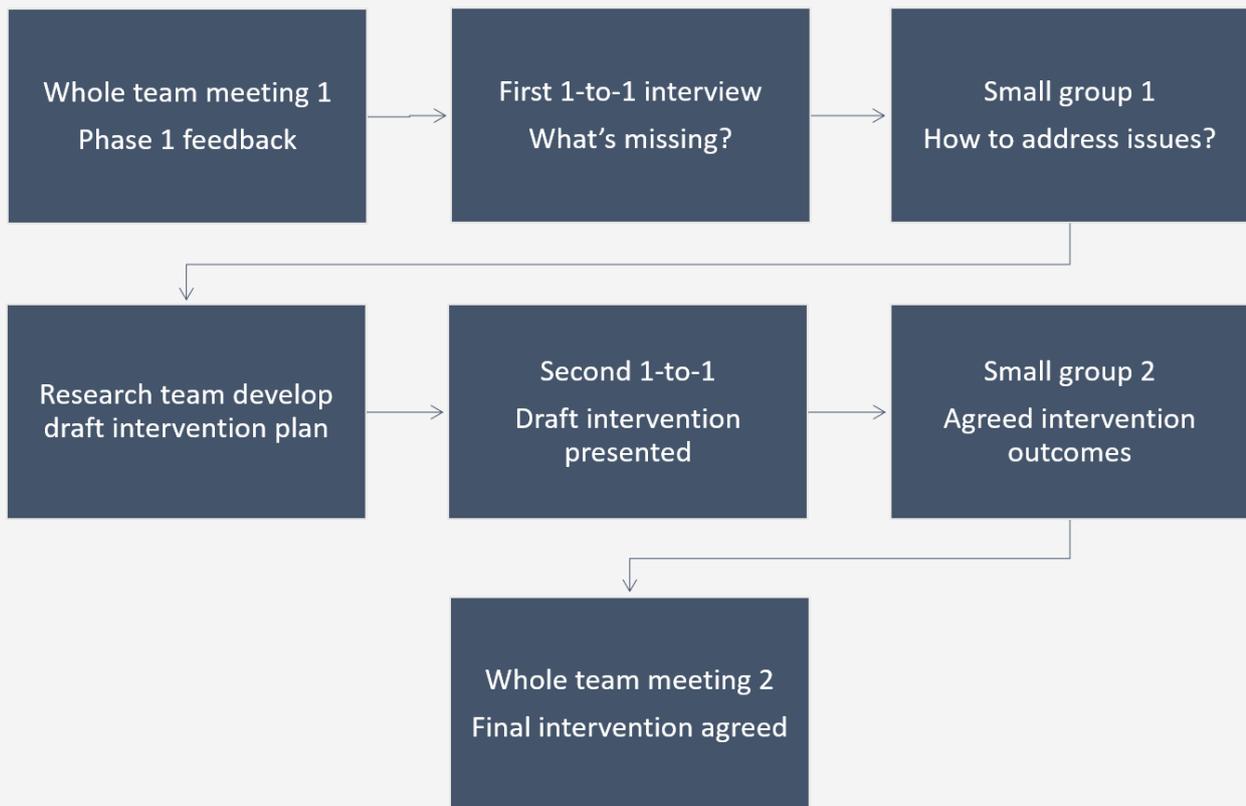


Figure 2: Intervention design process

### **First whole team meeting**

Once the intervention Design Team was assembled, a whole team meeting was held. In this initial meeting, Han presented an overview and summary of Phase One results, outlined the plan for Phase Two, and proposed a list of key considerations to be taken from Phase One. These key considerations served as a starting point for intervention design and are listed here:

- Individualised approach
- Individual physical activity aims and goals
- Motivation and mindset support
- Peer support
- Sharing of ideas
- Access to knowledgeable professionals
- Importance of knowledge

The intervention Design Team were asked to reflect on this list after the meeting and to each identify which three they considered to be most important to the intervention design process, as well as to identify any further considerations that they thought were missing from the list.

### ***Individual interviews (first round)***

After the first whole team meeting, Han held individual meetings with each of the 12 Thalidomide survivors in the intervention Design Team. These meetings followed up on each team member's thoughts and views on the list of key considerations previously presented. These individual interviews were included as part of the intervention design process to allow beneficiaries the opportunity to communicate any points that they felt unable to raise in a group setting. Questions posed to each member of the Design Team in these meetings included:

- Do you feel these points are important for us to consider in designing an intervention to help you be more physically active?
- From the list, what would you consider the top three most important to be and why?
- Is there anything missing from this list? Are there any other key points for consideration that you would add to this?
- What ideas do you have about how we could address these points in the intervention that we design together?
- What would you like to see from an intervention? What might this look like to you?

The discussions held in these individual meetings were then used to inform the first round of small group discussions.

### ***Small group discussions (first round)***

For this next round of meetings, the group of 12 were divided into four groups of three to facilitate small group discussions. Leading on from the previous individual interviews, the purpose of these discussions was to explore in more depth the Design Team members' ideas about what might be helpful/unhelpful in an intervention aimed to help increase their physical activity motivation and behaviour.

From the previous individual interviews, three core 'pillars' came through as what beneficiaries considered the most important points for the intervention to be focused on: motivation/mindset support, knowledge, and peer support. Beneficiaries also expressed in the individual interviews that it was important to them that each of these pillars was underpinned by the principles of an individualised approach that was accommodating of differing physical activity aims and goals. This feedback, plus early ideas expressed by beneficiaries for how each of these pillars might be addressed by the intervention, were brought together by the research team to form the focus of small group meetings, as can be seen in Figure 3 (next page). Specifically, to structure the small group discussions, we asked: Does this sound like something that would be beneficial to you? And practically, what would you like this to look like? If this does not sound beneficial to you, what could be more helpful instead?

Motivation/Mindset /Psychology Support	Knowledge	Peer Support
<p>Something informational/ educational?</p> <p>Individual support?</p>	<p>Access to knowledgeable professionals – perhaps a database? Help with what to look for?</p> <p>Knowledge – online resources / resource pack?</p>	<p>A mechanism for connecting people?</p> <p>A mechanism for the sharing of ideas?</p>
<p>Individualised approach accommodating of differing physical activity aims and goals</p>		

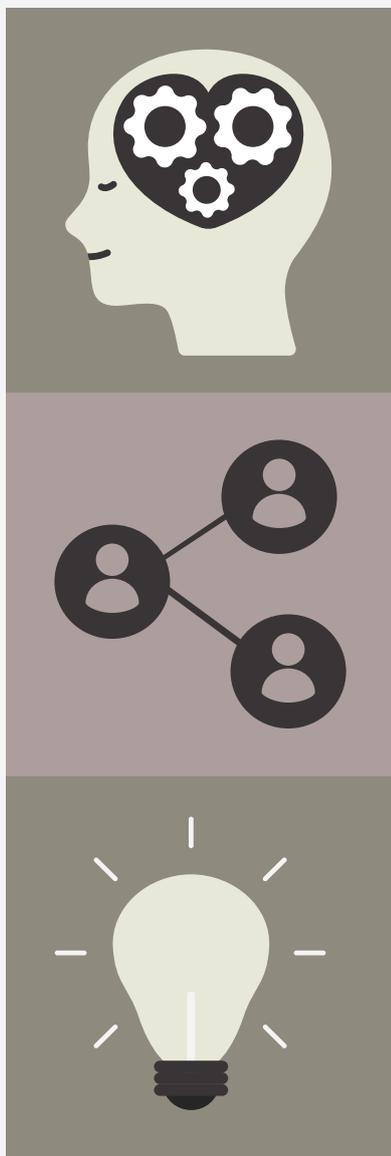
Figure 3: Intervention design - key considerations and early ideas

### **Developing an intervention plan**

Following the first round of small group discussions, the research team constructed a proposed intervention plan. This plan was assembled using the key points, ideas, and thoughts raised by the Design Team up until this point. These ideas from the Design Team were used as the basis of the intervention plan, taking into consideration what would be feasible within the time available to deliver the intervention and the research team's areas of knowledge and expertise.

One key example is that some members of the Design Team suggested ideas that involved being given direct, specific instruction of what exercises to do, or a training plan. In discussions with the Design Team, the lead researcher explained that this would be outside of our remit, but also re-emphasised the key principles underpinning this project – i.e., self-determined motivation and the importance of personal choice regarding physical activity. In this example, it was agreed with the Design Team that this may be where alternate support in connecting people with knowledgeable health and fitness professionals who could provide this type of information may be beneficial (e.g., other ideas the Design Team had expressed – including peers sharing information on professionals they had positive experiences of working with).

The full details of the intervention are presented later in this report, but the proposed intervention plan focused on addressing three elements: mindset, social, and knowledge (as can be seen in Figure 4, next page). The intervention aimed to empower people to make their own choices regarding physical activity.



### **Mindset – Me**

What are my aims and goals?  
Why? What is my motivation?  
How can I improve my relationship with physical activity?

### **Social – Us**

How can we support each other?  
What ideas or experiences can we share?

### **Knowledge – Others**

What do I need from others to help me achieve my goals?  
How do I find the right people to help me?  
Where can I access this information?

*Figure 4: Proposed intervention plan - 3 key areas*

The intervention plan included ideas for how each of these areas could be addressed:

#### **Mindset:**

- A series of pre-recorded, bitesize, informational, online videos relating to motivation and mindset – e.g., What is good quality motivation? Strategies to stay motivated. Reframing 'failures' and being compassionate to yourself.
- Individual motivation and mindset work with Han – support in identifying aims and goals, identifying reasons why (personal motivations), identifying challenges to achieving these goals, identifying strategies to help overcome these challenges.

#### **Social:**

- A 'buddy' system – giving the opportunity to connect with someone like-minded who is also working on their relationship with physical activity.
- A platform to facilitate the sharing of ideas from others in the intervention group, as well as other Thalidomide beneficiaries not involved in the intervention phase.

Knowledge:

- A resource that helps provide the skills and tools to find the knowledge/knowledgeable people needed (e.g., how to find a fitness professional?).
- The pooling of other online resources that may provide information and knowledge that is useful.

### ***Individual interviews (second round)***

In this second round of individual interviews, the full proposed intervention plan was presented to each member of the Design Team. During and after the presentation, discussion with each participant around the plan, and specific elements of it, generated their thoughts and feedback. Further opportunity was then given to beneficiaries to contact the research team after the individual meetings with additional feedback, once they had more time to digest the information. This feedback was then used by the research team to make further revisions to the proposed plan, which Han re-presented to the whole group in the final whole team meeting.

### ***Small group discussions (second round)***

Prior to the final whole team meeting taking place, the group were again split into four groups of three for another round of small group discussions. These discussions focused on intervention outcomes and measures – i.e., how we might measure the impact and effectiveness of the intervention. The aim was to determine what the beneficiaries perceived as being important potential outcomes of this intervention, and to do this, discussion focused on the following questions:

- What would be a valuable outcome for you of taking part in this intervention?
- What outcomes are important to you?
- What outcomes are not important to you?
- What outcomes do you value enough to want to be measured?

These questions were supported by ideas provided by the research team on the types of outcome typically measured: self-reported physical activity, mental health/psychological well-being, motivation, physical activity self-confidence, social-connectedness, quality of life.

The consensus from these small group discussions was that important potential outcomes of the intervention were increased motivation to be active, increased confidence in being active, positive impact on mental health/psychological wellbeing, and an increase in physical activity behaviour. Therefore, measures of these outcomes were perceived to be valuable and agreed to be taken immediately pre- and post-intervention, and once more two months after the intervention phase was complete.

Some beneficiaries expressed concerns about their physical health (specifically heart health) and felt it would be beneficial to have access to measures of physical health/heart health prior to increasing their activity levels. The research team discussed this concern with the Thalidomide Trust, and it was agreed that the Trust medical advisors would be available for a telephone consultation for any of those taking part in the intervention concerned about health in relation to increasing physical activity.

### ***Final whole team meeting***

In the final meeting of Phase Two, Han presented a revised version of the intervention plan to the Design Team following the feedback given on the previously proposed plan. The opportunity was given for any final thoughts and/or feedback to be shared and for questions to be asked, both in the meeting itself or afterwards on an individual basis. Full details of the agreed intervention are provided in the next section of this report.

# Phase Three

## Intervention pilot and evaluation

### Aims

The aim of Phase Three was to pilot the previously designed intervention with beneficiaries, and to evaluate it using the follow-up process evaluation interviews (exploring each participant's personal experience of taking part), and the previously agreed measures of outcomes.

### Beneficiaries

The 12 Thalidomide survivors who formed the intervention Design Team in Phase Two were invited to take part in Phase Three – of these, eight decided to take part. Recruitment was also re-opened and an email was sent out to Thalidomide Trust beneficiaries calling for participants. The only criteria for beneficiaries new to the project at this stage was that they describe themselves as inactive or struggling to make physical activity a regular part of their life. From this email, two more beneficiaries came forward. The pilot intervention period began with 10 beneficiaries (5 women and 5 men). Across the course of the intervention period, three beneficiaries formally ended their involvement in the process, citing reasons including not having the time to dedicate to it, prioritising other health issues, and/or the project not suiting their individual circumstances

and needs (see intervention evaluation for further details). Therefore, seven beneficiaries completed the pilot intervention (5 women and 2 men).

### The pilot intervention

Here we provide details of the pilot intervention as agreed with the intervention Design Team by the end of the design process in Phase Two.

### Intervention aims

- To give the knowledge and skills to empower beneficiaries to pursue the right activity for them, long term.
- To empower beneficiaries to make positive personal choices regarding physical activity.
- To give beneficiaries the tools they need to act on these choices.
- To equip beneficiaries with skills that will last beyond this intervention.
- To reinforce fun, enjoyment and self-compassion – leading to an improved relationship with physical activity.

## Intervention content

The pilot intervention sought to address three key areas: mindset, social, and knowledge.

### **Mindset**

#### Bitesize video series

The research team provided beneficiaries with a short series of bitesize pre-recorded psychoeducational videos relating to motivation and mindset. The topic areas covered by these videos were:

- **Finding your motivation**  
Dr Anthony Papathomas
- **Self-compassion**  
Dr Anthony Papathomas
- **Understanding willpower**  
Dr Ian Taylor
- **Goal-setting**  
Dr Han Newman

The content of these videos integrated relevant psychology theory and the key psychological principles described in Phase Two – i.e., self-determined motivations (exercising because we value and enjoy it) over controlling motivations (exercising because we feel we have to) (Ryan & Deci, 2017). Promoting self-determined motivation emphasises autonomy (personal choice) and the importance for each individual in finding an activity that they enjoy (Ladwig, Hartman, & Ekkekakis, 2017).

Subtitled versions of the videos were also provided, as were PowerPoint file versions which contained audio descriptions of any

images used. Full transcripts of each video were also provided in Microsoft Word format.

#### Individual support

Each participant was offered one-to-one support sessions with Han at the start of the intervention (Week 1), the mid-point (Week 3) and at the end of the intervention (Week 5).

The specific psychology and mindset support offered in these sessions addressed five key areas:

- **Identifying personal physical activity aims and goals** – based on the principles of self-determination theory, specifically autonomy (Ryan & Deci, 2017) and principles of self-set, realistic goal-setting (Locke & Latham, 2002).
- **Identifying personal motivations ('why')** – encouraging self-determined motivations over controlling motivations (Ryan & Deci, 2017).
- **Identifying types of activity** – encouraging those that the individual had previously, or thinks they could, find most suitable, practical, and enjoyable (Ladwig, Hartman, & Ekkekakis, 2017).
- **Identifying potential challenges to engaging in this activity** – based on each individual's personal circumstances, previously experienced barriers to activity, and anticipated challenges or barriers.

- **Developing strategies to overcome those challenges** – working with each participant to develop ideas about how to negotiate and/or overcome challenges to achievement of their physical activity goals as and when they arise. Also emphasising the importance of self-compassion (Neff, 2003), being self-kind instead of self-critical and accepting that setbacks are common.

The sessions also provided an opportunity for a more general 'check-in' with beneficiaries regarding their overall experience of taking part in the intervention, and offered space for them to ask questions about any aspect of the process. Flexibility was offered to beneficiaries to use these one-to-one sessions as they felt was most relevant and beneficial to them and to raise any specific points that they would like to discuss and be supported with.

## **Social**

### 'Buddy' system

The 'buddy' system was put in place to address the need for peer support identified by beneficiaries in Phase Two as important in supporting physical activity. It was also an opportunity to connect with someone like-minded who was looking to make changes regarding their relationship with physical activity. The approach drew upon previous physical activity studies that have used virtual 'buddy' systems (e.g., Rotheram-Borus, Tomlinson, & Gwegwe, 2012).

The 10 beneficiaries taking part in the pilot intervention were each matched with another beneficiary to form five buddy partnerships. As agreed with the

intervention Design Team in Phase Two, a confidential online-survey to express 'buddy' preferences was provided prior to the start of the intervention period. This survey asked beneficiaries if they had any preference in regard to the gender of their buddy: 'same gender', 'different gender', or 'no preference'; how important it was to the participant to be matched with someone with similar disabilities: 'very important' 'moderately important' 'slightly important' or 'not important at all'; and offered a free text box for beneficiaries to express anything further they would like to say about their preferences when being matched with a 'buddy' (see 'buddy' preferences form in Appendix A). Beneficiaries were duly matched with their buddy according to the preferences they expressed. Beneficiaries deemed this 'matching criteria' as highly important to the process, as have participants in past research that has implemented a 'buddy' system (Tucker & Irwin, 2006).

Due to beneficiary dropout, the five buddy partnerships had to be re-worked at points throughout the intervention period to ensure all beneficiaries continued to have access to buddy support. By the end of the intervention period there were instead two 'buddy groups', each comprising of three people, with one participant preferring to continue alone.

### Sharing of ideas platform

The intervention Design Team decided that it was important to have a mechanism that allowed beneficiaries in the project, and in the longer-term other Thalidomide Trust beneficiaries, to share ideas and experiences regarding physical activity. It was agreed by the Design Team that the mechanism should give opportunity for

the ideas shared to be moderated to ensure that the content was as focused and relevant as possible. This was also an attempt to address some beneficiaries' concerns that the sharing of ideas from others can sometimes feel 'preachy' and off-putting if not done in a helpful way. Therefore, an online survey was provided for beneficiaries that contained a structured template with targeted questions to focus and guide the ideas to be shared. The survey had four sub-sections: equipment/kit, types of activity, accessible facilities, and knowledgeable people. These sections also aligned with the findings from Phase One. Beneficiaries selected which of these sub-sections their ideas/contributions related to, and then answered a series of questions tailored to that sub-section. All questions were optional, free-text boxes where the contributor could share as much as they deemed appropriate (see Appendix B for full survey). Contributors were advised to complete the form multiple times if they had multiple ideas/experiences to share (e.g., one submission for a piece of equipment/kit, and a second submission for a type of activity).

Contributions made via this platform were submitted directly to the research team, who then worked with the contributor to agree the final content before it was shared with the intervention group. This platform was open and available to all beneficiaries taking part in the pilot intervention throughout the intervention period, and was also made available to the Advisory Group formed during Phase Two to submit their ideas as well.

## **Knowledge**

To address the previously identified barrier of difficulty in accessing knowledge/knowledgeable people, this third and final section of the intervention aimed to provide beneficiaries with resources that could help them to find/access the knowledge and/or knowledgeable people needed to improve their relationship with physical activity. There were two sections to this:

### Toolkit resources

The toolkit equipped survivors with the knowledge and tools to support them in their own searches for knowledgeable health and fitness professionals. Central to the toolkit were the 'Finding a fitness professional' and 'Finding a physiotherapist' information sheets, both of which provided details of qualification pathways and accreditation routes that beneficiaries may wish to look out for when looking to work with a professional. These resources also provided details of online search tools for fitness professionals and physiotherapists. Resources also offered here were 'Questions to ask a fitness professional' and 'Questions to ask a physiotherapist' which both offered a list of questions that beneficiaries might wish to ask a professional they were considering working with to enable them to better decide whether they have the right knowledge, skills, and experience to help them (e.g., are you REPs/CIMSPA accredited? Can you tell me a bit about your approach to working with clients? Have you had any specific training on working with disability?).

## General resource pool

This section provided beneficiaries with links to resources already made available by other sport, disability, and/or health organisations that may be useful and/or relevant. The main document provided here was a list of organisations and links to specific online resources that they had made available (e.g., Get Yourself Active's being active at home resources). This list was updated by the research team throughout the intervention period as and when new resources were identified and supported those looking to be active at home. Also made available in this section was a list of regional sport/activity organisations for those who may wish to find activities occurring in their local area. There was also a document collating all the exercise equipment and kit ideas that beneficiaries had shared via the sharing of ideas platform. These resources could be accessed by beneficiaries at any time throughout the intervention period via a shared drive.

All resources are available upon request.

## Intervention structure

The pilot intervention occurred across a five-week period summarised in Figure 5 below.

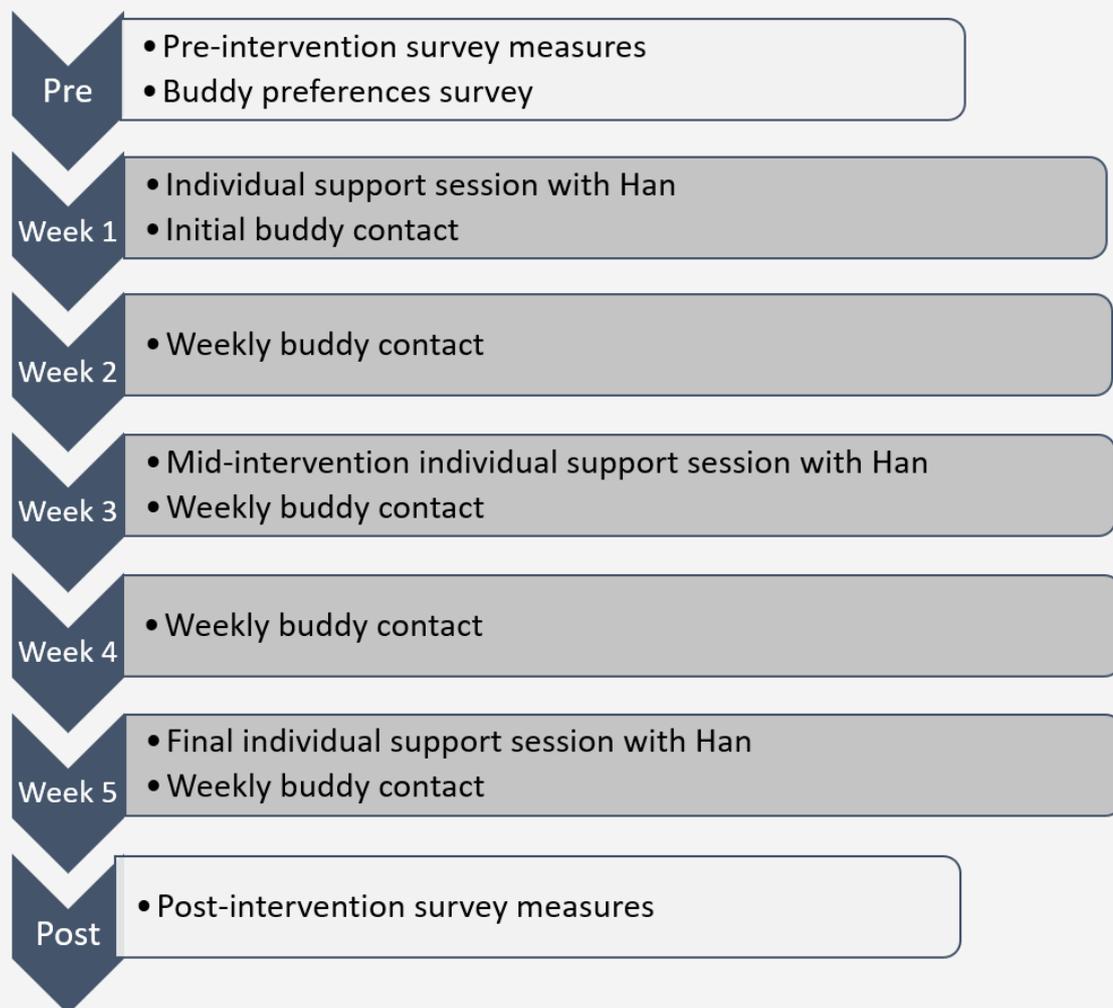


Figure 5: Intervention structure

The surveys were completed online by beneficiaries in the week prior to the five-week intervention period, the week following the five-week intervention period, and finally two months post-intervention. Details of these survey measures are summarised below in Table 3.

Outcome	Measures
Physical activity levels	<p>Godin Leisure-Time Exercise Questionnaire (LTEQ) (Godin &amp; Shepard, 1997)</p> <p>The Short Questionnaire to Assess Health Enhancing Physical Activity (SQUASH) (Wendel-Vos &amp; Schuit, 2002)</p>
Motivation	Physical Activity and Leisure Motivation Scale (PALMS) (Molanorouzi, Khoo, & Morris, 2014)
Physical activity self-confidence	The Exercise Self-Efficacy Scale (Kroll, Kehn, Ho et al., 2007)
Health	SF-12 Health Survey (Ware, Kosinski, & Keller, 1996)
Mental health	<p>Patient Health Questionnaire-9 for depression (PHQ-9) (Kroenke, Spitzer, &amp; Williams, 2001)</p> <p>Generalised Anxiety Disorder Assessment (GAD-7) (Williams, 2014)</p>

*Table 3: Measures of intervention outcomes*

Additionally, a logbook was provided to each beneficiary. The logbook was optional for beneficiaries to use if they wished, and was structured so that there were sections to complete every week for the five-week intervention period. This gave space for beneficiaries to set their initial physical activity aims and goals, identify 2-3 weekly action points that could help guide their interaction with the resources made available to them (e.g., I will watch the Finding my Motivation video), to reflect at the end of each week, and to revise their goals and think about their future with physical activity post-intervention. All resources remained available to beneficiaries for the duration of the intervention period and Han was available to contact throughout if any problems or questions arose.

# Intervention evaluation

Following the end of the five-week intervention period, we conducted six process evaluation interviews – five were with beneficiaries who completed the intervention (out of seven who took part), and the sixth was with one of three beneficiaries who withdrew from the process. Interviews aimed to explore beneficiaries' personal experiences of taking part in the pilot intervention, what they found helpful/unhelpful, and any further thoughts about the future promotion of physical activity in the Thalidomide population. Such information is vital for judging the potential for pilot work to be rolled out as a full intervention. A semi-structured interview guide was used; including questions such as 'what was your experience of taking part in the intervention?', 'what parts of the intervention do you think worked well/not so well?' and 'if this intervention were to be run again, or rolled out on a wider scale, what parts would you change or add?' We use these interviews to evaluate the pilot intervention.

**“  
It's been a very positive  
experience for me  
”**

**“  
It made me really think  
about my relationship  
with exercise, which  
I've never really done.  
”**

**“  
It has been the kick I  
needed really to do  
what I know to be the  
right thing.  
”**

**“  
It's made me spend the  
time to think about the  
issues to do with  
fitness for me. And I  
probably wouldn't have  
done that otherwise.  
Certainly not this year.  
Maybe not next year,  
and maybe never.  
”**

**“  
I found it very  
interesting.... I gained  
a lot out of it.  
”**

Beneficiaries reported varied levels of physical activity engagement prior to the start of the intervention. The types of activity that beneficiaries had previously or were currently engaged in were varied, as were the types of activity they hoped to engage in during the intervention period. The range of physical activity aims and goals of those taking part included increasing total daily activity (including moving more around the home), doing exercise at home (e.g. using home equipment or online classes), increasing engagement in outdoor activities such as walking, and finding accessible gyms and/or knowledgeable personal trainers or physiotherapists to work with.

The five interview participants who completed the intervention had all been involved in all three phases of the research. They reported positive experiences of taking part both in the pilot intervention, and the research project more broadly. The quotes on page 35 are used to illustrate this. To analyse the evaluation interview data we took a flexible, deductive approach, basing our analysis on the three key features of the intervention. Strengths and weaknesses were scrutinised according to these three components and general participation experiences. Here we address one beneficiary's reasons for withdrawing from the intervention, before giving a focused analysis of the key intervention features.

Darren, 58, withdrew from the pilot intervention at the beginning of week two, citing reasons of needing to prioritise other health concerns, but also feeling that the project was 'too impersonal' because of its online nature, and that it would have been better had it been possible for all to meet up as a group in person. In his evaluation interview, Darren stated:

**"It was all a bit too abstract for me. I don't know what I was expecting to be honest, I don't know whether, either have a load of exercises or plans do you know what I mean? It was all a bit too abstract. I mean, the premise of it, and the idea was good and the reason for it was good but for me translating that into like, practical sorts of exercise. It was just a bit abstract. The only thing I could think of was like moving round more on the floor, you know, get out of my wheelchair, but that was the only thing I could think of... like, you know, formulating some practical exercises that I could do, that I'm not aware of."**

In this quote Darren repeatedly uses the term 'too abstract' when describing the pilot intervention, and suggests that he would have liked more 'practical' advice on what types of exercise he could do or plans that he could follow. The aims of this intervention were to empower beneficiaries to make their own personal choices regarding physical activity and give them the tools they needed to act on these choices, rather than to prescribe specific exercises or training plans. Darren's experience, however, perhaps suggests that further support, advice, and/or ideas on what exercises to do could be beneficial for Thalidomide survivors looking to increase their engagement in physical activity. This more prescriptive approach could work alongside efforts to promote empowerment and more sustainable changes. We explore this point further in our recommendations for practice.

## **What did beneficiaries find helpful?**

In the evaluation interviews, each participant was asked which aspects of the intervention they found most helpful and/or they benefitted from the most, and which aspects they found not to be helpful and/or were not so beneficial for them. Here we take each of the three areas of the intervention (mindset, social, and knowledge) and summarise participant feedback for each one in turn.

### ***Mindset***

The mindset support aspect of the intervention consisted of one-to-one individual support sessions, and a mindset video series. Throughout the project, various beneficiaries suggested that mindset, in relation to being physically active and/or trying to be more physically active, was an area that they had not experienced support with before. For example, Claire, 59, said:

**"I found the mindset bit very interesting because I hadn't really... I bought a book on mindset a while ago, not specifically sport mindset, and I haven't read it yet, which says it all really. But it is something that's quite interesting."**

Most beneficiaries deemed this area of support important and found it to be helpful. Some suggested that it had prompted them to think about their relationship with physical activity in ways that they haven't done before. For example, Lynn, 59, said:

**"the mindset things worked really well... I think that's been key to me having those sort of mindset changes... I just don't think I would have had them otherwise."**

Doreen, 58, recognised that working on her mindset had been a key driver in starting to make changes to her physical activity behaviour:

**"the mindset has been the most important to be able to get me just being active and more mobile around the house and things like that."**

Mindset was not considered the most important area of support for all beneficiaries though. For example, Brian, 57, said:

**"I don't think I ever had a particular issue with mindset. So I don't think that was anything that particularly needed to change."**

Overall though, for those who identified their mindset around physical activity to be an area they felt they needed support in, this aspect of the intervention was considered beneficial and successful.

### Individual support sessions

Of the seven beneficiaries who completed the pilot intervention, six attended individual support sessions with Han at all three scheduled timepoints (week 1, week 3, and week 5). The seventh participant only attended an individual support session in week 1, but remained otherwise involved in the process until the end, meeting weekly with their buddy group.

The way that these sessions were used varied between beneficiaries. For those such as Brian, who felt that mindset wasn't a particular barrier to physical activity, the sessions served more as a 'check-in' type process (e.g., how things had been going, what actions they had taken, what actions they planned to take going forward, support with setting physical activity goals, and any support needed in accessing the supplied resources). For others who felt they needed more mindset-related support, the sessions included all of this, but also involved more focused work. For example, identifying challenges related to mindset that were impacting their relationship with physical activity or inhibiting their progress, and developing strategies to negotiate and/or overcome those challenges. Two beneficiaries deemed this mindset work to be particularly valuable. Doreen, 58, described the individual support as 'excellent, absolutely fantastic' and Claire, 59, stated:

**"The bits that I've probably benefitted from the most are the one to one with you, because that was quite good targeted time... you're experts in your field, and it was good to set targets with you on a one-to-one basis. And make them realistic, because I would put something really extreme in probably if I'd been on my own and then got depressed, and thought you know that's not going to happen. So yeah, it's about the expertise, the empathy. You know, the knowledge and the... it's been just really good. I think it's a really great opportunity."**

## Mindset video series

The mindset videos were uploaded to a shared document folder, along with the other knowledge-based resources described previously. The amount of time spent engaging with both the videos and the other resources varied between beneficiaries. Those who engaged with the videos gave positive feedback, and found them to be helpful regarding their relationship with physical activity. For example, Claire, 59, said:

**"I thought the videos were really good. I've got them downloaded. I probably will watch them again because I watched them early on when they were first sent through... it did make an impression on me, the videos, they're quite pertinent really and I will watch them again."**

Additionally, Michelle, 57, spoke about what she found helpful and interesting about one of the videos she had engaged with:

**"the one that he did about your fors and against, and the reason why we talk ourselves out of exercising. I thought that was all good. That video that he did. I thought it was really interesting... the way the guy did it as well, it could be for anybody. It wasn't just disabled, it wasn't just able bodied, it could be anybody and I thought that was really good."**

## **Social**

The social support aspect of the intervention consisted of the 'buddy' system and the 'sharing of ideas' platform.

### 'Buddy' system

All beneficiaries interviewed recognised the importance and potential benefits of having peer support and connecting with other like-minded people who are looking to make similar changes in relation to physical activity. Michelle, 57, described the benefits she experienced during the intervention from the contact she had with her buddy group:

**"We talk to each other every day to kind of encourage each other, I think that's good. And if we see that one of us slips, then the other one chirps in and it gives you a little pep talk, which is quite good. And I just think it keeps you a bit focused, really... And we're going to keep our buddy group because we all work together. We all enjoy each other's company."**

Doreen, 58, described similar positive experiences of contact with her buddy group, despite her initial scepticism of the idea:

**"the buddy system I did not think would work at the beginning, but it's proven to be good... but that's only because the three of us got on well, how it would have gone if it was somebody else, I don't know. But we all got on really well and we're still in contact... we were in contact at the beginning of the week and it was lovely."**

Doreen's comment regarding potential difficulties that could have arisen 'if it was somebody else' raises some of the challenges that came with implementing this 'buddy' system amongst such a small group. With only ten beneficiaries, the initial pairing options (considering all expressed preferences) were limited and further compounded by dropouts. As previously mentioned, these participant withdrawals inevitably resulted in two 'buddy groups' of three forming. Claire, 59, described the logistical challenges presented by a group of three:

**"I think it's an important part of the intervention. I do think, and it's nobody's fault. But working in a three didn't work as well as having two... We've just had communication problems.... When I've had contact, it's been really good... So yeah, although I think the buddy system is really important, just because of circumstances that didn't really happen."**

Lynn, 59, agreed that despite the logistical challenges, there were great benefits to the buddy system:

**"I think the social support had a bit of a shaky start, just setting up as a group... it just took time to get ourselves organised. But we've had some lovely, lovely interactions."**

The general sense from beneficiaries then was that, for the most part, pairs would probably work better when using a 'buddy' system to provide peer support. Matching pairs based on preferences, and allowing for potential re-matching of pairs if needed, would be easier if the system was implemented on a wider scale with a larger group of people – something we revisit in our recommendations for practice.

### Sharing of ideas platform

The sharing of ideas platform was open to contributions from both those who took part in the pilot intervention, and those in the Advisory Group. There were eleven contributions made in total across the intervention period. Nine of these came from members of the Advisory Group and two from those in the intervention group. As the contributions were submitted, Han moderated these to ensure the content was as focused and as useful as it could be. Once moderated, each was adapted into document format so that it could be easily shared with the intervention group. Han sent each of these documents to the respective contributor to discuss and agree final content before sharing with the group.

The most direct and obvious positive impact of this aspect of the intervention was that one beneficiary purchased a recumbent stationary exercise bike after someone else had shared the idea. She had previously had an upright exercise bike, but this was not easy for her to use due to difficulties with balance and being unable to reach the handlebars. The recumbent exercise

bike required less balance and removed the need for additional support from the handlebars.

The concept of a platform to share ideas is a form of peer support, but it also has the potential to help address some of the knowledge-based barriers to physical activity that Thalidomide survivors experience. It was demonstrated in the Phase One results that finding health and fitness professionals who have the right knowledge, skills, and experience is difficult. As alluded to by Claire, 59, the platform can be useful for sharing knowledge of professionals that beneficiaries have had positive experiences with:

**"I think also making a bit wider than you know, I've set up a gym at home or whatever... you know, what else do people do? What else do people enjoy? Where are they feeling welcomed? Who are good? Who are the expert professionals who are prepared to help and work and have the knowledge to work with disabled people?"**

Similar to the 'buddy' system, it was acknowledged by beneficiaries that the benefits of a platform for sharing ideas would be much greater if implemented on a wider scale, with the potential for a larger number of contributions from a wider group of people. This would, by nature, grow with time. The format of: 'structured submission – moderation – sharing' was generated by the intervention Design Team in Phase Two of the project as they felt this would

better ensure that the information being shared by contributors was focused and relevant. Post-intervention, beneficiaries still felt that this was a helpful format/platform for the sharing of ideas, and expressed their preference of this over other potential platforms such as discussion forums.

### ***Knowledge***

The knowledge aspect of the intervention consisted of the toolkit resources and the general resource pool. The documents that beneficiaries reported most engagement with were the ones that summarised exercise equipment that other beneficiaries had shared their experiences of and the document pooling other organisations' online resources. It could be suggested that these were the most engaged with partly because of the ongoing situation regarding COVID-19 (the intervention period coincided with England's second national lockdown in November), which meant that home equipment and online resources were likely to be useful at this time. For the same reasons, the resources that aimed to provide support in finding a knowledgeable health and fitness professional, accessible facilities, and local activities could be suggested as being less useful at this time, but this could change post-pandemic.

The knowledge aspect of the intervention was also the one that required less structured engagement from beneficiaries – the resources were available for beneficiaries throughout (and after) the intervention period to interact with as and when they found helpful and necessary. This may also have contributed to lower levels of engagement than with the mindset and social aspects of the intervention as these required more structured engagement, largely including contact time with others.

## Survey measure outcomes

For those who completed the pilot intervention, survey measures were taken pre-intervention, immediately post-intervention, and then two months after the end of the intervention period. Outcomes are reported for the six beneficiaries who completed the measures at all three time-points. We are not presenting these results as significant differences as sample size was too small for statistical testing. Rather, the analyses of means here provides evidence of "proof of concept" regarding the intervention ingredients. It also provides a clear rationale for testing the interventions tools on a larger scale.

### *Self-reported physical activity levels*

#### **Strenuous activity (heart beats rapidly)**

Pre-intervention, the mean score recorded by beneficiaries for strenuous activity was **0.33 times per week**. This increased to **2.17 times per week** post-intervention, which was maintained two months post-intervention.

#### **Moderate activity (not exhausting)**

Pre-intervention, the mean score reported by beneficiaries for moderate activity was **2.5 times per week**. This increased to **5.0 times per week** post-intervention, and decreased to **4.5 times per week** two months post-intervention.

#### **Mild activity (minimal effort)**

Pre-intervention, the mean score reported by beneficiaries for mild activity was **4.17 times per week**. This increased to **4.83 times per week** post-intervention, which was maintained two months post-intervention.

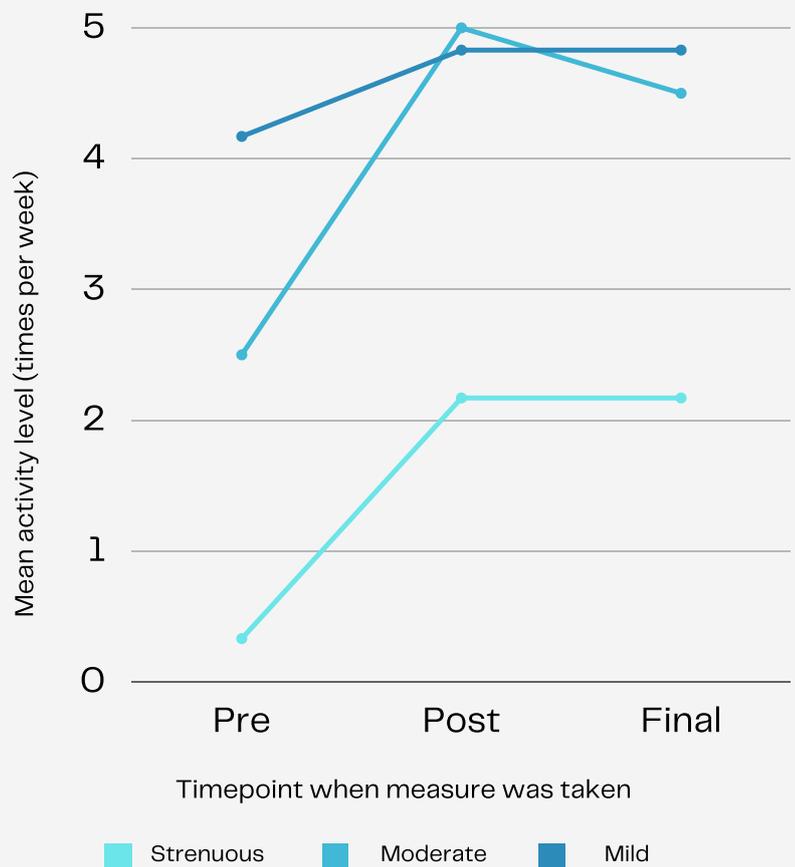


Figure 6: Mean self-reported physical activity levels

### Physical activity self-confidence

Measured by the Exercise Self-Efficacy Scale (ESES), beneficiaries reported a mean physical activity self-confidence level of **25.0** pre-intervention. This mean increased to **32.7** immediately post-intervention, with a small decrease to **31.0** two months post-intervention.

All six beneficiaries reported an increase in physical activity self-confidence immediately post-intervention. This decreased for some two months post-intervention, but all six still reported a higher level of physical activity self-confidence than they did pre-intervention.

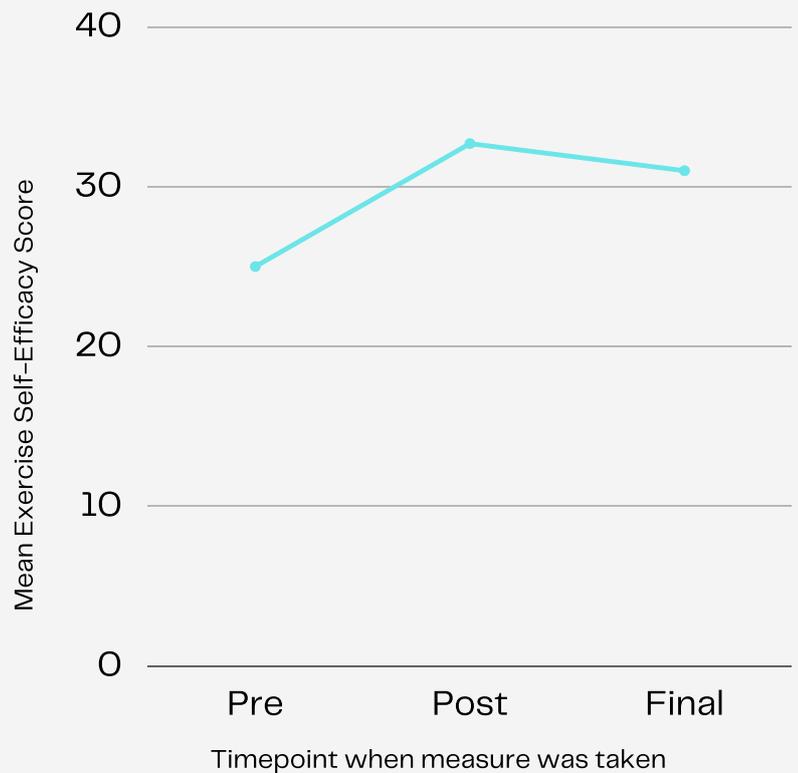


Figure 7: Mean scores for exercise self-efficacy

### Mental health

Mental health was measured using the Patient Health Questionnaire-9 (PHQ-9, depression) and the General Anxiety Disorder-7 (GAD-7).

The mean score for symptoms of depression amongst the six beneficiaries decreased from **11.83** pre-intervention, to **5.17** immediately post-intervention, and **6.0** two-months post intervention.

The mean score for symptoms of anxiety also decreased from **8.83** pre-intervention, to **4.0** immediately post-intervention, and **3.0** two months post-intervention.

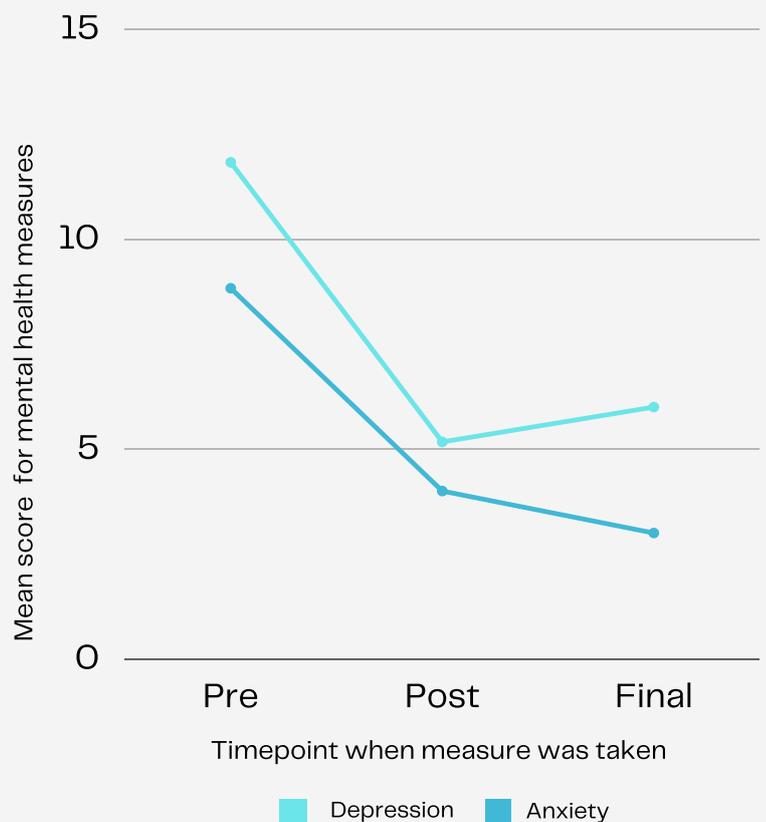


Figure 8: Mean scores for measures of mental health

### ***Physical activity motivation***

Motivation was measured using the Physical Activity and Leisure Motivation Scale (PALMS). '**Physical condition**' was reported as the most important motivator at all three time points, with a mean score of **23.5** pre-intervention, **24.0** immediately post-intervention, and **22.5** two months post-intervention.

Mean reported motivation from **others' expectations (15.8 to 14.83)**, **appearance (21.0 to 18.0)**, and **competition/ego (10.3 to 8.67)** all decreased from the pre-intervention survey to the final follow-up (two months post-intervention). Mean reported motivation from **psychological condition (15.12 to 18.5)**, **enjoyment (15.5 to 18.3)** and **'mastery' (18.0 to 18.3)** all increased from the pre-intervention survey to the final survey (two months post-intervention).

This suggests that, on average, beneficiaries who completed the intervention experienced some shift away from extrinsic forms of motivation, such as the expectations of other people, and a shift towards intrinsic forms of motivation, such as enjoyment of physical activity, or feelings of mastery.

### ***Summary of means analysis***

Although providing no indication of statistical significance, the results of our means analysis of outcome measures are hugely encouraging. All means moved in the intended direction post-intervention through to follow-up. Specifically, better quality intrinsic motivation increased, mental health improved, and more physical activity was reported. In particular, moderate and more strenuous forms of physical activity, the types likely to harness health benefits, increased. Important for future physical activity behaviour, beneficiaries also reported an increased sense of confidence to engage.

# Recommendations for practice

In this final section of the report, we use the findings from the research to make recommendations for practice regarding future support for Thalidomide survivors in relation to physical activity motivation and behaviour.

## General recommendations

Here we provide some guiding principles and general recommendations for future support given to Thalidomide survivors regarding their engagement with physical activity:

- 1 Each beneficiary has different physical activity needs, and hence physical activity advice should be person-specific. An individualised approach that focuses on personal motivations, individual barriers to activity, and developing realistic coping strategies is recommended.
- 2 We are more likely to stay active if we "want to" compared to if we feel we "have to". Physical activity support should encourage self-determined motivations – exercising because you value and enjoy it – ahead of controlling motivations (e.g., exercising because you feel you have to).
- 3 Self-determined motivation includes autonomy (personal choice). Beneficiaries should decide when they exercise, where, and who with. Physical activity should also be at a comfortable intensity and duration. All of this contributes to an enjoyable experience and the increased likelihood of sustainable lifestyle change.
- 4 There are diverse physical activity goals amongst this population. The 'best' type of activity will be the one that is most suitable, practical, and enjoyable for each individual. Activities that meet these needs should be supported and encouraged.
- 5 Willpower is finite/breakable, and so finding more enjoyable forms of activity that rely less on willpower to engage in will be more sustainable long-term.
- 6 While every Thalidomide survivor had different physical activity needs and goals, it is worth noting that being active at home is a viable option for many as it has the potential to remove several of the barriers to physical activity experienced by Thalidomide survivors (e.g., inaccessible facilities).
- 7 Being physically active is about more than just exercise. Physical activity includes any movement that is part of someone's daily life (e.g., everyday household tasks). Increases in overall daily activity will have benefits for both those who engage in structured exercise and those who don't. This may be a realistic and manageable physical activity goal for some, particularly those who are currently inactive.

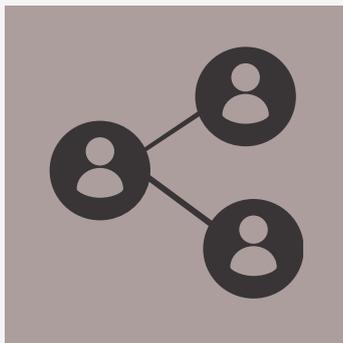
## Practical recommendations specific to the intervention

Here we re-visit the specific elements of the pilot intervention and give suggestions as to how positive intervention features can be implemented in the future.



### Mindset

Future opportunities for psychological support in relation to physical activity will help beneficiaries establish appropriate goals and fulfill them. Exercise psychologists are adept at supporting behaviour change in relation to physical activity and exercise. A more sustainable approach however, is to up-skill members of the community in key principles associated with exercise behaviour change. This could also be the focus of a follow-up intervention. In the short-term, the mindset resources developed through this research project, including the expert videos, should be promoted and made available to all beneficiaries.



### Social

Beneficiaries enjoyed the buddy system component of the intervention. Evaluative feedback also suggested future peer support initiatives relating to physical activity would be well-received. Given these research insights, and given the established link between a sense of connectedness and regular physical activity, we recommend the Trust implements a form of our buddy system on a wider scale. Further, the successful "sharing of ideas" platform could be continued and opened up to all beneficiaries.



### Knowledge

The informational and toolkit resources produced for the pilot intervention should also be shared more widely, via the trust website, for example. We recommend that resources that aid accessibility to knowledge and knowledgeable professionals are made widely available. The fact sheet and infographics produced from this research could also be made available via the Trust website.

## Concluding reflections

A study of this kind lends itself to tacit insights as well as insights from empirical data. Through our informal conversations with beneficiaries during the research process, we learned that some beneficiaries held concerns about cardiovascular health and the associated dangers of physical activity. Those beneficiaries expressed a desire for further support in this, and suggested that confidence could be aided by tests and/or assessments of heart health that would provide reassurance that it is safe to be more active. They envisaged this support being provided in the form of help to access these tests. For example, a list of tests that they could ask their GP for. It is likely such serious health worries exist across the broader Thalidomide population and a fear of this magnitude can immediately halt efforts to increase physical activity. To this end, meeting this need for expert reassurance may be a proactive, albeit indirect, means for the Trust to support more active living.

For most of the beneficiaries being more active was heavily linked to weight management. Although weight loss and nutritional support were not within the scope of this project; oftentimes beneficiaries assumed that our physical activity promotion efforts were driven entirely by a weight loss agenda. Physical activity can play an important role in weight management but such an exclusive extrinsic focus presents issues. We feel it is important that a culture of weight loss does not supersede the full range of health benefits that physical activity can bring. Weight loss should not dominate the variety of reasons that people may have for wanting to increase physical activity. We recommend that the Trust affords equal attention to a wide range of physical activity benefits when encouraging Thalidomide survivors to be more active. In particular, more intrinsic physical activity motivators – such as joy, social connection, and a sense of achievement – should be a focus.

In conclusion, this research project demonstrates that Thalidomide Trust beneficiaries are receptive to a physical activity promotion intervention. There was a smooth recruitment process, sound engagement in collaborative interviews, and timely completion of outcome measures. Dropout was minimal. A larger-scale roll-out of this work, incorporating lessons learned and targeting the entire UK Thalidomide community, represents a viable research initiative with the potential for great benefits to physical and mental health. The participatory action research approach, which integrated beneficiaries into every element of the research process including intervention design, was also successful. This project has remained faithful to the "nothing about us, without us" mantra and all subsequent projects should aspire for this too.

# References

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, p. 77–101.

Braun, V. & Clarke, V. (2017). Thematic analysis. *The Journal of Positive Psychology*, 12(3), p. 297–298.

Callahan, L.F. (2009). Physical activity programs for chronic arthritis. *Current Opinion in Rheumatology*, 21(2).

Crozier, A., Porcellato, L., Buckley, B.J.R., & Watson, P.M. (2020). Facilitators and challenges in delivering a peer-support physical activity intervention for older adults: a qualitative study with multiple stakeholders. *BMC Public Health*, 20(1904).

Dergance, J.M., Calmbach, W.L., Dhanda, R., Miles, T.P., Hazuda, H.P., & Mouton, C.P. (2003). Barriers to and benefits of leisure time physical activity in the elderly: differences across cultures. *Journal of the American Geriatrics Society*.

Godin, G., & Shepard, R.J. (1997). Godin Leisure Time Exercise Questionnaire. *Med Sci Sports Exerc*, p.S36–38.

Holloway, I. (1997). *Basic concepts for qualitative research*. Oxford: Blackwell Science.

Kilpatrick, M., Hebert, E., & Jacobsen, D. (2002). Physical activity motivation: A practitioner's guide to self-determination theory. *Journal of Physical Education, Recreation & Dance*, 73(4).

Kitzinger, J. (1995). Qualitative research: Introducing focus groups. *British Medical Journal*, 311, 299–302.

Koltyn, K.F. (2002). Using physical activity to manage pain in older adults. *Journal of Aging and Physical Activity*, 10(2).

Kroenke, K., Spitzer, R.L., & Williams, J.B. (2001). The PHQ–9. Validity of a brief depression severity measure. *Journal of General Internal Medicine*, 16(60).

Kroll, T., Kehn, M., Ho, P.S., & Groah, S. (2007). The SCI Exercise Self-Efficacy Scale (ESES): development and psychometric properties. *International Journal of Behavioral Nutrition and Physical Activity*, 4(34).

Krueger R.A. (1994) *Focus Groups: A Practical Guide for Applied Research*. Thousand Oaks, CA: Sage Publications.

Ladwig, M.A., Hartman, M.E., & Ekkekakis, P. (2017). Affect-based exercise prescription: An Idea Whose Time Has Come? *ACSM's Health & Fitness Journal*, 21(5), 10–15.

Locke, E.A., Latham, G.P. (2002). Building a practically useful theory of goal setting and task motivation: A 35-year odyssey. *American Psychologist*, 57(9).

- Mead, S., Hilton, D., & Curtis, L. (2010). Peer support: a theoretical perspective. *Psychiatric Rehabilitation Journal*, 25(2).
- Middleton, R., Moxham, L., & Parrish, D. (2018). Exercise and psychological benefits for older people. *Australian Nursing and Midwifery Journal*, 25(7), 30–30.
- Molanorouzi, K., Khoo, S., & Morris, T. (2014). Validating the physical activity and leisure motivation scale (PALMS). *BMC Public Health*, 14(909).
- Neff, K. (2003). Self-compassion: An alternative conceptualisation of a healthy attitude toward oneself. *Self and Identity*, 2(2).
- Rotheram-Borus, M.J., Tomlinson, M., & Gwegwe, M. (2012). Diabetes buddies: Support through a mobile phone buddy system. *The Science of Diabetes Self-Management and Care*.
- Ryan, R.M., & Deci, E.L. (2017). *Self-determination theory: Basic psychological needs in motivation, development, and wellness*. Guilford Publications.
- Sparkes, A.C., & Smith, B. (2014). *Qualitative research methods in sport, exercise and health: From process to product*. London: Routledge.
- Springer, A.E., Helder, S.H., & Hoelscher, D.M. (2006). Social support, physical activity and sedentary behavior among 6th grade girls: a cross-sectional study. *International Journal of Behavioral Nutrition and Physical Activity*, 3(8).
- Tucker, P., & Irwin, J.D. (2006). Feasibility of a campus-based “buddy system” to promote physical activity: Canadian students’ perspectives. *Journal of Physical Activity and Health*, 3(3).
- Veldhuijzen van Zanten, J.J., Rouse, P.C., Hale, E.D., Ntoumanis, N., Metsios, G.S., Duda, J.L., & Kitas, G.D. (2015). Perceived barriers, facilitators and benefits for regular physical activity and exercise in patients with rheumatoid Arthritis: A review of the literature. *Sports Med*, 45.
- Wallerstein, N., & Duran, B. (2010). Community-based participatory research contributions to intervention research: the intersection of science and practice to improve health equity. *American Journal of Public Health*, 100(S1), S40–S46.
- Ware, J.E. Jr, Kosinski, M., & Keller, S.D. (1996). A 12-item short-form health survey: Construction of scales and preliminary tests of reliability and validity. *Med Care*, 34, p. 220–233.
- Wendel-Vos, G.C.W., & Schuit, A.J. (2002). *Short questionnaire to assess health enhancing physical activity*. Bilthoven Netherlands Institute for Public Health and Environment.
- Williams, N. (2014). The GAD-7 questionnaire. *Occupational Medicine*, 64(3), p. 224.
- Williams, T., Smith, B., & Papathomas, A. (2014). The barriers, benefits and facilitators of leisure time physical activity among people with spinal cord injury: a meta-synthesis of qualitative findings. *Health Psychology Review*, 8(4).

# Appendices

## Appendix A: 'Buddy' preferences form

### Buddy preferences

As you will already be aware, as part of this intervention we will be pairing every participant with a 'buddy' - another beneficiary who is also participating in this phase. This will give you the opportunity to connect with someone else who is also looking to improve their relationship with physical activity. You will **commit to 'meeting' virtually (or by telephone) with your buddy at least once per week** throughout the course of the intervention.

This section gives you the opportunity to **confidentially express your preferences** for us to consider when matching you with a 'buddy'. These preferences **will not be shared** beyond the research team, and anything you say in this form **will remain strictly confidential**.

If, for any reason, you have any problems regarding your 'buddy' throughout the intervention process, you will be able to contact the research team who will help work towards an alternative resolution.

**If you have any questions, or would like to speak with the research team about this in any more depth, please contact Han Newman - [h.newman2@lboro.ac.uk](mailto:h.newman2@lboro.ac.uk)**

What is your preference regarding the gender of your buddy? **\*(required)** |

same gender

different gender

no preference

How important is it to you to be matched with someone with similar disabilities? **\*(required)**

very important

moderately important

slightly important

not important at all

If you know at this stage, can you say anything about the types of changes/actions you think you may be looking to make regarding physical activity? **(optional)**

Is there anything further you would like to say regarding your preferences when being matched with a buddy for the intervention? **(optional)**

## Sharing of Ideas (offline version)

This form provides a platform for the sharing of physical activity ideas and experiences in relation to **equipment/kit, types of activity, accessible facilities, and knowledgeable fitness and/or health professionals.**

Please use this form to share any ideas/experiences in relation to the above topics that you feel may be useful for other beneficiaries to hear about.

Choose the category that your contribution falls under. Once you have chosen a category, go to the corresponding section of the form which will have a series of open questions. All of these are optional questions, please feel free to answer only those that are relevant and give as much detail as you would like to.

**Please complete this form multiple times if you have more than one contribution that you would like to make.** (e.g., one type of activity and one accessible facility).

If you feel that you would like to contribute something that does not fall neatly under one of the four categories listed, please get in touch with Han Newman ([h.newman2@lboro.ac.uk](mailto:h.newman2@lboro.ac.uk)).

Once you have completed this form, please send it by email to Han Newman ([h.newman2@lboro.ac.uk](mailto:h.newman2@lboro.ac.uk)). A member of the research team will review your submission and contact you to finalise the content that is shared with other beneficiaries.

Which category best suits the information you would like to share? **\*(required)**

Equipment or kit

Type of activity

Accessible facility

A knowledgeable person/professional

Contact email address: **\*(required)**

Please go to the set of questions that match the category you have chosen above.

## Equipment or kit

What piece of equipment and/or kit are you sharing information about?

Where did you purchase this piece of equipment/kit and how much did it cost?

When you were shopping for this piece of equipment/kit, what features did you consider to be important for you?

What is it about this piece of equipment and/or kit that you have found particularly helpful?

What, if anything, about this piece of equipment/kit is not so useful or makes things more difficult?

If you wish, please use this space to include any further information about this piece of equipment/kit (and/or your experiences of it).

**Would you be willing to be contacted if another beneficiary has further questions about the information that you have shared?** – if you answer yes, a member of the research team will contact you if/when this occurs (your contact details will not be shared until you give specific permission to do so). **\*(required)**

Yes

No

## Type of activity

What activity are you sharing your experiences of?

For those who may not have tried it before, can you say a bit about what this activity entails?

What do you enjoy about this activity?

What is it about this activity that makes it work for you?

What, if anything, do you not like/enjoy about this activity? Have you encountered any challenges to engaging in this activity?

If you wish, please use this space to share any further details that you would like to about this activity/your experiences of this activity.

**Would you be willing to be contacted if another beneficiary has further questions about the information that you have shared?** – if you answer yes, a member of the research team will contact you if/when this occurs (your contact details will not be shared until you give specific permission to do so). **\*(required)**

Yes

No

## Accessible facility

What type of activity are you sharing your experiences of? (e.g., gym/swimming pool/leisure centre)

What is the name of the facility and where is it based?

What do you like about this facility? Are there any specific features that have made it accessible for you?

What challenges, if any, have you encountered to using this facility?

If you wish, please use this space to add any further details about this facility and your experience of using it.

**Would you be willing to be contacted if another beneficiary has further questions about the information that you have shared?** – if you answer yes, a member of the research team will contact you if/when this occurs (your contact details will not be shared until you give specific permission to do so). **\*(required)**

Yes

No

## A knowledgeable person/professional

What type of fitness and/or health professional are you sharing your experiences of? (e.g., personal trainer, physiotherapist, yoga instructor)

Please provide their name/company name, contact details, and website if they have one.

How did you find this fitness and/or health professional?

What have been the benefits for you of working with this person?

What, if any, challenges has there been for you in working with this person?

Please use this space to provide any further detail, if you wish, on this fitness and/or health professional and your experiences with them.

**Would you be willing to be contacted if another beneficiary has further questions about the information that you have shared?** – if you answer yes, a member of the research team will contact you if/when this occurs (your contact details will not be shared until you give specific permission to do so). **\*(required)**

Yes

No