Taylor & Francis
Taylor & Francis Group

Disability and Rehabilitation

ISSN: (Print) (Online) Journal homepage: www.tandfonline.com/journals/idre20

# A personalised activity programme helps reduce fatigue in people after Guillain-Barré Syndrome in a replicated single system design

Suzie Mudge, Greta Smith & Gareth J. Parry

**To cite this article:** Suzie Mudge, Greta Smith & Gareth J. Parry (2025) A personalised activity programme helps reduce fatigue in people after Guillain-Barré Syndrome in a replicated single system design, Disability and Rehabilitation, 47:6, 1442-1454, DOI: 10.1080/09638288.2024.2374486

**To link to this article:** https://doi.org/10.1080/09638288.2024.2374486

DISABILITY AND REHABILITATION
2025, VOL. 47, NO. 6, 1442–1454
https://doi.org/10.1080/09638288.2024.2374486

Taylor & Francis
Taylor & Francis Group

RESEARCH ARTICLE

OPEN ACCESS Check for updates

# A personalised activity programme helps reduce fatigue in people after Guillain-Barré Syndrome in a replicated single system design

Suzie Mudge[a], Greta Smith[a] and Gareth J. Parry[b]

[a]Centre for Person Centred Research, Auckland University of Technology, Auckland, New Zealand; [b]Department of Neurology, University of MN, Minneapolis, MN, USA

**ABSTRACT**

**Purpose:** We evaluated the effectiveness of an online activity-focussed programme to decrease fatigue in people with prior Guillain-Barré Syndrome and explored the perspectives of participants regarding the acceptability and feasibility of the programme.

**Materials and methods:** We recruited eight people diagnosed with Guillain-Barré Syndrome more than two years previously who still had fatigue limiting daily activity. We used mixed methods with a replicated single system design using repeated outcome measures across the three phases (baseline, intervention, follow-up) to evaluate the impact of the intervention on fatigue, activity, wellbeing and confidence to exercise. We used qualitative interviews to explore participants' perspectives of the programme.

**Results:** All participants developed a personalized plan to manage fatigue using goals and feedback, which was effective in reducing fatigue for most participants. Participants were positive about what they had learnt about fatigue, themselves and strategies to manage fatigue. Some participants also experienced improvements in activity, exercise confidence and health and wellbeing. Not all changes were sustained past the follow-up period, which reflects participants' differing levels of confidence to continue with their plan.

**Conclusion:** Graduated physical activity in association with developing a personalised plan were key features effective in managing fatigue after Guillain-Barré Syndrome.

**> IMPLICATIONS FOR REHABILITATION**

- Carefully graded activity can improve fatigue for people with Guillain-Barré Syndrome.
- Telehealth is a useful medium for delivering a fatigue management programme as it removes the need to travel and improves access for those who live remotely.
- Collaboratively developing a fatigue management programme that is individualized to a person's context is probable to contribute to their sense of ownership and likelihood to sustain the plan.
- Although people may have the skills and knowledge to set goals, use feedback and change their plan, many appreciate the accountability they perceive from ongoing sessions for fatigue management.

**ARTICLE HISTORY**
Received 19 December 2023
Revised 11 June 2024
Accepted 13 June 2024

**KEYWORDS**
Activity; behaviour change; fatigue; Guillain-Barré Syndrome; self-management; telehealth

## Introduction

As many as 60–80% of people with Guillain Barré Syndrome (GBS) report persistent fatigue of sufficient severity that it significantly limits everyday functioning [1–3] despite motor recovery [4, 5]. In other conditions such as multiple sclerosis and Parkinson's disease, there is evidence that regular exercise (aerobic and/or resistance training) reduces fatigue [6–8] and it is plausible that exercise might have a similarly positive effect for people with GBS. There is some evidence that aerobic training is effective in increasing physical fitness for people with GBS [3, 9] with a related decrease in self-reported fatigue [3, 10–12], however this is a significantly under-researched area [13] and none of these studies have focused on changing persistent fatigue in individuals who have reached their expected maximal recovery (usually identified as two years [14]).

Those studies that have examined the effects of physical activity on fatigue have utilised supervised exercise sessions in tertiary care centres, which is often both impracticable and unsustainable. In the New Zealand context, such a programme excludes many individuals who live at a distance from a main centre, especially those who live in rural areas and those with fewer resources, factors that are likely to particularly disadvantage Māori and Pasifika peoples. In the context of the global COVID-19 pandemic, healthcare is increasingly being delivered remotely where possible [15] which has the advantage of being an efficient form of delivery more able to reach rural populations and people for whom transportation is difficult. Driven by this context, we developed a physical activity focussed programme based on behavioural change principles to be delivered *via* telehealth.

We explored the effectiveness of an online physical activity focussed programme based on behavioural change principles to decrease fatigue, modify physical activity and improve the sense of wellbeing and confidence to exercise in people who have had prior GBS. Secondly, the study explored the perspectives of

**CONTACT** Suzie Mudge suzie.mudge@aut.ac.nz Centre for Person Centred Research, Auckland University of Technology, Auckland, New Zealand
Supplemental data for this article can be accessed online at https://doi.org/10.1080/09638288.2024.2374486.

participants regarding the acceptability and feasibility of the programme and the physical and psychological benefits of taking part.

## Materials and methods

### Design

We used mixed methods with a single system design to evaluate the first aim and qualitative interviews to address the second aim. We used repeated measures of the outcomes across the three phases (baseline, intervention, follow-up) of the single system withdrawal (A-B-A) design [16–18] to test for effectiveness of the programme to reduce fatigue, replicated across each participant. No elements of randomisation were used, however we included replication across participants as a feature of the design as we considered it possible that the range of potential participant characteristics would act as confounding variables on the outcome of the intervention.

The study was prospectively registered with the Australian New Zealand Clinical Trials Registry (ACTRN1262100178831) on 2/9/2021. The study was completed with the approval of the national Health and Disability Ethics Committee (approval = 21/NTB/232). All participants provided written informed consent at the outset of the study.

### Participants

We aimed to recruit a total of 10 individuals who had GBS more than two years prior and who self-identified as experiencing fatigue that interfered with their daily functioning. Recruitment was through presentations, invitations in the GBS Support Group NZ newsletters and through clinical networks. Eligibility criteria included aged at least 18 years, diagnosis of GBS more than two years prior, resident in New Zealand, community-dwelling, Rivermead Mobility Index of greater than 10 [19] and fatigue of ≥4 on the Fatigue Severity Scale [20]. Exclusion criteria were currently receiving rehabilitation, another health condition limiting physical activity, a contraindication for physical activity (as indicated by the Physical Activity Readiness Questionnaire (PAR-Q)) [21] or unable to access the internet after all support options have been excluded, such as support with data costs, providing access to a suitable device or assisting with accessing suitable wi-fi enabled facilities.

### Intervention

We developed a 12-week programme focussed on modifying activity, supplemented by general fatigue management principles, delivered using a collaborative coaching style based on behavioural change principles [22–24]. Weekly sessions were held by video-conferencing or phone with participants being located in their own homes or workplaces.

The physiotherapist (SM) was an experienced neurorehabilitation practitioner. She followed a standardised session plan for each participant with the ability to tailor the content of the session to each participant's goals, concerns, problems and ability by selecting from a menu of options based on the behavioural change taxonomy [25, 26]. The key behavioural change techniques used were goal setting, provision of feedback, problem solving, action planning, encouragement and education [27].

The aim of the first session was for the physiotherapist and participant to identify an activity the participant would most likely engage in (acceptable, pleasant and practical), negotiate and agree a weekly goal and action plan. In this context, the physiotherapist provided information about activity guidelines [28] appropriate to each participant's current level of activity and fatigue [29–31]. The physiotherapist and participant jointly decided how best to integrate the use of the Fitbit (more detail about Fitbit in following section) into the participant's plan [32] (e.g., used for goal setting, feedback and/or prompts). Text messages or emails were offered as encouragement to the participant between sessions [29, 33]. The first session was about 60 min in duration.

The content of each of the subsequent sessions included review of the participant's progress, identification of barriers encountered and discussion of possible solutions, and establishing a goal and action plan for the following week. Subsequent sessions were 15–45 min duration each. Adherence to treatment procedures was facilitated by use of session records which acted as a prompt of the key intervention elements as well as a record the physiotherapist completed for each session. The full intervention protocol is available on request.

### Data collection

Participants were sent a Fitbit to wear throughout the study period and they completed other outcome measures at three assessment points spaced regularly through each study phase (baseline, intervention, follow up), followed by one 3-month follow-up assessment i.e., a total of 10 assessment points over 40 weeks (see Figure 1 for the predetermined length of the phases and timings of outcome measures). Because of the nature of the intervention, it was not possible to blind participants to the phases.

### Outcome measures

We selected standardised, valid and reliable outcome measures that could be administered remotely. Our primary outcome was the modified Fatigue Severity Scale [20, 34]. We also used the Personal Wellbeing Index [35] to measure general wellbeing and Exercise Self-Efficacy Scale [36] to capture confidence to exercise. These three outcome measures and details of any adverse events were collected by an online survey *via* REDCap v13.7.7 database and survey software. The study coordinator (GS) emailed participants with the links to the assessment surveys and sent reminders by text or email if required. The study coordinator was not blinded

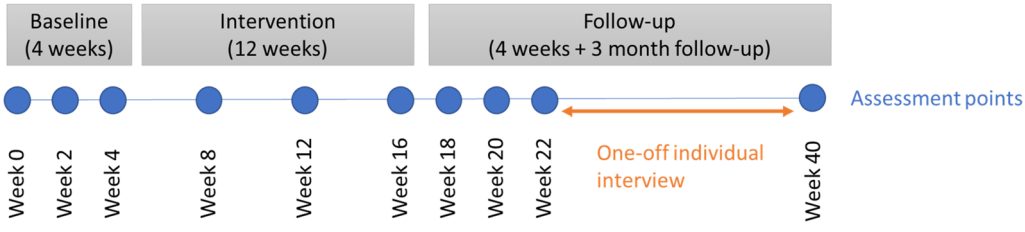


**Figure 1.** Overview of study design.

to study phase but did not collect the data as collection was automated nor was she involved in the delivery of the intervention.

We chose the Fitbit as it was commercially available, easy for participants to wear and use and because of these advantages, we accepted the potential limitations in accuracy compared to ankle mounted accelerometers (which are less easy to wear) [37–40]. The face of the Fitbit was covered with black electrical tape for the baseline phase of the project to prevent feedback influencing behaviour. Participants were asked to synchronise their Fitbit data weekly. The data from the Fitbits were downloaded from which we extracted average daily steps [37, 38] and sedentary time [41]. For each assessment point, the Fitbit data were averaged over the first consecutive seven-day period ("catchment week") for each participant. If a participant had not worn the Fitbit for seven consecutive days, any missing day was replaced by data from the same day of the previous or following week of the assessment period. If no data were available for the replacement day(s), then the average was taken over the existing remaining days of the catchment week.

#### *Individual interviews*

A one-off structured interview (Appendix 1) was carried out with each participant *via* teleconferencing by the study coordinator between the final two outcome assessment points in the follow up period. The questions explored personal experiences of taking part in the programme and any perceived impact to supplement the other data that focussed on physical aspects [42]. The interviews explored participants' perspectives of the programme, what aspects they particularly liked, as well as any aspects they did not like. The interviews were between 30 and 60 min, were video recorded in Zoom and transcribed verbatim.

### *Data analysis*

The single system design yielded data for each of the outcome measures, which we graphed against time for each participant. We used visual inspection to initially look at level, trend, variability, immediacy of effect, overlap and consistency in data patterns within and between phases [43]. We tested for changes between the baseline and intervention and follow up phases using non-overlap of all pairs (NAP) analysis [44] calculated by a web-based application [45]. Because we had only 10 data points for each participant across three phases, we opted for a conservative NAP interpretation, such that a NAP of 1 indicated a clear change from baseline in the direction of improvement and 0 indicated a clear deterioration.

All interview transcripts were imported into QSR NVivo 1.7.1 and sentences or phrases were coded manually by SM. Preliminary codes were examined and grouped into meaningful clusters by SM and GS. Constant comparative methods informed analysis [46], with coded data checked within and between identified clusters and across participants against new data to test and refine themes. The qualitative data analysis was completed prior to the single system design analysis.

### *Advisory group*

In order to optimise the acceptability of the intervention to end-users, we invited people with lived experience of GBS ($n = 3$) and physiotherapists ($n = 2$) onto an advisory group who provided input on the design of the intervention, the potential burden of the research design, advice on recruitment and readability of written material. One critical aspect we discussed was how to design the intervention to balance the value Māori traditionally place on face-to-face meetings with a telehealth intervention.

## Results

Twelve potential participants expressed an interest in taking part in the study. Of these, four people were ineligible on screening (two had a fatigue severity score <4; one had GBS onset <2 years prior; 1 did not have GBS).

### *Demographics*

Eight participants enrolled in and completed the three phases of the study. Four were male and four were female. One participant was Māori, six were New Zealand European and one European. The average age was 66.5 years (range 58–81 years). Time since GBS diagnosis ranged from 2.1 to 12.4 years. Participants had a median score of 14.5 on the Rivermead Mobility Index (range 10–15). The average FSS score was 5.8 on screening (range 4.6–6.9) and the average daily steps was 5706 (range 1544–9888).

### *Attendance*

The number of intervention sessions that participants attended is shown in Table 1. Attendance was high and ranged from 10 to 12 out of a total of 12 sessions. Outcome data were available for all assessment points except for week 20 (follow-up phase) questionnaires for participant E (did not complete) and sedentary time at week 0 (baseline phase) for participant B due to technical error.

### *Adverse events*

There were two adverse events that were considered related to participation in the study - a fall at the gym (participant D) during the intervention phase and a rash from the Fitbit band (participant F) during the baseline phase. Neither had ongoing consequences nor were considered serious.

### *Single system design*

#### *Fatigue*

Six participants showed a decrease in fatigue on visual inspection from baseline to the follow-up period (Figure 2), confirmed by NAP values of 1 (Table 1). One additional participant (D) also had a NAP of 1, however this decrease was not clinically significant. Participant E showed an increase in fatigue from baseline to follow-up.

Fitbit – average daily steps and sedentary time: Five participants made a goal to increase their physical activity but only one participant (C) showed a clear increase in average daily steps (Figure 3), supported by a NAP value of 1. Participants A and G showed increases in average daily steps on visual inspection with the exception of one outlying data point for each participant (thus their NAP values did not equal 1). The other two participants (F and H) described increased activity, however this was not evident in the Fitbit data. Sedentary time did not change significantly for any participant (Figure 4).

#### *Personal wellbeing index*

Two participants (A and C) showed increased general wellbeing attributable to participation in the programme (Figure 5). Participant G showed improved wellbeing on visual inspection

**Table 1.** Overview of results.

| Participant | General goal | Sessions attended | Outcome measures direction of change from baseline to follow up | | | | | Comments |
|---|---|---|---|---|---|---|---|---|
| | | | Fatigue | Steps/day | Sedentary time | PWI | ESS | |
| A | Increase activity | 12 | ↓[1] | → | → | ↑[1] | ↑[1] | Visual inspection showed increase in steps/day across intervention and follow up periods compared to the baseline phase, however this effect was lost by the final data point. |
| B | Incorporate fatigue management strategies into work routine, including short bouts of activity | 10 | ↓[1] | → | → | → | ↑[1] | Did not expect any change in activity as high steps/day on entry to programme. |
| C | Increase activity | 12 | ↓[1] | ↑[1] | → | ↑[1] | ↑[1] | Developed COVID-19 at end of programme period. |
| D | Structure activities in day and improve sleep habits | 10 | →* | → | → | → | → | Did not expect any change in activity as high steps/day on entry to programme. |
| E | Structure activities and regular rest period in day and improve sleep habits | 12 | ↑[0] | ↓ | ↑ | → | ↑[1] | Did not expect any change in activity as high steps/day on entry to programme. |
| F | Increase activity and reduce sedentary time | 10 | ↓[1] | → | → | → | → | Developed a second bout of GBS during the follow up period. |
| G | Increase activity | 12 | ↓[1] | ↑ | → | ↑ | ↑ | Developed COVID-19 during follow-up period, which coincides with one outlying point for three outcomes. |
| H | Increase activity | 12 | ↓[1] | → | → | → | ↓[0] | Developed unrelated illness during the follow up period. |

Arrows (↑↓) indicate the direction of change or no change (→) on visual inspection, with a 1 in superscript if NAP = 1 and with a 0 in superscript if NAP = 0.
*Note:* *NAP = 1, however visual inspection does not indicate a significant clinical change.

but one point was an outlier coinciding with the time he contracted COVID-19, so he did not achieve a significant NAP value.

### *Exercise self-efficacy scale*

Four participants (A, B, C and E) showed improved confidence to exercise as a consequence of taking part in the programme (Figure 6). Participant G also showed improved confidence to exercise with the exception of one data point when he had COVID-19. Participant H showed decreased confidence to exercise following the programme.

## *Qualitative findings*

Participants were very positive about the programme of online coaching sessions. They described three aspects of how and why the programme worked for them which are represented by the first three themes. Firstly, participants identified that the programme "was personal" to each participant, which meant they felt supported and they specifically valued the personal connection they formed with the therapist. Secondly, participants described "things I've learnt" about fatigue, themselves and strategies to cope with fatigue. Thirdly, the intervention helped participants develop and carry out "my plan" to manage fatigue using goals, feedback and ways to keep themselves on track. Because of the programme, participants identified "change" in fatigue and other aspects of their lives. Participants questioned how long they would be able to maintain these changes "… but for how long?" recognising they had the skills to carry on with their plan but different levels of confidence to do so. The five themes are represented schematically in Figure 7.

### *It was personal*

Participants highlighted the personal relationship they developed with the physiotherapist as an important feature of the programme. Participants described characteristics such as empathy, care and respect shown to them that contributed to this connection and they felt the physiotherapist understood them as a person.

> So I could talk if I had problems with pain or I had a real hard dark time and a dark moment and I could still talk about those things. And she was good, she can actually respond and talk to that as well and show that empathy and that care as well. (F)

Participants specifically identified "feeling heard" by the physiotherapist, such that they felt they could talk about a range of topics without fear of being judged. They felt the physiotherapist listened to them and responded to their concerns.

> She was engaging to talk to and work through the things and very alert and attentive to every aspect of it. So yeah, it wasn't like I was talking to someone who wasn't there for me at all. It was good. (E)

One participant even felt heard through the text messages they received, which were offered as part of the programme.

> The reason they [the text messages] were so great was because they were so relevant. She didn't forget anything I'd said and she'd touch on something that I'd said that I had forgotten I'd said myself and I would think, "Oh yes that's right." Amazing. (H)

The physiotherapist's attributes as well as the regularity of the weekly sessions contributed to participants feeling supported throughout the programme.

> I felt supported and guided. I think that was the most useful thing to me, that there was somebody helping me navigate this journey of fatigue and that was really powerful. (D)

### *Things I've learnt*

One of the features of the intervention was education about fatigue, the importance of gradual increases in activity and

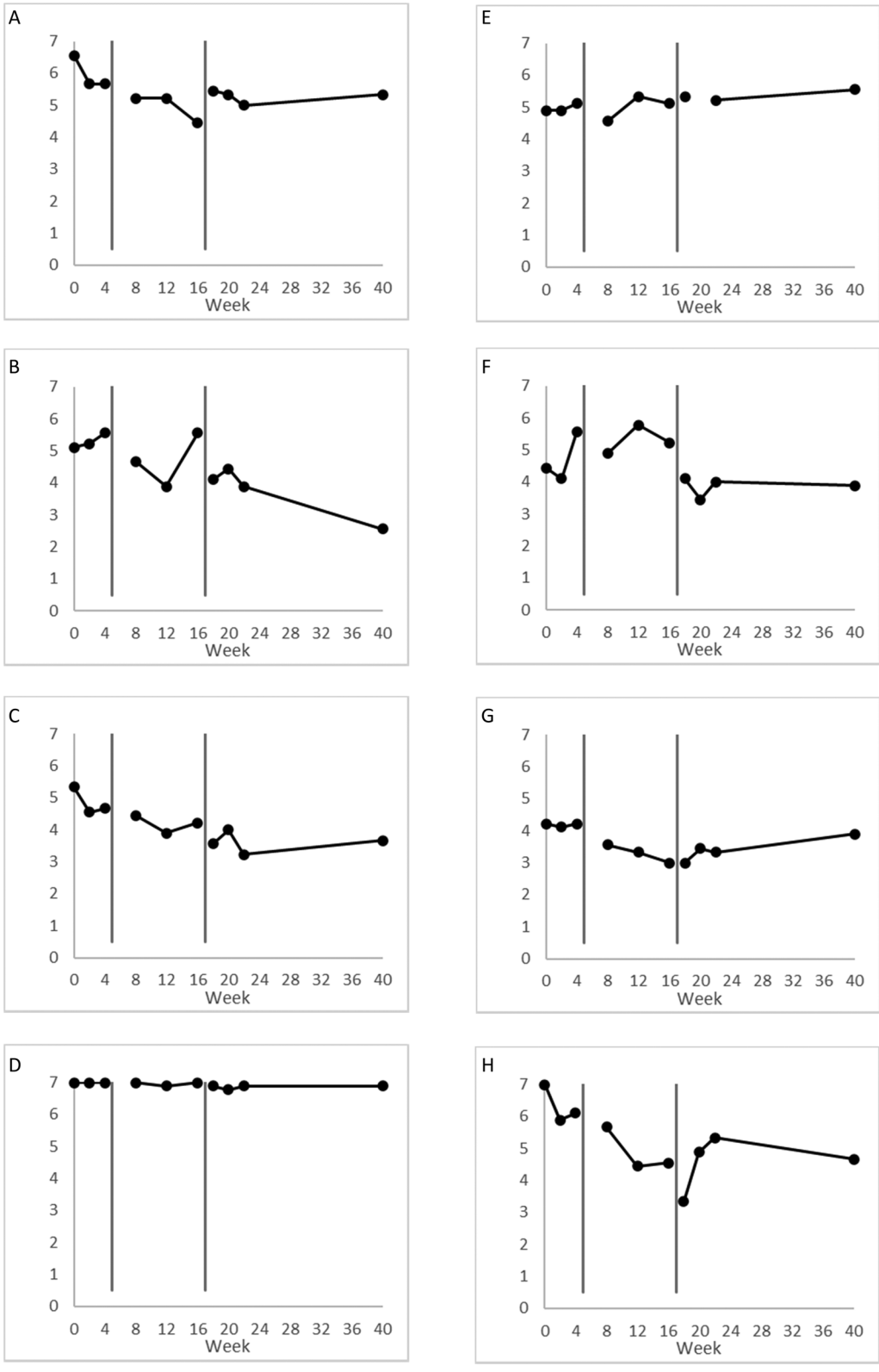


**Figure 2.** Fatigue severity scale score by assessment time points.

examining participants' unique fatigue patterns in responses to activities or events in their week. For some participants, much of the education was new information and this programme was the first time they had discussed fatigue with a health professional. During the programme, some of the participants kept a diary of fatigue and activities and used this to identify triggers for fatigue, which was used in sessions to develop strategies to manage it.

> I know that was overdoing my case, I know that I was doing more than what I needed to and [therapist], on reflection and doing the fatigue diary, made me realise that I can still do that exercise but not as much or not as hard and still have a positive outcome. (B)

Participants developed insights about their activity and more broadly, their behaviour. The Fitbit sometimes illuminated activity or lack of activity and was generally found to be useful. Many participants felt

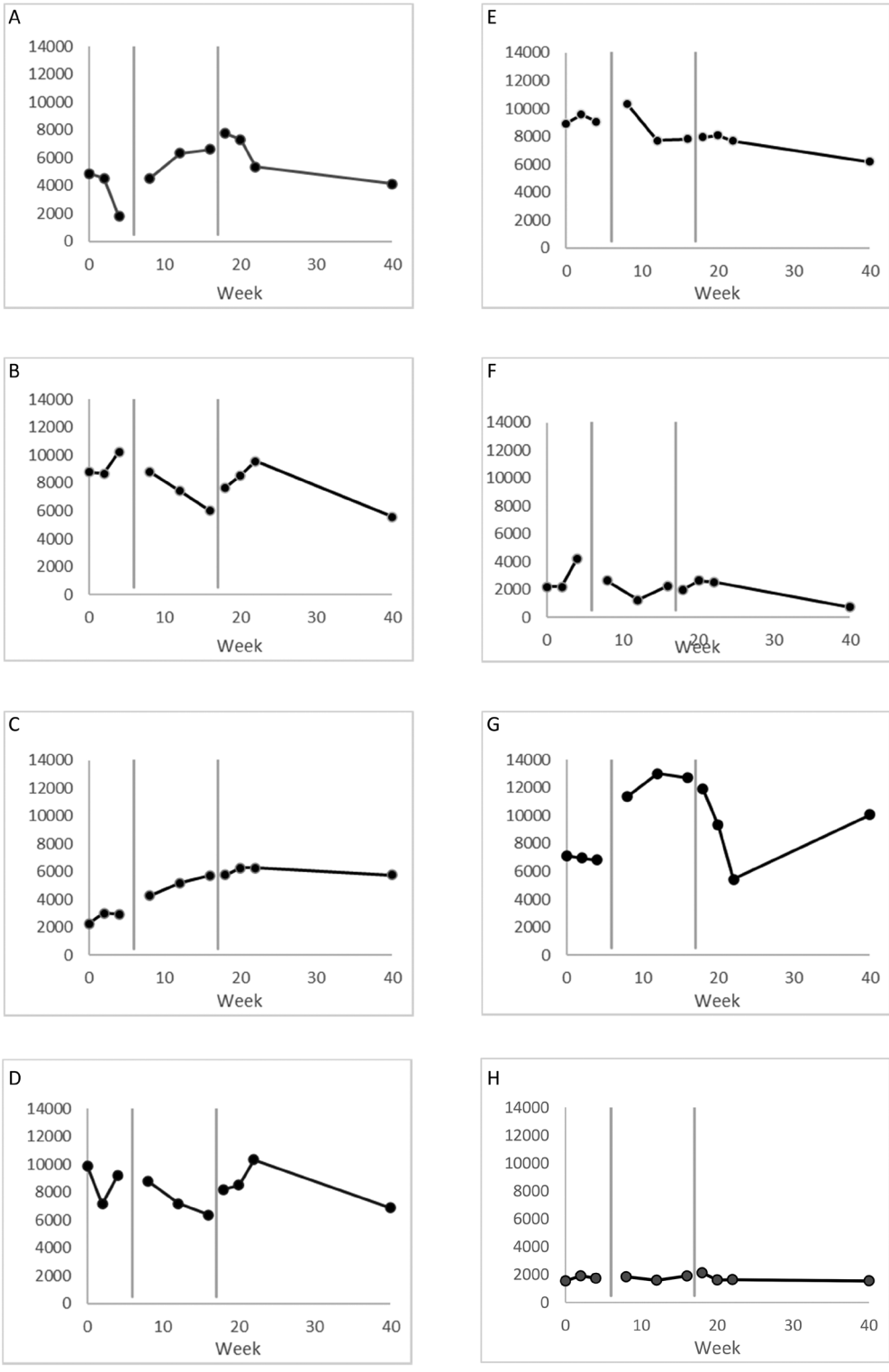


**Figure 3.** Average daily steps by assessment time points.

they became more reflective about how fatigue impacted them, a skill they developed through discussion throughout the programme.

> I'm reflective normally anyway, but she made me reflect over things that I thought that I already had a handle on. (B)

### *My plan*

All participants talked about "my plan" with a sense of ownership, giving specific details of targets, using feedback (including from the Fitbit) to keep themselves on track and ultimately forming a habit. Participants recognised the individuality of "my plan" that was optimised for them in their specific context. One participant describes particular features of his plan that made it work for him.

> …that was a regime which personally appealed to me because the quantum of it meant that I had to physically get out and do something additional, do some specific walking additional to a daily routine. … And I found, personally, that I was better to, I understood the background to the 5,000, the five-day type approach but personally I found that I'm, my nature is that if I "slip" then I have the risk that I find the

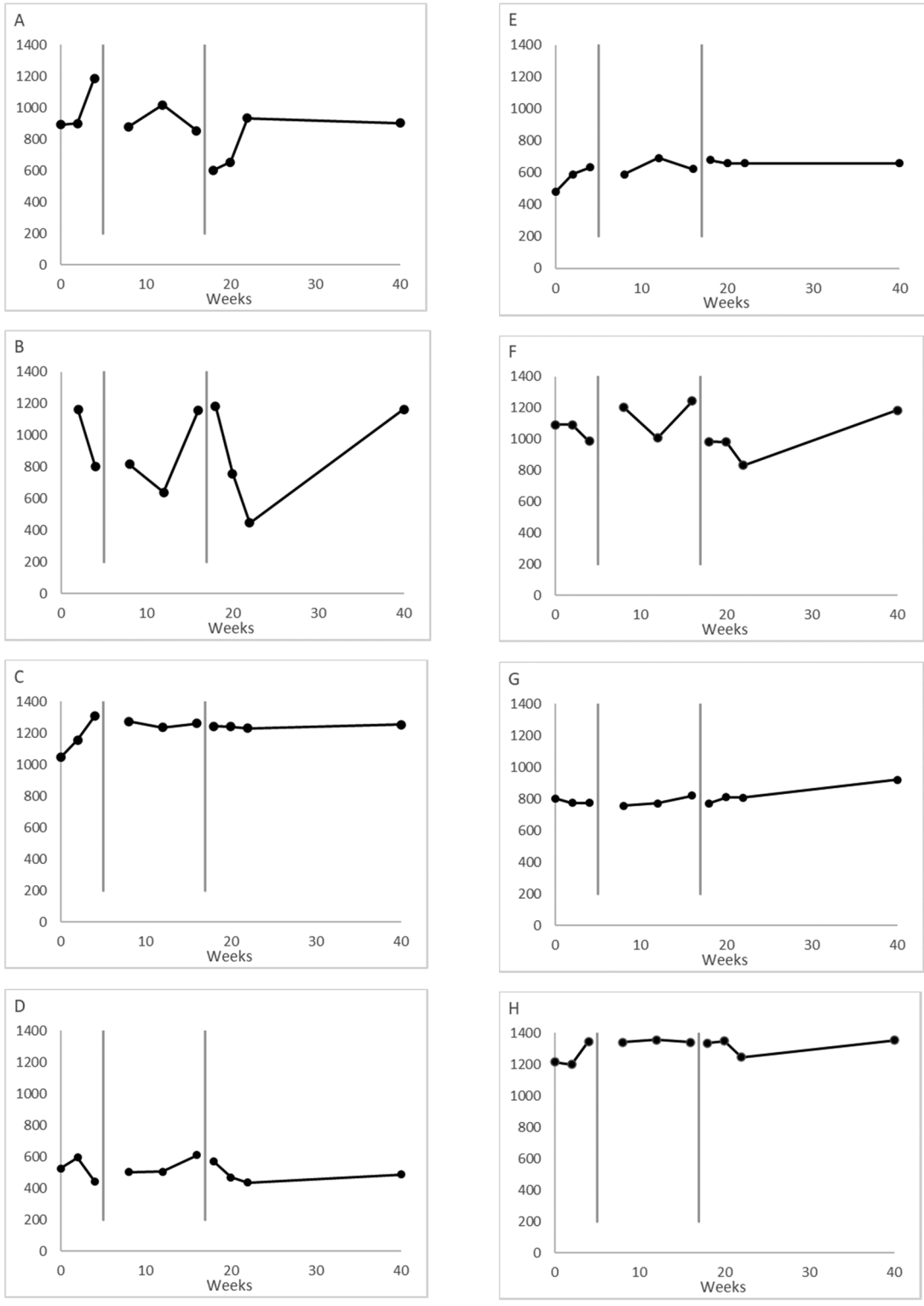


**Figure 4.** Average daily sedentary time (minutes) by assessment time points.

> following day that, "Oh I just can't be bothered." …the measurability of it [referring to the Fitbit] and lastly it was also as a result of the fact that I can listen to podcasts. … That is actually important to me because I still feel walking is relatively not wasted. (G)

Although participants described the skills and habits they had developed, many participants also valued the sense of accountability they felt from having to "front up" (C) to a weekly session.

> It probably allowed me to understand how to approach things and even plan and to establish good routines and set goals as well. (A)

Participants identified the importance of making their plan part of their regular routine, which led to the formation of a habit.

> I think like as long as I'm sticking to the plan, you know, which I have been, you know, give or take, it's been pretty much sticking with what I learned and what I was putting into practice and it really became a habit. (D)

One participant described a feature of her plan (home exercise programme requiring no equipment) meant that the weather did not present a barrier.

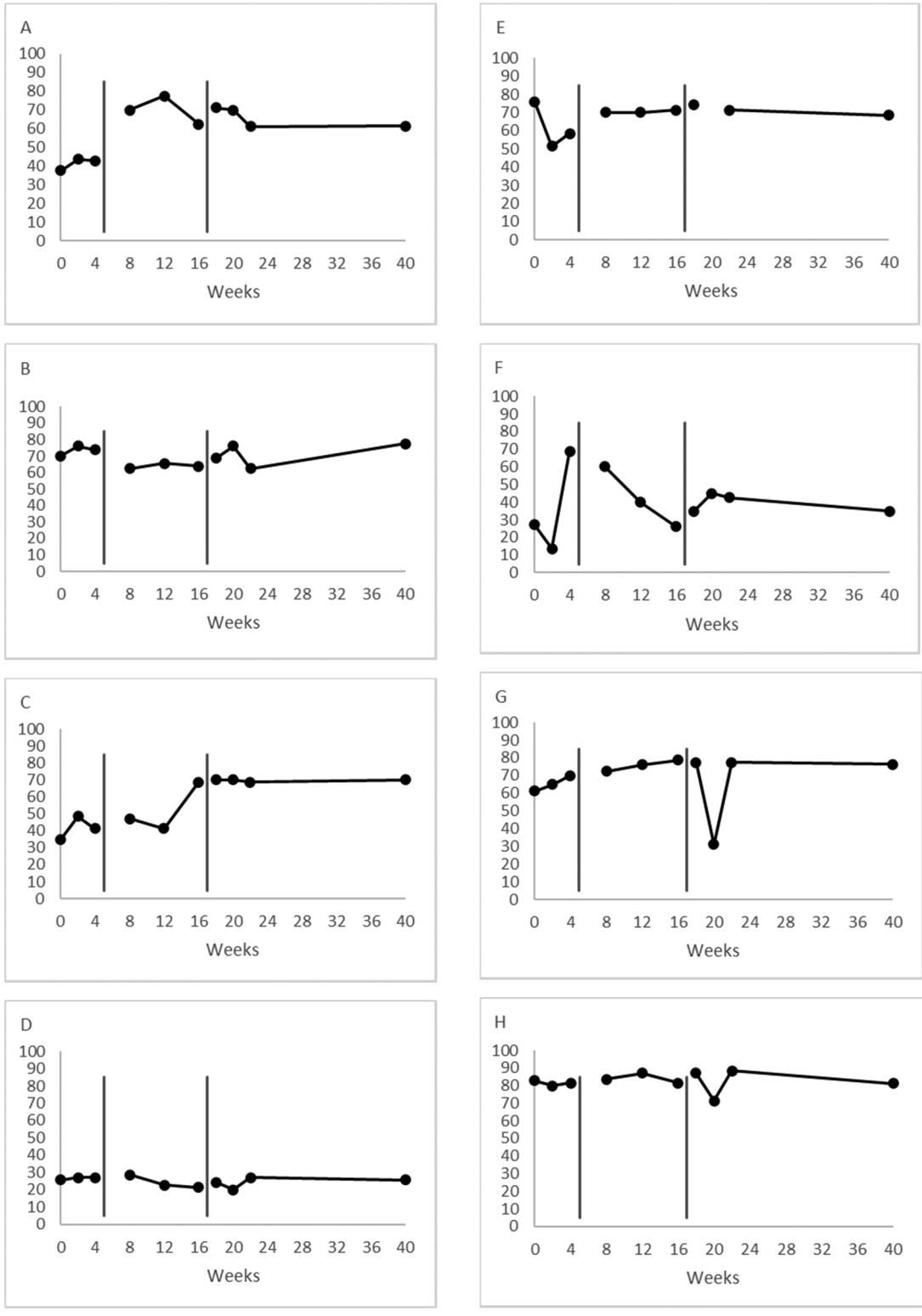


**Figure 5.** Personal wellbeing index by assessment time points.

> The reality is coming into winter that [rain] happens a lot and so the things that are set up, because they're set up at home, I think, it makes them much more sustainable. (C)

### *Changes*

All participants felt they made positive changes over the course of the programme. Participants described being better able to cope with situations they would have previously found fatiguing. Most participants described being more active as a consequence of the programme, tangible to those who used the Fitbit as feedback. Changes were also associated with more confidence around functional activities, that weren't necessarily directly related to "my plan."

> There was a lift to go up but I said, "No, I want to use the stairs." There was an escalator but I wanted to use the stairs and I said, "Right, no problem." What I've been through, through the programme. I said, "Oh well, I can do this, I think I can do this." Yeah, it's good, so being able

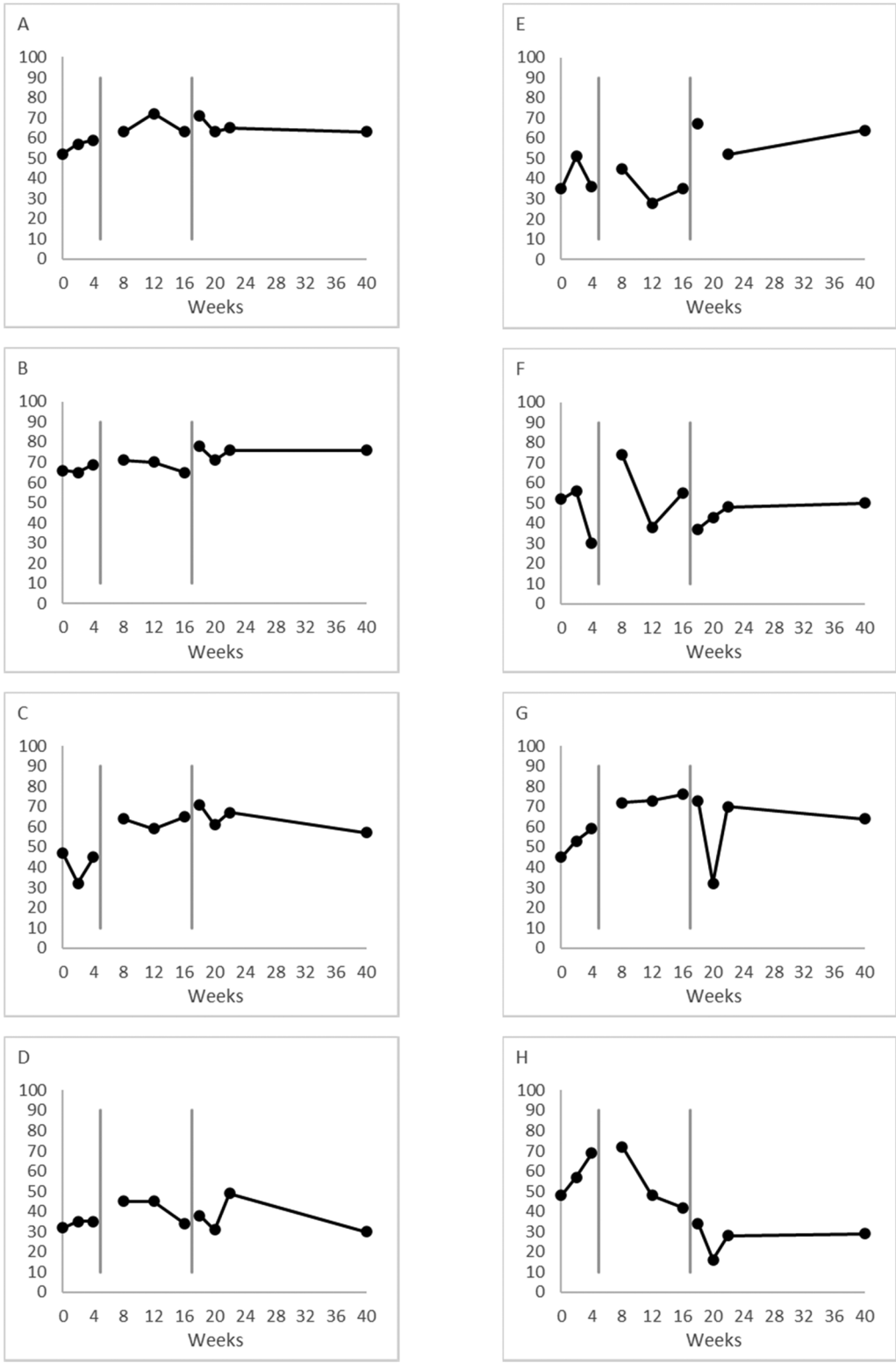


**Figure 6.** Exercise self-efficacy scale by assessment time points.

> to get out in the public and amongst the community and made me a bit more confident as well. (F)

Participants described broader health benefits, such as loss of weight, better sleep and mood. Many participants also described a change in attitude.

> I had achieved, you know, a fundamental change in attitude towards daily exercise. (G)

### *…but for how long?*

Before the end of the programme, participants recognised they had the skills to set goals, monitor feedback and change their plans. They also acknowledged that the onus was on themselves to do so to continue to experience the improvements they had made during the programme: "It's up to me." (G) Participants expressed a range of levels of confidence to carry on, from a couple of participants who said they were not continuing with 'my plan'

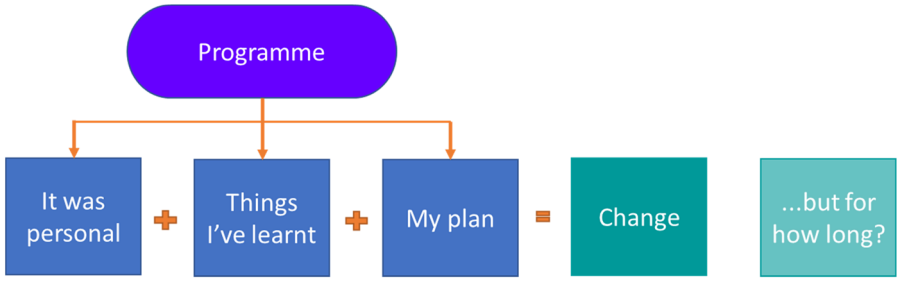


**Figure 7.** Themes.

at the time of interview and others who were: "Overall, definitely I'm sticking to that plan and employing those same strategies." (D)

## Discussion

Our results show that six participants had less fatigue after the programme (greater than the minimally important difference of 0.45 reported [47]), which concurs with the qualitative findings that participants perceived they had an individualised plan and strategies that worked to manage fatigue. The replication of this finding across participants supports the generalisability that participants had a clinically meaningful change in fatigue [17]. Although five of these six participants had a goal to increase activity, only one participant had a clear increase in activity sustained to the end of the follow up period. Two other participants showed increases in activity (A, G) which were not sustained throughout the entire follow up period. The other two participants reported doing more activity despite no changes evident in the Fitbit data. This may indicate that small changes in activity, even if they are not sustained, may have a positive impact on fatigue.

Shah et al.'s recent study for people with chronic GBS showed a reduction in fatigue related to a supervised exercise intervention greater than the improvement in the control group who were prescribed a home programme [59]. The current study showed that an activity programme that is tailored to an individual's abilities, goals and resources with follow up to assist with minimisation of barriers and encourage goal striving may be features that add to a home programme's effectiveness.

At the outset of the study, we anticipated that the intervention for most participants would be focussed on increasing their activity. However, because we decided not to exclude individuals with a high number of daily steps, we acknowledged that for such participants, it might be more constructive to modify their patterns of activity. Three participants had an average of over 8700 daily steps during the baseline period and so their programmes were focussed on structuring their activity within their daily routine and with the addition of sleep hygiene for the two that identified poor sleep habits as an issue. Although all three reported deriving some benefit from the programme, one participant had an increase of fatigue following the programme, one had no clinical change of fatigue and only one had a decrease in fatigue. This does raise the question of whether individuals with lower levels of activity have more to benefit from an activity focussed programme.

Most participants had received little or no information about managing fatigue prior to participation in this study. This was initially surprising given how prevalent fatigue is known to be after GBS [2, 4], however, there are probably several factors that contribute to this circumstance. Firstly, rehabilitation is very focussed on maximising physical recovery for people with GBS [11, 48], so fatigue management may be perceived by both clinicians and people with GBS to be less of a priority. During the programme sessions, some participants described their bout of GBS as traumatic and consequently adopted a future-focussed perspective as a coping mechanism, which also may have contributed to their initial lack of recognition of fatigue as a symptom. Thirdly, it is possible that people with GBS are aware that their recovery is generally greater in magnitude and speed than for people with other neurological conditions [49], which leads them to feel grateful in a way that minimises residual symptoms, including fatigue.

Although telehealth sessions have become more common as a consequence of the COVID-19 pandemic, most patients express a preference for in-person sessions [50, 51]. In contrast, the participants in this study appreciated telehealth as a mode of delivery because of the convenience; which had a less detrimental impact on fatigue because it removed the need to travel, an important factor for those that lived at some distance from a main centre. Convenience is well-recognised as one of the benefits of telehealth that patients perceive [52]. On the other hand, poor connectivity and accessibility to telehealth are often seen as limitations [52]. Several of the participants were unfamiliar with technology at the outset of the study and we spent time to get them set up with video conferencing, including offering help with troubleshooting throughout the study, which supported their competent use [15]. Several participants appreciated developing new skills in their use of such technology. We are aware that this study sample may have been predisposed to appreciate technology and developing skills in this area and so may not be representative of those who do not have access to technology nor the inclination to upskill in this area.

One of the main disadvantages of telehealth is that it is perceived to be less engaging and personalised and consequently patients report it is more difficult to develop a relationship with an unknown health practitioner [52]. In contrast, in this study, the theme "It was personal" describes characteristics participants valued about the programme, which align with the key features of person-centred practice [53–55]. It is encouraging that these attributes were evident to participants despite the absence of in-person sessions, similar to other work that shows that people after stroke felt supported and cared for, even with a limited intervention supplemented by text messages [33]. This difference with other telehealth uses may be attributed to the deliberately personalised nature of the programme, with a conscious intention to translate relational skills to the digital space [15]. We also acknowledge that self-selection of participants to the programme, knowing that it was going to be delivered *via* telehealth, may have different attitudes to health users and practitioners who were required to adapt quickly to telehealth because of the COVID-19 pandemic [15].

Participants expressed a sense of positive achievement from taking part in the programme and it is possible that this focus

limited the attention they gave to fatigue in the interviews. Initially we developed a node "hesitant to push" from one transcript with the definition "fear of fatigue can make people with GBS scared of doing more activity" however after one transcript, no further data were coded to this node. Although surprising, there may be several explanations. At the outset of the intervention, the physiotherapist defined and explained fatigue and discussed the anticipated impacts of the intervention on fatigue with each participant. She provided reassurance about the gradual progression of the intervention and outlined the possibility of exacerbating fatigue and together they considered whether the goal or plan should be adjusted at the goal setting stage throughout the programme. However, although participants experienced fatigue during the intervention, nobody expressed a fear of activity inducing fatigue during the programme or during the interviews, which is in contrast to other studies where participants are fearful of participating in physical activity because it may exacerbate fatigue [7, 56–58]. It is possible that the participants in this study were favourably disposed to physical activity as they were aware of the study premise before entering the study and as such, may not be representative of all people with fatigue related to GBS.

Although all participants recognised their ability to set goals and change their plans, some expressed a lack of confidence in carrying on beyond the end of the programme. Many spoke of the added accountability of having to "front up" to a session that acted as an incentive to keep themselves on track. Even those with high confidence to continue by themselves, stated they would prefer to continue with sessions, even if on a less frequent basis. Support from others is well recognised to be an important factor in maintaining health behaviours [30] and alternative options for support such as an encouraging family member or an exercise buddy may meet this need [59] and could be considered by therapists. Research to establish whether a similar intervention that transitions to natural supports sustains the ability of participants to continue with their plans would be beneficial.

## Limitations

There are known limitations of measuring steps in free living situations using a Fitbit worn on the wrist [60]. The Fitbit can overcount steps when there are extraneous arm movements and can underestimate steps when the arm is stationary (for example holding onto the bar of a treadmill) [61]. We accepted these limitations given the data were used for within-participant comparisons and as the limitation were balanced with the ease and therefore likelihood of wearing the Fitbit compared to ankle mounted devices. We also selected the Fitbit because of its ability to be easily integrated into goal setting and in providing prompts and feedback. It is possible that the diminished accuracy contributed to only one participant with a clear increase in activity but we think this unlikely, given the within-participant comparisons we used and because of the other contributory factors already discussed.

We aimed to recruit ten participants but were only able to recruit eight during the study period. Twelve people expressed interest in participating in the study but three were ineligible because their mean FSS was less than 4 and the other because the onset of GBS was less than two years previously. A cut-off of 4 on the FSS may be a limitation, however this is the accepted cut-off for the presence of fatigue [3, 62].

We did not exclude participants with other health conditions that may have contributed to fatigue and the other outcomes. We acknowledge this decision may have impacted our findings, however we also believe the participants were more typical of those commonly seen in clinical practice.

The qualitative component revealed that all participants were overwhelmingly positive about the intervention. This appreciation of the intervention was likely contributed to by participants' prior lack of exposure to fatigue management principles and strategies and because the timing of the intervention occurred when all rehabilitation had been completed. This may be considered as a limitation as participants could have been positively predisposed to any type of input.

## Conclusion

The online activity-focussed programme was effective in reducing fatigue for the majority of participants and other improvements in activity, confidence to exercise, general wellbeing and other health benefits were also experienced. Not all changes were sustained past the follow-up period, which reflects participants' differing levels of confidence in their ability to maintain their plan after the coaching intervention finished. Participants were very positive about what they had learnt about fatigue, themselves and strategies to manage fatigue and all developed a personalized plan to manage fatigue using goals, feedback and ways to keep themselves on track.

## Acknowledgements

We wish to acknowledge the support from the advisory group, who provided guidance on intervention development and dissemination.

## Disclosure statement

No potential conflict of interest was reported by the author(s).

## Funding

We are grateful for funding from the Neuromuscular Research Fund, the GBS Support Group NZ and the AUT Faculty Development Fund.

## ORCID

Suzie Mudge http://orcid.org/0000-0003-3106-6777
Greta Smith http://orcid.org/0000-0003-1404-4090
Gareth J. Parry http://orcid.org/0000-0001-5670-809X

## References

[1] Forsberg A, Widén-Holmqvist L, Ahlström G. Balancing everyday life two years after falling ill with Guillain-Barré syndrome: a qualitative study. Clin Rehabil [Internet]. 2015;29(6). :601–610. https://journals.sagepub.com/doi/10.1177/0269215514549564. doi: 10.1177/0269215514549564.

[2] Drory VE, Bronipolsky T, Bluvshtein V, et al. Occurrence of fatigue over 20 years after recovery from Guillain–Barré syndrome. J Neurol Sci. 2012;316(1–2):72–75. https://www.jns-journal.com/article/S0022-510X(12)00048-2/abstract.

[3] de Vries JM, Hagemans MLC, Bussmann JBJ, et al. Fatigue in neuromuscular disorders: focus on Guillain–Barré syndrome and Pompe disease. Cell Mol Life Sci. 2010;67(5):701–713. doi: 10.1007/s00018-009-0184-2.

[4] Ranjani P, Khanna M, Gupta A, et al. Prevalence of fatigue in Guillain-Barre syndrome in neurological rehabilitation setting. Ann

Indian Acad Neurol. 2014;17(3):331–335. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4162023/. doi: 10.4103/0972-2327.138521.

[5] Davidson I, Wilson C, Walton T, et al. What constitutes a 'Good' recovery outcome in post-acute Guillain–Barré syndrome? Results of a Nationwide Survey of post-acute GBS sufferers in the United Kingdom. Eur J Neurol [Internet]. 2010;17(5):677–683. http://onlinelibrary.wiley.com/doi/abs/10.1111/j.1468-1331.2009.02906.x. doi: 10.1111/j.1468-1331.2009.02906.x.

[6] Motl RW. Benefits, safety, and prescription of exercise in persons with multiple sclerosis. Expert Rev Neurother. 2014;14(12):1429–1436. doi: 10.1586/14737175.2014.983904.

[7] Halabchi F, Alizadeh Z, Sahraian MA, et al. Exercise prescription for patients with multiple sclerosis; potential benefits and practical recommendations. BMC Neurol. 2017;17(1):185. doi: 10.1186/s12883-017-0960-9.

[8] Cruickshank TM, Reyes AR, Ziman MR. A systematic review and meta-analysis of strength training in individuals with multiple sclerosis or Parkinson disease. Medicine (Baltimore). 2015;94(4):e411. doi: 10.1097/MD.0000000000000411.

[9] Bussmann JBJ, Garssen MP, van Doorn PA, et al. Analysing the favourable effects of physical exercise: relationships between physical fitness, fatigue and functioning in Guillain-Barré syndrome and chronic inflammatory demyelinating polyneuropathy. J Rehabil Med. 2007;39(2):121–125. doi: 10.2340/16501977-0007.

[10] Smith C, Hale L. The effects of non-pharmacological interventions on fatigue in four chronic illness conditions: a critical review. Phys Ther Rev [Internet]. 2007;12(4):324–334. doi: 10.1179/108331907X223056.

[11] Arsenault NS, Vincent P-O, Yu BHS, et al. Influence of exercise on patients with Guillain-Barré syndrome: a systematic review. Physiother Can. 2016;68(4):367–376. https://ezproxy.aut.ac.nz/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=ccm&AN=119164113&site=eds-live.

[12] Graham RC, Hughes RAC, White CM. A prospective study of physiotherapist prescribed community based exercise in inflammatory peripheral neuropathy. J Neurol. 2007;254(2):228–235. doi: 10.1007/s00415-006-0335-4.

[13] White CM, Pritchard J, Turner-Stokes L. Exercise for people with peripheral neuropathy. Cochrane Database Syst Rev. 2004;18(4):CD003904. doi: 10.1002/14651858.CD003904.pub2.

[14] Khan F, Pallant JF, Ng L, et al. Factors associated with long-term functional outcomes and psychological sequelae in Guillain-Barre syndrome. J Neurol. 2010;257(12):2024–2031. doi: 10.1007/s00415-010-5653-x.

[15] Signal N, Martin T, Leys A, et al. Implementation of telerehabilitation in response to COVID-19: lessons learnt from neurorehabilitation clinical practice and education. N Z J Physiother [Internet]. 2020;48:117–126. https://eds-b-ebscohost-com.ezproxy.aut.ac.nz/eds/detail/detail?vid=0&sid=d05bb45f-9f27-4040-905a-8752f05d394d%40pdc-v-sessmgr04&bdata=JnNpdGU9ZWRzLWxpdmU%3d.

[16] Perdices M, Tate RL. Single-subject designs as a tool for evidence-based clinical practice: are they unrecognised and undervalued? Neuropsychol Rehabil. 2009;19(6):904–927. doi: 10.1080/09602010903040691.

[17] Tate RL, Perdices M, Rosenkoetter U, et al. The Single-Case Reporting Guideline In BEhavioural Interventions (SCRIBE) 2016 statement. Arch Sci Psychol. 2016;4:10–31.

[18] Kazdin AE. Single-case experimental designs: characteristics, changes, and challenges. J Exp Anal Behav. 2021;115(1):56–85. https://onlinelibrary.wiley.com/doi/abs/10.1002/jeab.638. doi: 10.1002/jeab.638.

[19] Antonucci G, Aprile T, Paolucci S. Rasch analysis of the Rivermead Mobility Index: a study using mobility measures of first-stroke inpatients. Arch Phys Med Rehabil. 2002;83(10):1442–1449. doi: 10.1053/apmr.2002.34618.

[20] Van Nes SI, Vanhoutte EK, Faber CG, et al. Improving fatigue assessment in immune-mediated neuropathies: the modified Rasch-built fatigue severity scale. J Peripher Nerv Syst. 2009;14(4):268–278. https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1529-8027.2009.00238.x. doi: 10.1111/j.1529-8027.2009.00238.x.

[21] Shephard RJ. Qualified fitness and exercise as professionals and exercise prescription: evolution of the PAR-Q and Canadian Aerobic Fitness Test. J Phys Act Health [Internet]. 2015;12(4):454–461. http://search.ebscohost.com/login.aspx?direct=true&db=s3h&AN=103674620&site=ehost-live&scope=site. doi: 10.1123/jpah.2013-0473.

[22] Stretton C, Mudge S, Kayes NM, et al. Activity coaching to improve walking is liked by rehabilitation patients but physiotherapists have concerns: a qualitative study. J Physiother. 2013;59(3):199–206. doi: 10.1016/S1836-9553(13)70184-X.

[23] Lyons EJ, Swartz MC, Lewis ZH, et al. Feasibility and acceptability of a wearable technology physical activity intervention with telephone counseling for mid-aged and older adults: a randomized controlled pilot trial. JMIR Mhealth Uhealth. 2017;5(3):e28. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5359416/. doi: 10.2196/mhealth.6967.

[24] Dunn EE, Robertson-Wilson J. Behavior change techniques and physical activity using the Fitbit Flex®. Int J Exerc Sci [Internet]. 2018;11:561–574. https://ezproxy.aut.ac.nz/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=edo&AN=128084993&site=eds-live.

[25] Michie S, Richardson M, Johnston M, et al. The behavior change technique taxonomy (v1) of 93 hierarchically clustered techniques: building an international consensus for the reporting of behavior change interventions. Ann Behav Med. 2013;46(1):81–95. doi: 10.1007/s12160-013-9486-6.

[26] Saywell NL, Vandal AC, Mudge S, et al. Telerehabilitation after stroke using readily available technology: a randomized controlled trial. Neurorehabil Neural Repair. 2021; 35(1):88–97. doi: 10.1177/1545968320971765.

[27] Stretton CM, Mudge S, Kayes NM, et al. Interventions to improve real-world walking after stroke: a systematic review and meta-analysis. Clin Rehabil. 2016;31(3):310–318. doi: 10.1177/0269215516640863.

[28] US Department of Health and Human Services. Physical activity guidelines for Americans. 2nd ed. Washington, DC; 2018. [Internet]. https://health.gov/paguidelines/second-edition/pdf/Physical_Activity_Guidelines_2nd_edition.pdf.

[29] Hale LA, Smith CM, Mulligan HF, et al. Exploring the Blue Prescription intervention to promote physical activity in people with long-term conditions. Int J Ther Rehabil [Internet]. 2018;25(7):365–376. http://www.magonlinelibrary.com/doi/full/10.12968/ijtr.2018.25.7.365.

[30] Mudge S, Kayes N, Stavric V, et al. Living well with disability: needs, values and competing factors. Int J Behav Nutr Phys Act. 2013;10(1):100. doi: 10.1186/1479-5868-10-100.

[31] Learmonth YC, Adamson BC, Balto JM, et al. Multiple sclerosis patients need and want information on exercise promotion from healthcare providers: a qualitative study. Health Expect. 2017;20(4):574–583. doi: 10.1111/hex.12482.

[32] Lyons EJ, Lewis ZH, Mayrsohn BG, et al. Behavior change techniques implemented in electronic lifestyle activity monitors: a systematic content analysis. J Med Internet Res. 2014;16(8):e192. https://www.jmir.org/2014/8/e192/. doi: 10.2196/jmir.3469.

[33] Saywell NL, Mudge S, Kayes NM, et al. A six-month telerehabilitation programme delivered via readily accessible tech-

nology is acceptable to people following stroke: a qualitative study. Physiotherapy [Internet]. 2023;120:1–9. https://www.sciencedirect.com/science/article/pii/S0031940623000275. doi: 10.1016/j.physio.2023.05.001.

[34] Tyson SF, Brown P. How to measure fatigue in neurological conditions? A systematic review of psychometric properties and clinical utility of measures used so far. Clin Rehabil. 2014;28(8):804–816. doi: 10.1177/0269215514521043.

[35] Misajon R, Pallant J, Bliuc A-M. Rasch analysis of the Personal Wellbeing Index. Qual Life Res. 2016;25(10):2565–2569. doi: 10.1007/s11136-016-1302-x.

[36] Resnick B, Jenkins LS. Testing the reliability and validity of the Self-Efficacy for Exercise Scale. Nurs Res. 2000;49(3):154–159. doi: 10.1097/00006199-200005000-00007.

[37] Bunn JA, Navalta JW, Fountaine CJ, et al. Current state of commercial wearable technology in physical activity monitoring 2015-2017. Int J Exerc Sci [Internet]. 2018;11:503–515. https://ezproxy.aut.ac.nz/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=edo&AN=128084987&site=eds-live.

[38] Kooiman TJM, Dontje ML, Sprenger SR, et al. Reliability and validity of ten consumer activity trackers. BMC Sports Sci Med Rehabil. 2015;7:24. https://ezproxy.aut.ac.nz/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=s3h&AN=110435618&site=eds-live.

[39] Hergenroeder AL, Barone Gibbs B, Kotlarczyk MP, et al. Accuracy and acceptability of commercial-grade physical activity monitors in older adults. J Aging Phys Act. 2019;27(2):222–229. doi: 10.1123/japa.2018-0036.

[40] Imboden MT, Nelson MB, Kaminsky LA, et al. Comparison of four Fitbit and Jawbone activity monitors with a research-grade ActiGraph accelerometer for estimating physical activity and energy expenditure. Br J Sports Med. 2018;52(13):844–850. doi: 10.1136/bjsports-2016-096990.

[41] Ptomey LT, Vidoni ED, Montenegro-Montenegro E, et al. The feasibility of remotely delivered exercise session in adults with Alzheimer's disease and their caregivers. J Aging Phys Act. 2019;27(5):670–677. https://ezproxy.aut.ac.nz/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=s3h&AN=140086196&site=eds-live.

[42] Mulligan H, Armstrong A, Francis R, et al. Engagement in exercise for people with Parkinson's: what is meaningful? N Z J Physiother [Internet]. 2018;46:19–28. https://ezproxy.aut.ac.nz/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=ccm&AN=129676871&site=eds-live.

[43] Nourbakhsh MR, Ottenbacher KJ. The statistical analysis of single-subject data: a comparative examination. Phys Ther. 1994;74(8):768–776. doi: 10.1093/ptj/74.8.768.

[44] Lobo MA, Moeyaert M, Baraldi Cunha A, et al. Single-Case Design, Analysis, and Quality Assessment for Intervention Research. J Neurol Phys Ther. 2017;41(3):187–197. doi: 10.1097/NPT.0000000000000187.

[45] Vannest KJ, Parker RI, Gonen O, et al. Single Case Research: web based calculators for SCR analysis (Version 2.0); 2016 [Internet]. http://singlecaseresearch.org/calculators/nap.

[46] Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. Qual Health Res. 2005;15(9):1277–1288. doi: 10.1177/1049732305276687.

[47] Rooney S, McFadyen DA, Wood DL, et al. Minimally important difference of the fatigue severity scale and modified fatigue impact scale in people with multiple sclerosis. Mult Scler Relat Disord [Internet]. 2019;35:158–163. https://www.sciencedirect.com/science/article/pii/S2211034819303190. doi: 10.1016/j.msard.2019.07.028.

[48] Prada V, Massa F, Salerno A, et al. Importance of intensive and prolonged rehabilitative treatment on the Guillain-Barrè syndrome long-term outcome: a retrospective study. Neurol Sci. 2020;41(2):321–327. doi: 10.1007/s10072-019-04077-x.

[49] Andrews A, Williams MS, Middleton A. Improvement during inpatient rehabilitation among older adults with Guillain-Barré Syndrome, multiple sclerosis, Parkinson disease, and stroke. Am J Phys Med Rehabil. 2023;97(12):879–884. https://oce-ovid-com.ezproxy.aut.ac.nz/article/00002060-201812000-00004/HTML. doi: 10.1097/PHM.0000000000000991.

[50] Predmore ZS, Roth E, Breslau J, et al. Assessment of patient preferences for telehealth in post–COVID-19 pandemic health care. JAMA Netw Open. 2021;4(12):e2136405. doi: 10.1001/jamanetworkopen.2021.36405.

[51] Rasmussen B, Perry R, Hickey M, et al. Patient preferences using telehealth during the COVID-19 pandemic in four Victorian tertiary hospital services. Intern Med J. 2022;52(5):763–769. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9545930/. doi: 10.1111/imj.15726.

[52] Toll K, Spark L, Neo B, et al. Consumer preferences, experiences, and attitudes towards telehealth: qualitative evidence from Australia. PLoS One [Internet]. 2022;17(8):e0273935. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9432716/. doi: 10.1371/journal.pone.0273935.

[53] Ahmad N, Ellins J, Krelle H, et al. Person-centred care: from ideas to action. London: The Health Foundation; 2014.

[54] Terry G, Kayes N. Person centered care in neurorehabilitation: a secondary analysis. Disabil Rehabil. 2019;42(16):2334–2343. doi: 10.1080/09638288.2018.1561952.

[55] Darlow B, Williams A. Person and Whānau centred care in Aotearoa New Zealand; 2018. Physiotherapy New Zealand. [Internet]. https://pnz.org.nz/pwcc.

[56] Kayes NM, McPherson KM, Taylor D, et al. Facilitators and barriers to engagement in physical activity for people with multiple sclerosis: a qualitative investigation. Disabil Rehabil. 2011;33(8):625–642. doi: 10.3109/09638288.2010.505992.

[57] McCormack C, Cullivan S, Kehoe B, et al. "It is the fear of exercise that stops me" – attitudes and dimensions influencing physical activity in pulmonary hypertension patients. Pulm Circ. 2021;11(4):20458940211056509. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8573491/. doi: 10.1177/20458940211056509.

[58] Busse M, Latchem-Hastings J, Button K, et al. Web-based physical activity intervention for people with progressive multiple sclerosis: application of consensus-based intervention development guidance. BMJ Open [Internet]. 2021;11(3):e045378. https://bmjopen.bmj.com/content/11/3/e045378. doi: 10.1136/bmjopen-2020-045378.

[59] Stretton CM, Mudge S, Kayes NM, et al. What does real-world walking mean to people with stroke? An interpretive descriptive study. Disabil Rehabil. 2020;44(2):315–322. doi: 10.1080/09638288.2020.1767704.

[60] Bassett DR, Toth LP, LaMunion SR, et al. Step counting: a review of measurement considerations and health-related applications. Sports Med. 2017;47(7):1303–1315. http://link.springer.com/ doi: 10.1007/s40279-016-0663-1.

[61] Feehan LM, Geldman J, Sayre EC, et al. Accuracy of fitbit devices: systematic review and narrative syntheses of quantitative data. JMIR Mhealth Uhealth. 2018;6(8):e10527. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6107736/. doi: 10.2196/10527.

[62] Valko PO, Bassetti CL, Bloch KE, et al. Validation of the fatigue severity scale in a swiss cohort. Sleep [Internet]. 2008;31(11):1601–1607. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2579971/. doi: 10.1093/sleep/31.11.1601.