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Research Article

Fatigue after CriTical illness (FACT): Co-production of a self-management intervention to support people with fatigue after critical illness

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ABSTRACT

Purpose: Fatigue is a common and debilitating problem in patients recovering from critical illness. To address a lack of evidence-based interventions for people with fatigue after critical illness, we co-produced a self-management intervention based on self-regulation theory. This article reports the development and initial user testing of the co-produced intervention.

Methods: We conducted three workshops with people experiencing fatigue after critical illness, family members, and healthcare professionals to develop a first draft of the FACT intervention, designed in web and electronic document formats. User testing and interviews were conducted with four people with fatigue after critical illness. Modifications were made based on the findings.

Results: Participants found FACT acceptable and easy to use, and the content provided useful strategies to manage fatigue. The final draft intervention includes four key topics: (1) about fatigue which discusses the common characteristics of fatigue after critical illness; (2) managing your energy with the 5 Ps (priorities, pacing, planning, permission, position); (3) strategies for everyday life (covering physical activity; home life; leisure and relationships; work, study, and finances; thoughts and feelings; sleep and eating); and (4) goal setting and making plans. All material is presented as written text, videos, and supplementary infographics. FACT includes calls with a facilitator but can also be used independently.

Conclusions: FACT is a theory driven intervention co-produced by patient, carer and clinical stakeholders and is based on contemporary available evidence. Its development illustrates the benefits of stakeholder involvement to ensure interventions are informed by user needs. Further testing is needed to establish the feasibility and acceptability of FACT.

Implications for clinical practice: The FACT intervention shows promise as a self-management tool for people with fatigue after critical illness. It has the potential to provide education and strategies to patients at the point of discharge and follow-up.

Introduction

Around two-thirds of patients recovering from critical illness will experience physical, cognitive, and psychological impairments leading to increased morbidity, mortality, and a reduction in health-related quality of life (HRQoL) for many months after discharge from intensive care units (ICU) (Ramnarain et al., 2021; Geense et al., 2021). The constellation of these impairments is referred to as post-intensive care syndrome (PICS). Fatigue is one of the three most significant problems reported by people who have experienced critical illness, along with a lack of physical strength and decreased walking distance (Nedergaard et al., 2018). It is defined as a persistent and overwhelming feeling of exhaustion that affects daily functioning and is not relieved by sleep (Herdman and Kamitsuru, 2015). The prevalence of fatigue after critical illness is estimated to be between 14 and 81 %, with some people continuing to experience fatigue long-term (Bench et al., 2021a).

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Fatigue leads to physical, psychological, emotional, and social impacts, such as poor physical stamina, reduced socialising, and depression (Bench et al., 2021a,b). Common problems include loss of identity and self-worth as patients rely more on others and are no longer able to fulfil their former roles (Bench et al., 2021a,b). Patients also report disrupted sleep and cognitive fatigue, presenting as pronounced difficulty with concentration, thinking, and memory (Geense et al., 2021; Colman et al., 2015). A previous systematic review identified no existing rehabilitation interventions specifically for this population (Bench et al., 2021a). There is therefore an urgent need for new interventions to support fatigue management after critical illness.

Our recent umbrella review identified the potential of self-management to manage fatigue in people who have experienced critical illness (Brown et al., 2023). The use of self-management in rehabilitation is expanding, showing positive impacts on health outcomes for patients with cancer and long-term conditions (Brown et al., 2023; Cravo et al., 2022). Although definitions of self-management vary, it typically involves some form of self-directed activity from the patient, who takes a leading role in the management of their symptoms, with the goal being improved coping and illness management rather than objective symptom improvement, though this may occur (Brown et al., 2023). Activities may include patient education, symptom tracking, setting goals, and monitoring improvements (Cravo et al., 2022; Lorig and Holman, 2003). Self-management is multi-faceted and influenced by a range of factors, such as support from healthcare professionals (HCPs) and social networks, resources availability, and self-efficacy (Schulman-Green et al., 2012).

Support from facilitators or HCPs (e.g. through regular phone calls) in fatigue self-management appears to have a positive impact on outcomes and acceptability (Brown et al., 2023; Agbejule et al., 2022). Similarly, goal setting is not always used but has shown positive effects in other populations such as stroke rehabilitation (Scobbie et al., 2021). Self-management interventions can be offered in a variety of formats, including online, making it a flexible tool for patients who may struggle to take part in 'live' or in-person activities due to fatigue (Brown et al., 2023).

To address the need for appropriate fatigue management for people who have experienced critical illness, this study aimed to co-produce and perform initial user testing of a draft fatigue self-management intervention, known as FACT (managing Fatigue After CriTical illness), based on self-regulation theory, elements from pre-existing interventions, and input from patient, carer, and health professional stakeholders. The aim of this article is to report the process of co-production and the results of the initial user testing.

Theoretical framework

Development of the FACT intervention was guided by Leventhal et al.'s self-regulation theory, which proposes that patients choose how they manage illness based on their own understanding of the illness experience (Leventhal et al., 2016). These factors can be influenced both by patients' internal responses to the event and external information from health professionals and wider society. Discrepancies between actual and desired level of function lead to the formulation of goals, using whichever available strategies feel most useful. These goals then lead to goal-directed actions, which may involve personal behaviours or adjusting the environment (Leventhal et al., 1998). Patients adapt their actions over time according to their experience of the illness and the perceived outcomes of strategies (Johnson, 1999). The goal of coping is achieved when the patient reaches a level of functioning that is satisfactory to them (Johnson, 1999). The theory has previously been used successfully in the development of a critical care discharge information pack for patients and family members (Bench et al., 2015).

Self-regulation theory is a valuable foundation for self-management, which aims to equip patients with the tools they need to effectively cope with an ongoing condition or the aftermath of a healthcare event (Taylor et al., 2014). We therefore sought to provide a 'scaffold' for people with fatigue after critical illness to carry out self-regulation by equipping them with sufficient information to create their own set of effective management strategies and making the process of formulating and pursuing goals explicit and guided. In accordance with the aim of self-management, the goal of the intervention developed was to support people to manage and cope with their fatigue leading to an improved HRQoL, rather than to reduce the level of fatigue. A logic model illustrating the mechanism of action is provided in Fig. 1. The GUIDED checklist has been used to guide reporting of the intervention development process (Supplementary File 1).

Materials and methods

The study followed the Medical Research Council (MRC) and National Institute of Health Research (NIHR) framework for developing and evaluating complex interventions (Skivington et al., 2021). The FACT intervention was first developed with patient, carer, and health professional stakeholders and subsequently provisionally tested with people experiencing fatigue after critical illness (Fig. 1). Involving patient, carer, and healthcare professional partners in intervention design helps to ensure that the intervention is relevant and acceptable by centring on the needs and preferences of the target users (O'Cathain et al., 2019). Ethical approval was obtained from the University Research Ethics Committee at Oxford Brookes University (reference: 221611). The study took place between November 2022 and April 2023. The study process is detailed in Fig. 2.

Phase 1: intervention development

We co-produced the draft intervention via a series of three online workshops involving patient, carer, and healthcare professional partners: seven people who had experienced critical illness and were currently reporting fatigue, one carer/family member, and seven critical care healthcare professionals (one physiotherapist, three psychologists, two nurses, and one occupational therapist). Partners were recruited via the national critical illness support charity ICUSteps, social media, and patient representative and professional networks. All healthcare professionals had experience of both ICU and post-ICU care through inpatient and outpatient services. Patients were at varying stages of recovery, ranging from a few months to several years post-ICU, and continued to experience fatigue at the time of the workshops. Reasons for ICU admission had included COVID-19, sepsis, and post-operative complications.

Partners were compensated for their time in accordance with NIHR guidance on patient and public involvement (NIHR 2019) and were involved in all decisions about intervention design, including checking all drafts. They were not involved in reporting due to practical limitations on time and energy. All partners attended at least one workshop. Where partners were not able to attend a workshop due to illness or schedule conflicts, they provided feedback via Two partners used email for two feedback rounds, and three partners used email for one feedback round. Workshops were led by members of the research team [LS, EB, WCD], all of whom had appropriate experience.

Workshop 1

Workshop 1 included a short presentation of three cancer-related fatigue interventions identified in the umbrella review. These were a telephone and face-to-face support programme (Yates et al., 2005) and two fully self-directed web-based interventions (Foster et al., 2016; Yun et al., 2012). These were deemed suitable due to having a range of possible self-management characteristics, such as being self-directed or having support. Partners were asked to select one or a combination of fatigue interventions that they felt would most closely meet the needs of people with fatigue after critical illness. There was an overall preference for flexibility in the format of the intervention, allowing for both online

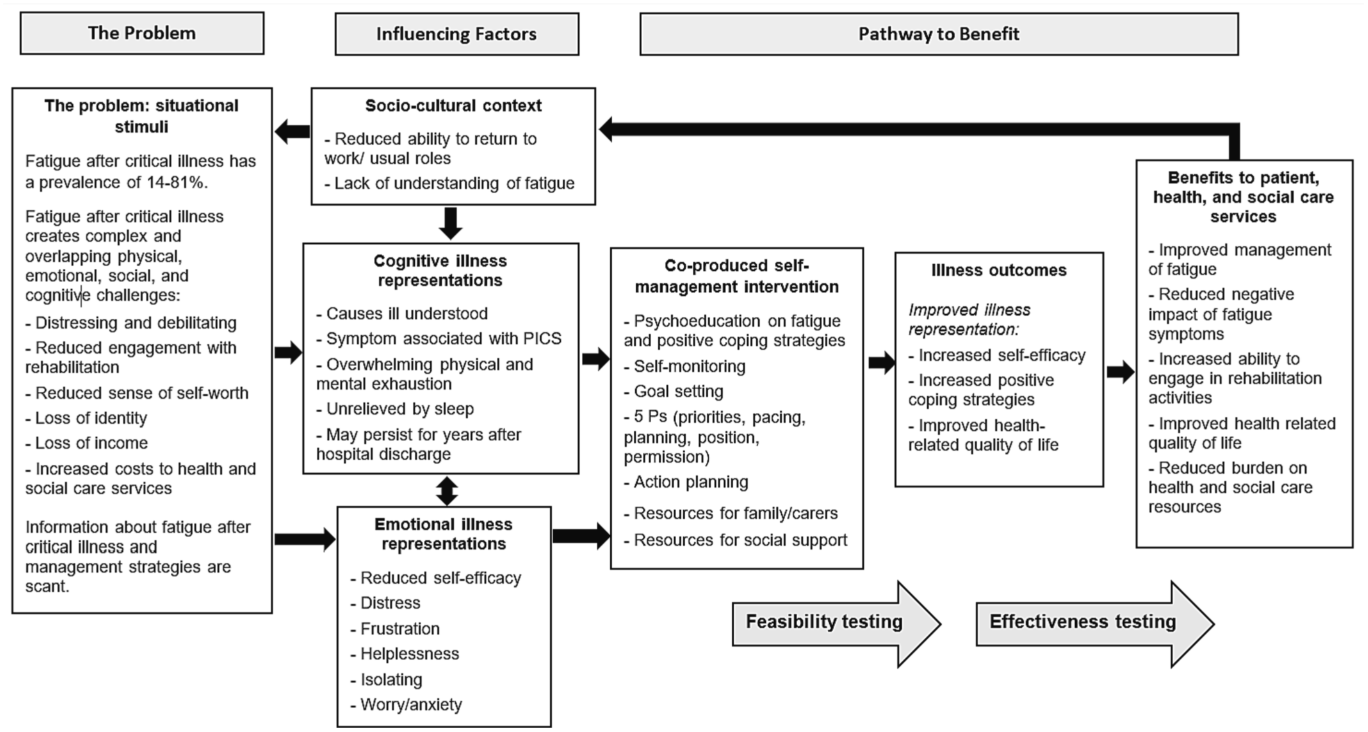

Fig. 1. Intervention development logic model using self-regulation theory (*PICS = Post Intensive Care Syndrome).

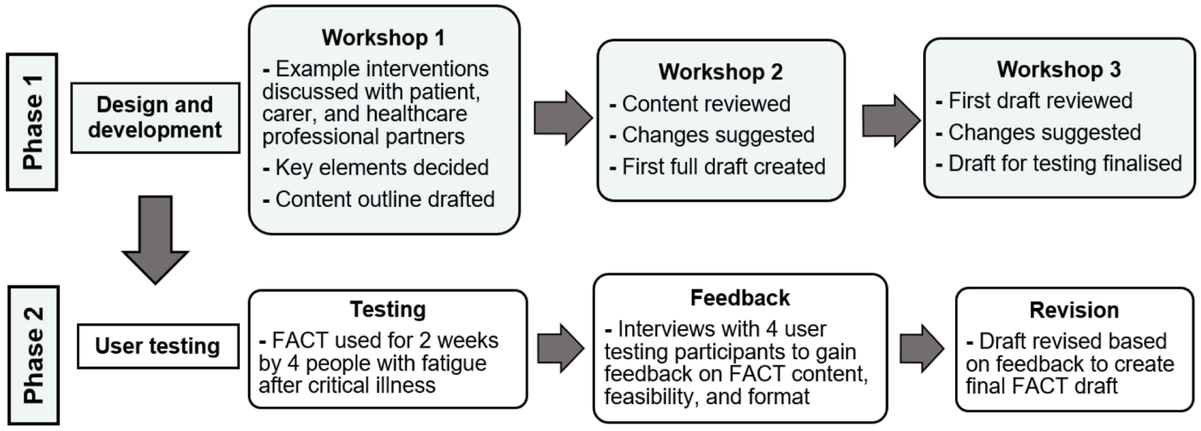

Fig. 2. FACT intervention development process.

and offline options, and for some degree of 'live' support from a health professional or other facilitator. Goal setting was generally seen as an useful element to include, but patients particularly emphasised the need for sensitivity around the language of goal setting and allowing users to choose if and when to utilise it.

Following the workshop, the research team drafted a content outline based on partner suggestions and example topics from the presented intervention in an electronic document. This focused on four key areas: (1) information about fatigue and its effects; (2) the '5 Ps' (priorities, pacing, planning, permission, position); (3) strategies for daily life (e.g. cooking, leisure, relationships); and (4) goal setting and making plans. The '5 Ps' is a set of strategies used in fatigue management across various conditions including myalgic encephalomyelitis (ME) (Royal Free London NHS Trust, n.d.) and stroke (Stroke Association, 2023). Also sometimes presented as the 3 Ps (pace, plan, prioritise) or 4 Ps (pacing, planning, priorities, position or posture), for this intervention, 'permission' (i.e. permission to do or not do an activity) was also included based on input from the occupational therapist in the partner group. Example strategies for daily living were drafted to allow partners to add from their own experience.

The Goal setting and Action Planning (G-AP) framework was used to provide a structured process for setting and pursuing goals with support from a facilitator. G-AP is a theory and evidence-based framework that has been used successfully in stroke rehabilitation and involves four stages: (1) goal negotiation; (2) goal setting; (3) action planning and coping planning; and (4) appraisal and feedback (Scobbie et al., 2016; Brown et al., 2022). Goals are treated as broad, overarching aims, such as returning to work, while action planning involves determining the specific, sequential steps needed to reach the goal. Patients are encouraged to consider what support they may need to carry out plans, any potential barriers, and strategies for dealing with setbacks. The process of appraisal and feedback is particularly important to allow for reflection and recalibration of goals based on progress, which may include adjusting a goal or creating a new one (Scobbie et al., 2021).

Workshop 2

In workshop 2, partners reviewed and provided feedback on the draft. For example, it was suggested to emphasise fatigue as ‘unexplained, overwhelming exhaustion’ and avoid the term ‘tiredness’ to avoid misconceptions. Partners suggested adding example patient stories to make information more relevant. Partners valued the G-AP framework, particularly the inclusion of a diagram to visualise the process. A full draft of the intervention was created based on collated feedback. Elements of MEAction’s (2020) Pacing and Management Guide for ME/CFS (myalgic encephalomyelitis/chronic fatigue syndrome) were adapted and included to support the ‘planning’ exercise, encouraging patients to think about priority, difficulty, person, and support for an activity.

Workshop 3

In workshop 3, partners reviewed the full draft of the intervention commenting on the accuracy of information, suggested activities, relevance to their specific needs, participant burden and readability, literacy level, and visual clarity. Minor adjustments were suggested for the format and wording of the content. Recommendations included, adding a summary at the start of each section to help reduce cognitive load and adding further interactive elements such as being able to tick off strategies used that day. Revisions were made based on the feedback, and partners reviewed and approved the final draft.

First draft

The first draft of FACT resulting from the workshops included information and interactive exercises (e.g. planning a series of activities and setting goals). Based on partner preferences, the material was presented in several formats, including a website, simply formatted and printable electronic documents, ‘bite-sized’ narrated and subtitled videos, and infographics. The website also included all other available formats to download. The topics covered included:

(1) Information about fatigue (covering effects, causes, and ‘measuring’ energy using a battery analogy)
(2) Managing your energy with the 5 Ps (priorities, pacing, planning, permission, position)
(3) Strategies for everyday life (covering physical activity; home life; leisure and relationships; work, study, and finances; thoughts and feelings; sleep and eating)
(4) Goal setting and making plans.

Two patients ‘stories’ reflecting common experiences were also included, in addition to information about fatigue for family and friends (including a child-appropriate version).

The draft intervention was designed to be self-directed, with users completing it at their own pace. Based on evidence from the umbrella review (Brown et al., 2023) and partner preferences, the format also included a call with a facilitator, intended to provide support with goal setting and using strategies. The draft intervention included completing a fatigue assessment scale at the start and end of the intervention period to assess any progress in self-reported fatigue. Both the Functional Assessment of Chronic Illness Therapy Fatigue Scale (FACIT-F; version 4) (Webster et al., 2003) and a modified version of the Inflammatory Bowel Disease-Fatigue Self-assessment scale (IBD-F) Czuber-Dochan et al., 2014) were included to allow assessment of the most suitable tool for use in the final intervention. Modifications to the IBD-F included replacing references to IBD with critical illness and removing IBD from the title. As previous systematic reviews have found a lack of evidence for any particular self-management intervention duration for other conditions (Brown et al., 2023; Eysenbach et al., 2011), a pragmatic choice was made to design FACT to be flexible – undertaken in a supported way with a facilitator for six weeks but with users able to continue using the tools as needed.

Phase 2: user testing

Participants

Four people experiencing fatigue after critical illness were recruited from a critical illness support group in the UK. No limitations were placed on time since hospital discharge. As there are currently no bespoke fatigue assessment scales for this population, for the purposes of recruitment to this initial user-testing, people who continued to self-report experiencing fatigue were included. All participants described severe exhaustion unrelieved by sleep.

Participants included one male and three females between the ages of 21 and 63. Three participants identified their ethnicity as white and one as mixed heritage. Two of the four participants were married or partnered, and three were in employment. Diagnosis resulting in ICU admission included sepsis ($n = 1$), COVID-19 ($n = 2$), and cardiac arrest ($n = 1$). Days in ICU ranged from 7 to 97 days (mean = 35.5), and time since discharge (at the time of interview) ranged from 6 to 27 months (mean = 20.25). Three of the four participants had no significant past medical history prior to their critical illness.

User testing procedure

Participants used the FACT draft intervention for a period of two weeks; although shorter than the planned duration in clinical use, it was considered sufficient for participants to be able to try out and comment on features of the intervention. They had a 30-minute support call from one of the researchers [LS] acting as a facilitator in week 2. Participants had the option of using the intervention either via the website or the downloadable and printable booklets. Participants completed both the FACIT-F and the modified IBD-F at the start and end of the two-week period to assess participant preferences, with a view to one being selected for inclusion in the final intervention.

Data collection and analysis

Participants took part in semi-structured interviews lasting between 30 and 60 min. The format was informed by cognitive interviewing (Wolcott and Lobczowski, 2021), involving prompting participants to describe their impressions of the intervention, experience of using it, and any suggested changes. The interviews were conducted in this way to allow participants to respond to the intervention and their experience of it, commenting on both general and specific aspects of the design and use of the of FACT. The interview questions are available in Supplementary File 2. Interviews took place over Zoom and were audio recorded and transcribed verbatim. Interview data were stored on NVivo 12. Qualitative content analysis was performed, with data deductively mapped against the key themes of content, feasibility, and format and codes generated within these themes. Corresponding categories and subcategories were generated based on the codes. The MoSCoW tool (Kuhn, 2009) was used to prioritise all changes suggested in the interviews (M – Must have; S – Should have; C – Could have; W – Would like if time permits), and the first draft of the intervention was revised accordingly.

Findings

Data were grouped under three themes: content, format, and feasibility (see Table 1). It is important to note that participants’ experiences of the intervention and their opinions of its acceptability and usefulness will have been influenced by variations in age, length of stay in ICU, and time since hospital discharge. Differences in experiences are reflected in the range of opinions and suggestions expressed.

Content

Participants found the content easy to understand and pitched at the correct level to allow users to take what they needed. One participant also commented that the positive tone of the content was encouraging. All participants appreciated the information for family and friends and

Table 1
FACT user testing analysis summary.

Themes	Categories	Sub-categories	Example participant comments
Content	Information	Family and friends	*P1: …it was nice to have that breakdown to show them, be like I can't say it very well but this is exactly what's happening, and it was really helpful for me to be able to do that.* *P3: I mean you don't feel you can ask support from somebody that doesn't understand … so yeah I mean I think it's so important to do that.*
		Fatigue analogies	*P3: …the spoon theory, which I understand it but they (family) just would zone out. Whereas the mobile phone I think is really good, because everybody can immediately picture that frustration of an old phone that just doesn't hold its charge.*
		Relatability	*P1: I think as like a first thing, like it's amazing and it's so well targeted to kind of a big group, it's not like fatigue affects everyone the same.* *P2: It (explanations of fatigue and effects/causes) was just helpful to feel like I wasn't alone, and what I was experiencing was normal, because you need that reminder to get yourself out of the rut.*
		Sources of support	*P3: So one thing I don't think is mentioned in this is the impact of PTSD on fatigue … that would be useful, I think.* *P4: More sort of links towards mental health, you know, how you could say to yourself, well am I normal or is this normal.*
		Work circumstances	*P3: I have to work for as long as I need to for the work to be done, which because we work at home it can be late into the evening, when actually I just want to curl up in a corner.* *P3: I find it quite frustrating that that [being self-employed] gets overlooked, that there isn't a return-to-work policy, there isn't the option of having phased return, there isn't the options of part time work, you've just got to get on with it.*
	Strategies and activities	The 5 Ps	*P2: … pacing was the only thing that's really helped me get to where I am right now. Just I think breaking stuff up, and then knowing when you're gonna have to say no to people, I mean it's hard.* *P3: I'm in a very busy household, multitasking, constantly spinning plates, so to give yourself permission to actually it's OK to have a ready meal tonight, it's OK to sit on the sofa for half an hour during the day.*
		Daily living	*P3: I think when people are so fatigued and you get that downward spiral, and the thought of having to cook a meal like you used to do… ideas, suggestions, strategies on healthy nutrition to support fatigue, but in a way that is manageable, that would be quite useful.* *P2: There were some key parts about meeting people, like your friends and stuff, like going into restaurants, like making sure to be in a place where it's not so stimulating and loud to help the fatigue, that was something new that I learned.*
		Goal setting	*P1: …sometimes you're like, I have no idea where to start with this. Whereas giving you like a nice structure was super helpful, especially for me, because I like to have a plan.* *P2: …this was a helpful reminder, and to get myself out of a rut, it was sometimes, when you're so fatigued you don't feel motivated, so it helps me to be motivated.*
	Tone and language		*P1: I kind of felt that everything was covered quite nicely, and I think in the fact as well everything was quite positive, because I think sometimes when you talk about this stuff it can be like oh, well you're not where you want to be yet, and it can kind of get very like dark and like damper.* *P1: I think it (the language) was perfect for me because obviously you can take what you want from that information anyway, but I think leaving it at a base level, that's like leaving it out to interpretation, because you're always winning with that.*
	Fatigue scales		*P2: It gives you a picture of where you're at, and I find them helpful … Yeah, and then it helps you keep doing goals.* *P3: I think in the questionnaires it asks about do you feel you need to have a rest during the day or sleep, I would have said yes but can't … I think if I lived on my own, if I worked on my own, I'd do things differently.*
Format	Intervention structure		*P1: I think it was a good way of kind of like gradually easing in, kind of the first bit was kind of based on yourself, and then it kind of branched out into kind of how to deal with that in your everyday life and other people and kind of how to put that into everyday life situations, so I think it was structured very well.* *P4: …there needs to be little sort of stops at certain stages, just to recap or encapsulate what's happened or gone on, and are you OK with going on to the next.* *P4: I think if we could do it more sort of, not so much bullet points, but more sort of how is your fatigue affecting your life currently? Has that improved or deteriorated? Go to this page or look at this.*
	Presentation and design		*P1: I really liked the way, like if I talk about the website, that that was laid out, that it was super easy to navigate, like each thing, it was easy to work through as well.* *P1: I think I broke it down into two evenings, so I split all the reading, and I'm dyslexic so it was good that the videos were there for me as well, so I really enjoyed having those on, which really helped me.* *P3: It's nice to have the different formats, stuff you can print off and keep and read, but also the videos, you hear it as well as read it.*
	Alternative formats		*P1: …perhaps you could just do like one PDF with all the information on, like a downloadable resource so that it's all in one place for people to kind of refer back to.* *P3: I think when you've got this sort of tendency for too much information be overwhelming and you just sort of shut down, I think it was fine for me [paper version], easily set out.*
	Support call		*P1: I think even just kind of talking it through … I mean we focused a lot in my call about the goal setting, that was kind of like our main focus … Then after that call I was like yeah, OK, I know what I'm doing now, like I've kind of got the process and now I can take it on my own.* *P3: I think it was nice to have it halfway through it, because it gave me time to have looked at the stuff, the information and questions, but also to see how it resonated with your own situation.* *P3: I got a bit emotional afterwards because I think just to hear that it is real … and not to underestimate it I think … So yeah, that was the thing I came off with, feeling slightly emotional but validated and felt stronger.*
	Timing	Discharge support or information received	*P3: So in my journey there's been no point where I would have seen a health professional that may have provided this information … I'm struggling with memory, dropping stuff, why am I so exhausted all the time? I haven't had that opportunity to ask those sort of questions.* *P4: …community nurses and physiotherapists, nobody really touched on about fatigue or really feeling down and depressed.*
		Pace	*P1: …the fact that it was kind of nicely paced as well, it wasn't like reading through the information really quickly, the fact that kind of you could go through it and process it at the same time as it was saying it.*

(*continued on next page*)

Table 1 (*continued*)

Themes	Categories	Sub-categories	Example participant comments
		When to start	*P1: I think that it was kind of perfect timing for me, because I mean once you've gone through the information, you've downloaded the resources, like then you've kind of got everything you need in terms of that* *P1: I think that the initial information would be good when you leave hospital.* *P3: From my point of view, as a patient, because I was so ill, I don't think I would have started to look for this information until about sort of 3 to 6 months.*
Feasibility	Accessing the intervention		*P3: … it does depend geographically where people are as to what support people get.* *P4: …it needs to be put forward as a package for community nurses, physiotherapists, occupational therapists, re-enablement teams to pick up on it.*
	Time and energy commitment		*P1: …that's another thing with fatigue, you can obviously quickly lose routine … so I think by having a routine with this it gives at least something to kind of stick to … if you know that each day you're gonna kind of set out your goals or you're gonna try and look through your week, I think that's super helpful.* *P4: …you have to be ready for it, you have to be psychologically, physically ready to take that on board. It's a commitment, isn't it.*

thought that it would be useful to support conversations with others. They highlighted the additional challenges that arise in trying to manage fatigue when others are unsupportive due to a lack of understanding. One participant particularly noted the usefulness of information coming from a 'professional source', as this could be seen as more objective and helped to highlight the difference between tiredness and fatigue.

Participants found that the information was relatable and relevant to their own situation. The information about fatigue was also felt to be validating, confirming their own experiences and helping them feel less alone. One participant noted that reading the fictionalised patient stories could be triggering to some, highlighting the importance of giving users forewarning of potentially emotionally challenging content. Participants found the signposting to sources of support helpful but also suggested including additional resources, such as more information on post-traumatic stress disorder (PTSD) and general mental health after critical illness.

While the signposting to resources for work, study, and benefits was considered useful, one participant described the added challenge of being self-employed, as they could not access the support systems suggested in the interventions. Fatigue affected their confidence and made it difficult to manage the workload and irregular hours required. This highlighted the need to clearly acknowledge diverse employment circumstances and ensure that suitable strategies are provided in the absence of employer or government support.

Participants described the strategies (e.g. the 5 Ps, tips for daily living, goal setting) and activities (e.g. practising prioritising and planning) as helpful for managing fatigue. Participants highlighted the benefits of being able to break down planning into smaller steps, to avoid it becoming overwhelming, and of using the priority exercise to support day-to-day planning.

Strategies for daily living (e.g. for cooking and cleaning, leisure, and relationships) were helpful and resonated with participants. Some already used several of the strategies suggested, but still felt that the content was relevant. It was suggested to add more content on nutrition, including diet and managing food preparation, because of its relationship to fatigue. Participants found the goal setting straightforward and felt it would be motivating and useful for tracking progress over time. One participant highlighted the step-by-step structure of the goal setting instructions and activity as particularly helpful to avoid feeling overwhelmed.

Participants completed both the FACIT-F and modified IBD-F at the beginning and end of the intervention, and there was no preference for either tool, though it was noted that they could be formatted in a simpler way to make it easier to complete in stages. They felt that the scales would be helpful to track progress, and one participant suggested that shorter appraisals could also be completed throughout the intervention period (e.g. every two weeks) to allow users to see their progress throughout.

Format

The format was found to be straightforward and helpful overall. Participants reported that the intervention was well structured and easy to navigate and appreciated the range of formats. Participants found that the intervention was well paced and appreciated that the content was broken down into individual topics, making it easier to engage with in short sessions at their own pace. Most participants exclusively used the website, with one using both the website and the downloadable booklets. They found the website visually appealing and easy to navigate. All engaged with both the videos and the text and found it useful to have the combination to reduce cognitive effort. One participant suggested that it may be useful to add podcasts with health professionals and patients as a further way to engage with fatigue management.

All participants described the support call in week 2 of the intervention as very helpful. They reported that it helped them to reflect on the strategies and their fatigue and validated their experiences. While not all participants used the calls for specific goal setting, those that did found it useful to talk through the process and receive tailored guidance. All participants highlighted that more than one call would be needed across the intervention to discuss the information and their circumstances and to check in. Two participants also felt that there was potential for group calls or meetings with other intervention users to provide peer support.

Most participants described a general lack of information or support in their own experience of critical illness at discharge and beyond. All participants said that they would not have been ready to engage in the intervention immediately at discharge. However, having access to information early in recovery was considered important, and it was suggested that patients could be provided with basic information about fatigue and recovery only (rather than the full intervention) at discharge to know what to expect.

One participant also suggested giving information to family while their loved one is still in hospital to prepare them for the more 'invisible' challenges that can persist (such as fatigue) beyond the more obvious 'physical' recovery. This is supported by existing work providing patients and families with a critical illness information pack at discharge (Bench et al., 2015). It was noted that multiple opportunities to engage may be needed to accommodate different recovery experiences, particularly with severe fatigue and brain fog. One participant suggested that the timing should be left to individuals, allowing them to access the intervention as needed.

Feasibility

Participants found the intervention straightforward to use and were able to fit it around their usual schedules and energy levels. This was supported by instructions early in the intervention material encouraging users to move at their own pace and engage in a way that suited them.

However, it was also noted that patients need to be ready to both initiate and use the intervention, making it important for patients to be given the option of when to engage. One participant highlighted that the intervention structure supported building it into a routine, which helped to engage consistently. It was suggested that the intervention should be initiated and managed by a healthcare team so that patients are not left to find support on their own; however, in order to ensure that the intervention is feasible for the largest number of people, it will not be restricted only to those accessing supported recovery and rehabilitation.

Final draft

A summary of modifications made to the intervention is in Table 2, based on changes deemed 'Must have' and 'Should have'. The final draft includes minor adjustments to the content of the first draft, including further signposting to mental health support resources and strategies for nutrition. As no preference was expressed for either the FACIT-F or IBD-F assessment tools, both will be explored further in future feasibility testing.

The final draft is summarised in Table 3. The intervention is designed to be completed via four key topics over a six-week period with facilitator support but may continue to be used over a longer period. Based on participant preferences, two support calls will be provided in the fully supported version with the aim of allowing users to first orient themselves to the intervention and plan goals in week 2 and later 'check in' with the facilitator to reflect and discuss progress in week 6. However, the intervention can also be used fully independently without facilitator support, which will allow it to be available to the widest range of users.

Both the website and electronic document versions contain the same information. The material starts with a welcome page with an explanation of the intervention and instructions for use. Users are encouraged to proceed through the topics in the order that they are presented, at their own pace, but can choose what to engage with based on relevance to their needs. Topic 1 covers information about fatigue after critical illness, including effects, causes and triggers, an analogy to explain fatigue using a low battery, and a fictionalised patient story. Topic 2 focuses on using the 5 Ps to manage energy, with brief 'tips' for each P, a 'checking in' page inviting users to reflect on their use of the 5 Ps, and another patient story. Topic 3 covers strategies for everyday life, with specific examples, and topic 4 focuses on goal setting and making plans, encouraging users to think about what is important to them and how they can work towards that.

The information on each website page is presented both as text and in the form of a short, narrated video with images. Links to further resources are provided throughout, with reminders to discuss any concerns with HCPs. Information for family and friends is available as a downloadable electronic documents, videos, and infographics (one general and one for children).

Users will complete a formal fatigue assessment at the beginning and end of the intervention, with shorter prompts after completion of each topic to reflect on how they feel and how they are using the strategies. Supportive messages will also appear as users move through the intervention, encouraging them on their progress and prompting them to continue to the next topic. The interactive activities, such as planning, goal setting, and fatigue assessment, will be embedded into the website with data analytics to allow users to see their progress easily. However, users will also still have access to alternative formats if preferred.

Discussion

This article reports the process of the co-production of a self-management intervention for people with fatigue after critical illness and the results of some initial user testing. The feasibility and acceptability of conducting a randomised controlled trial evaluating the FACT intervention will be tested in the future. Suitable outcome measures will be explored during the feasibility trial, however, in accordance with self-regulation theory, it is predicted that this intervention will primarily improve coping, potentially leading to a subsequent improvement in HRQoL.

User involvement is increasingly recognised as invaluable to improve the relevance and acceptability of health research (Skivington et al., 2021) and has been used successfully in the development of behavioural health interventions for other conditions (Foster et al., 2015; Dack et al., 2019; Jones et al., 2016). The co-production of complex interventions in a population with complex needs is pragmatically and conceptually challenging. Ensuring equity of power and decision making within all co-production activities is critical to its success, however, may be difficult to operationalise (Madden et al., 2020). The complex needs of our patient partners, their ongoing fatigue and other health needs, presented further challenges. We adopted a flexible and compassionate approach to the design of this study to effectively accommodate patient and carer partners' needs. Valuing patients, carers, and healthcare professionals as partners ensured that the intervention was informed by the needs of future users.

Implications for clinical practice

FACT intervention shows promise in improving coping and self-management skills of people experiencing fatigue after critical illness, thereby supporting better quality of life. Fatigue is not well recognised by HCPs and is often under-reported (Morel et al., 2022). The intervention therefore has the potential to raise awareness of fatigue as a consequence of critical illness, leading to more patients accessing support for their symptoms. Finally, FACT can act as an educational tool for healthcare professionals involved in post-critical care management, providing them with strategies to share with patients.

Limitations and future research

While partners in phase 1 of this study had the opportunity to contribute either during the workshops or via email, not all were able to give feedback on each draft due to other commitments. The time and energy commitment required, particularly for those experiencing fatigue or chronic illness, should therefore be considered when developing future interventions.

It is important to acknowledge that three of the user testing participants were more than one year post critical illness and had therefore already developed some coping strategies. However, none had previously accessed a fatigue management intervention or formal support from a healthcare team and continued to experience fatigue. Their feedback illustrates the potential usefulness of FACT at any stage of recovery. Future feasibility research will test the intervention with people at discharge from ICU to determine any additional support needs.

As highlighted in previous reviews, there is a lack of evidence for fatigue management approaches in people recovering from critical illness (Bench et al., 2021a). The initial draft was therefore informed by low-level evidence for the effectiveness of self-management in physical conditions such as cancer. In the absence of clear evidence some pragmatic decisions were made relating to content and format of the intervention in partnership with people with direct experience of living with or supporting fatigue after critical illness.

Conclusions

This article reports the co-production of a novel fatigue self-management intervention in partnership with patients, carers, and HCPs and results of preliminary user testing. This method proved feasible and resulted in a draft that was acceptable and straightforward to use. Flexible options for engaging with FACT make it suitable for a population who can have unpredictable energy levels over long periods of time.

The methods described illustrate the benefits of user partnerships in

Table 2
Modifications to FACT based on participant feedback from interviews.

Code/suggested change	Change made
Add link to ICUSteps groups for family	Link to ICUSteps family support groups added to sections on relationships/friends and family
Add more strategies for nutrition	More information and signposting to other resources added to 'Strategies for everyday life'
Add more ways to relax	Further examples added to 'Strategies for everyday life'
Build in checkpoints and encouragement	To be built into the website
Fatigue scales could be formatted more clearly	Blank space increased to allow for distinct sections and make it easier to read or complete in chunks
Family video is too long	Split into two videos: (1) information about fatigue and (2) tips for supporting
Have a single downloadable version	Separate booklets compiled into a single PDF, but separate booklets kept to provide a range of options
Include more information on mental health and PTSD	Further signposting to support services/resources included
Lack of information or support if self-employed	Acknowledgement of added challenges when self-employed and signpost to planning/pacing strategies
More examples of support	More examples added to 'Strategies for everyday life'; information about GP social prescribing added to leisure and physical activity sections
Multiple calls needed	Second support call to be added at end of intervention period
Patient stories and support call could be triggering	Information on patient stories page that content could trigger unpleasant memories; information also added that people may want someone with them for the support call
Smart speakers help and could be added	Added as an example of tools in 'Strategies for everyday life'
Would help to have both spoon and battery analogies	Spoon theory analogy included so that users can choose what resonates

Table 3
FACT final draft intervention content.

Topic	Content	Format
1. About fatigue	**Effects, causes, and triggers** - Information about fatigue **Measuring your energy** - Battery and spoon theory analogies to visualise energy levels **Lara's story** - Fictionalised patient story	- Text - Videos - Infographic (measuring your energy)
2. Managing your energy with the 5 Ps	**Priorities** - How to decide on priorities with examples - Tip for making a record of what's important to the person **Pacing** - How to use pacing to conserve energy - Tip for keeping a record of how certain activities affect energy levels **Planning** - How to plan using 'priority, difficulty, person, and support' - Activity to practise planning - Tip for using a planner to visualise the week **Permission** - Encouragement to give yourself permission to do or not do an activity and to ask for support if available - Tip for having back-up plans in case too fatigued for a planned activity **Position** - How to use physical position to conserve energy - Tip for having notes around the house as reminders to adjust position	- Text - Videos - Activity - Infographic
3. Strategies for everyday life	**Physical activity** - Encouragement to do suitable light movement - Examples of gentle activity and supports **Home life** - Housework (e.g. cooking, cleaning, looking after pets) - Day-to-day admin (e.g. appointments and schedules) **Leisure and relationships** - Tips for adjusting activities - Sharing the information for family and friends **Work, study, and finances** - Returning to work or study - Accessing supports for returning to work or study (links to resources)	- Text - Videos - Infographics (information for family and friends; children's infographic)

(*continued on next page*)

Table 3 (*continued*)

Topic	Content	Format
	- Advice on employment law (links to resources) - Benefits (links to resources) - Financial advice (links to resources) **Thoughts and feelings** - Encouragement to talk to others about difficult feelings (e.g. healthcare team) - Examples of restful activities (e.g. mindfulness) - Link to access support groups **Sleep and eating** - How sleep and eating can be affected by fatigue - Advice for sleep hygiene - Strategies for maintaining nutrition when fatigued	
4. Goal setting and making plans	**What is goal setting?** - How to conceptualise goal setting using the four stages of the Goal Setting and Action Planning (G-AP) process **Goal examples** - Three examples of goals, including an overall goal, steps to get there, and supports or adjustments **My goals** - Activity to consider and record personal goals	- Text - Videos - Activity

intervention development and that flexibility is key to supporting the involvement of people with fatigue.

This study advances the literature on fatigue management after critical illness and provides a model for developing self-management interventions in partnership with people living with fatigue after critical illness and those who support them.

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Ethical statement

Ethical approval for the FACT intervention study was obtained from the Oxford Brookes University Ethics Committee (ref 221611). All stakeholders and participants gave informed consent to take part in the study.

CRediT authorship contribution statement

Sophie Eleanor Brown: Data curation, Writing – original draft, Writing – review & editing, Visualization, Investigation, Formal analysis, Project administration, Software. **Akshay Shah:** Conceptualization, Funding acquisition, Data curation, Writing – review & editing, Supervision. **Wladyslawa Czuber-Dochan:** Conceptualization, Funding acquisition, Methodology, Writing – review & editing. **Suzanne Bench:** Conceptualization, Funding acquisition, Data curation, Writing – review & editing, Analysis, Supervision. **Louise Stayt:** Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Writing – review & editing, Funding acquisition.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper. One of the authors (SB) is an Associate-Editor for Intensive & Critical Care Nursing and was not involved in the editorial review or the decision to publish this article.

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Appendix A. Supplementary data

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