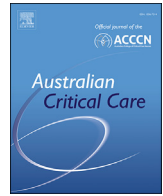




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Research paper

Using patient and care partner experiences to confirm outcomes of relevance for inclusion in a core outcome set for trials of physical rehabilitation in critical illness: A qualitative interview study



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ABSTRACT

Background: Incorporating the perspectives of patients and care partners is crucial in the development of core outcome sets. One effective approach for achieving this involvement is by seeking input to refine the outcomes for consensus.

The objectives of the study were to: i) to determine patient and care partner views on outcomes that should be measured in trials of physical rehabilitation interventions across the critical illness recovery continuum; (ii) to map these views with a pre-established list of thirty outcomes for potential inclusion in a core outcome set for these trials; and (iii) to identify any new outcomes that could be considered for inclusion.

Methods: A qualitative semistructured telephone interview study was conducted with a convenience sample of post-critical illness patients and care partners, as part of core outcome set development work. Anonymised interview transcripts were analysed using a framework approach, and exemplary narrative quotes from participants were reported used to illustrate outcome reporting.

Findings: Fourteen participants were recruited (male:female ratio = 8:6, age range [minimum–maximum]: 50–80 years, 13 former patients, one spouse). Time since intensive care unit discharge ranged from less than 1 year to 10 years at the time of interview. Participants described a range of outcomes that could be measured in trials of physical rehabilitation after critical illness that mapped closely with the pre-established list. No new outcomes were introduced by participants during the interviews. Experiences described by participants commonly reflected outcomes related to physical ability and performance, functional level, activities of daily living, and emotional and mental wellbeing. Participants spoke to how the different outcomes directly impacted their day-to-day lives and highlighted their priorities centred around resumption of tasks and activities that had value to them at personal, functional, and societal level.

Conclusion: Qualitative interviews confirmed the relevance of existing outcomes for potential inclusion in a core outcome set for trials of physical rehabilitation interventions across the critical illness recovery continuum. The added significance of our findings is to provide real-world meaning to these outcomes. **Registration:** COMET Initiative, ID288, <https://www.comet-initiative.org/studies/details/288>.

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1. Introduction

Quality of survival following critical illness is central to patients' and care partners' experiences of recovery, and appreciating this experience is vital for clinicians and researchers to inform how best to design interventions to support the journey of survivorship. In keeping with this, incorporating the perspectives of patients and care partners is crucial in the development of core outcome sets.^{1,2} Core outcome sets reflect agreed sets of outcomes for measurement across all trials of interventions focussing on a particular topic,³ and a number already exist in relation to optimising the management of critically ill patients during the acute stages of illness and during recovery.^{4–6}

Development of a core outcome set for trials of physical rehabilitation interventions across the critical illness recovery continuum is currently underway.⁷ As part of this process, a list of outcomes for potential inclusion was identified through systematic reviews of quantitative,⁸ and qualitative,⁹ literature. Outcomes from quantitative literature were those reported in studies evaluating physical rehabilitation interventions in critical illness, and those from qualitative literature were identified from patient and care partner reports of experience of recovery and physical rehabilitation following critical illness. Outcomes from these literature sources underwent deduplication and removal of redundancy, and revision and refinement by the core outcome set team, to form a list of 30 outcomes that were supplemented by a brief explanatory descriptor and classified into domains and areas according to an established taxonomy specific for core outcome set development.¹⁰

The unique perspectives of patients and care partners may enable identification of priority outcomes not previously or traditionally considered by clinicians and researchers¹¹ and ensure meaningful relevance of findings. We therefore conducted this study to confirm our process for developing our core outcome set was sufficiently rigorous and met methodological recommendations³ and that the ultimate core outcome set would have maximum applicability and relevance to researchers delivering future trials of physical rehabilitation across the critical illness recovery continuum, as well as those patients and care partners involved in receipt of interventions. Crucially, recovery and rehabilitation following critical illness is highly individual due to the heterogenous nature of critical illness; we wanted to facilitate an active patient and care partner voice in our work to represent some of these diverse experiences. The objectives of this study were therefore to (i) determine patient and care partner views on outcomes that should be measured in trials of physical rehabilitation after critical illness; (ii) map these views with the pre-established list of 30 outcomes; and (iii) identify any new outcomes that could be considered for inclusion in the core set.

2. Methods

2.1. Research team, study design, and setting

This study involved semistructured interviews with former critically ill patients and care partners (people who are non-healthcare professionals, with current or past experiences of providing care for a person after critical illness, e.g., family members, loved ones, or friends)¹² and is reported using the Consolidated criteria for reporting qualitative research reporting guideline.¹³ This qualitative study was part of a wider programme of work, developing a core outcome set to standardise outcomes for physical rehabilitation trials in critical care.⁷ Patient- and family-centred interviews are an important part of core outcome set development to ensure the outcomes being considered are relevant to people's experiences.^{14–16} The study is registered as part of a core

outcome set development project on the COMET Initiative, ID288, <https://www.comet-initiative.org/studies/details/288>. Interviews were conducted by a highly experienced clinical academic consultant, PhD-level, (female) physiotherapist working and researching in physical rehabilitation and follow-up of this patient population, and with training in qualitative research methods (BC), overseen by an expert qualitative researcher (NP). Interviews were conducted by telephone, at a convenient time and date, for pragmatic ease to avoid the need for participants to attend a hospital, university, or other physical setting in person to participate.

2.2. Participant recruitment and selection

A convenience sample of participants were recruited through advertisement via UK patient and care partner support groups, local registers at the study site of former patient research participants who had indicated consent to be contacted for future studies or who were patient members of the local study-site research advisory group, snowballing, social media, and existing patient/care partners who had expressed interest for participation in the consensus stage of developing the physical rehabilitation core outcome set. Eligible participants were adult (≥ 18 years of age), former patients or care partners with experience of critical illness, able to recall the critical illness recovery process (either within the intensive care unit [ICU], or following discharge to the ward, or following hospital discharge) including the role of physical rehabilitation, and able to provide informed consent. Participants with cognitive impairment were excluded, and those unable to converse in English, with lack of telephone communication, or who were admitted to the ICU during pregnancy or with neurological, e.g., stroke and acquired brain injury, or traumatic, e.g., amputation, multiple fractures, injury.

2.3. Data collection

A single telephone interview was conducted with each participant. The lead researcher (BC) provided background of their role and a brief reiteration of the study context, aims, and relevant conceptual content, which mirrored content from the participant sheet thus demonstrating credibility.¹⁷ No other researcher was present during interviews, but participants were able to have a chosen individual present with them should they wish, e.g., family member. A topic guide was used that had been iteratively developed and refined by BC and NP (Supplementary File, Section S1). This topic guide drew on the prior work conducted in the Delphi and the outcomes from the qualitative metasynthesis,^{9,14} centring on key outcomes from those elements of the work programme, as per good conduct in core outcome set development.¹⁵ This topic guide encompassed questions around physical recovery and rehabilitation after critical illness, information around outcomes of importance, and ended with the opportunity for participants to offer any additional comments of perceived value in relation to the topic. Prompts were used if necessary to acquire richer data and more information about a topic. The interview approach allowed use of a structure to guide discussion of pertinent topics with participants but with flexibility to enable broad dialogue. Interviews were audio-recorded with participants' permission, and audio files were independently transcribed. Field notes made by the lead researcher (BC) were used to provide nonverbal contextual information to supplement the transcription where necessary.

2.4. Analysis

Participants were given an identification code denoting their interview number for referencing quotes. A framework analysis approach was adopted, involving the following stages:^{18–22}

- i) *Familiarisation*: Two researchers (BC, RMC) iteratively read all interview transcripts to gain content familiarity.
- ii) *Developing the coding framework*: the coding framework comprised the pre-existing list of 30 outcomes developed specifically for potential inclusion in the core outcome set, following the systematic reviews of quantitative⁸ and qualitative⁹ literature, and reported in Table 1. The outcomes were organised according to area and domain of classification.
- iii) *Coding interview data*: One researcher (RMC) identified and highlighted any interview content pertaining to outcomes in the framework. A 'key-word-in-context' approach (as used in Content Analysis²³) was included within this coding to ensure that salient outcomes could be identified and used within the developing framework. Content that could represent other outcomes in relation to recovery and physical rehabilitation after critical illness and that could potentially be included in the core outcome set was also highlighted. Data were compared across the core categories developed. Details pertaining to participants' primary medical diagnoses, illness severity, and/or clinical care/medical management (e.g., investigations, medical procedures) were not extracted as this was outside the remit of the study. This process was independently duplicated by the lead researcher (BC). A third researcher (NP) read a random sample ($n = 4$, approximately 30%) of the transcripts and cross-checked findings for accuracy, dependability, and transferability, adding supplementary content and comments where necessary.¹⁷ The in-depth and prolonged engagement with the data further enhanced credibility, along with transparency in analytical decision-making processes (confirmability).²⁴
- iv) *Charting the data*: A matrix depicting outcome reporting across individual participants was created and summarised across all participants in tabular format; data were descriptively summarised using counts and percentages. Exemplar narrative quotes from interviews were used to illustrate outcome reporting.
- v) *Mapping and interpretation with any coding refinements*: Data were explored for concepts, patterns, connections, or explanatory themes.

2.5. Ethical approval and informed consent

This study was approved by King's College London BDM (Biomedical Sciences, Medicine, Dentistry, and Natural and Mathematical Sciences) Research Ethics Panel (LRS-17/18-4603). All participants had contact with the lead researcher (BC) during the recruitment process, were provided with an information sheet before participation, and had the opportunity to discuss any queries in advance. At interview, verbal consent was obtained and recorded, with a written confirmation copy of the consent form provided after the interview (either in electronic, paper, or both, formats) via a preaddressed envelope.

3. Findings

3.1. Participants

Fourteen participants were recruited between March 2018 and April 2019 (male:female ratio = 8:6, age range [minimum–maximum]: 50–80 years). All but one participant (who was a care partner, a spouse) were former patients. Four participants were employed, two were not working on medical grounds, and

eight were retired. The time since discharge from the ICU to interview ranged from <1 year to 10 years. Interviews ranged between 30 and 60 min, with no repeat interviews conducted with any participants and no participant withdrawals from the study.

3.2. Framework analysis findings

Of the 30 outcomes included in the framework, 26 were reported across participants, with four (joint function, reintubation, frailty, sexual relationships) not being featured. Participants reported a median (interquartile range) of 13 (12–13) outcomes each, with a range (minimum–maximum) of 11–17. Salience, frequency, and key-word-in-context of reporting of all 30 outcomes are detailed in Table 2. We not only mapped across the core outcomes identified from our previous work but also tried to draw out relevant wording from participants that might be distinct from the *a priori* categories (as outlined in the analysis section).¹⁵

All participants ($n = 14$, 100%) described the outcomes of 'Muscle and/or motor nerve function' and 'Physical function', and 13 participants (92.9%) described experience related to 'Activities of daily living', 'Emotional and mental wellbeing', 'Healthcare resource utilisation', and 'Patient experience of physical rehabilitation'. 'Exercise capacity', 'Place of residence', 'Health-related quality of life', and 'Social roles, activities, or relationships' were all reported by at least 10 participants. The 10 most frequently reported outcomes are illustrated with exemplar quotes in Table 3. Outcomes reported by only one (7.1%) participant included 'Communication difficulties', 'Duration of mechanical ventilation', 'Financial impact on patient', and 'Urinary function'. Lesser frequently reported outcomes are characterised with exemplar quotes in Table 4. A matrix of individual presentations of participants' outcomes is presented in Table 5. Participants did not describe any new outcomes that could not be mapped to the existing framework categories.

4. Discussion

This qualitative study explored the experiences of patients and one care partner following critical illness specifically in the context of confirming the relevance of a list of outcomes for potential inclusion in a core outcome set for trials of physical rehabilitation after critical illness. The majority of outcomes were corroborated with narrative examples, which highlighted their real-life meaning and impact for participants. Participants did not describe any new content that reflected additional outcomes for consideration in the core outcome set.

4.1. Clinical significance

Post-intensive care syndrome has evolved since its first inception, describing new or worsening impairment across physical, cognitive, or mental health facets in survivors of critical illness, and in mental health for family members.²⁵ Over a decade later, the expansion of post-intensive care syndromemeans that it may be considered more an umbrella term encapsulating wide-ranging, multidomain impairment spanning additional components such as swallow disorders, fatigue, sleep disruption, pain, reduced health-related quality of life, financial consequences (including return to work), social problems, and increased healthcare resource utilisation.²⁶ Certainly our list of 30 outcomes within this study, drawn from searches of the quantitative⁸ and qualitative⁹ literature, reflects this evolution. When classified according to an established taxonomy, these outcomes spanned four areas (Death, Physiological/Clinical, Life Impact, Resource Use) and 18 domains.¹⁰

Table 1
Coding framework.

Area	Outcome	Domain	Descriptor
Death	Survival	Mortality/survival	Surviving (being alive) after ICU admission, hospital admission, or after hospital discharge
Physiological/clinical	Fatigue	General outcomes	An overwhelming, sustained feeling of exhaustion, mental or physical tiredness, having little energy for physical and mental work
	Pain	General outcomes	Any bodily pain
	Frailty	General outcomes	Decreased reserve (capacity) in an individual that may mean a stressful experience could have significant impact on health and wellbeing
	Exercise capacity	Musculoskeletal and connective tissue outcomes	Ability to carry out exercise, a person's level of fitness
	Muscle and/or motor nerve function	Musculoskeletal and connective tissue outcomes	Feeling weak, sore, or numb
	Joint function	Musculoskeletal and connective tissue outcomes	Stiff or aching joints
	Nutrition-related parameters	Metabolism and nutrition outcomes	Weight change, changes to appetite, changes to taste
	Respiratory (pulmonary) function and symptoms	Respiratory, thoracic and mediastinal outcomes	Trouble breathing, shortness of breath, coughing
	Gastrointestinal symptoms	Gastrointestinal outcomes	Nausea, vomiting, constipation
	Urinary function	Renal and urinary outcomes	Incontinence (frequency or urge)
	Delirium and related symptoms	Psychiatric outcomes	Having an episode of acute confusion, hallucinations, delusions, or nightmares
Life impact	Communication difficulties	Physical functioning	Problems communicating with others, e.g., by speech, writing, or gesture
	Sexual function	Physical functioning	Decreased desire to have sex, inability to have sex
	Activities of daily living	Physical functioning	Being able to complete usual everyday tasks including self-care, e.g., bathing, dressing, or feeding, or other activities, e.g., cooking, cleaning, managing finances, or shopping
	Physical function	Physical functioning	How well a person can perform physical functional activities, e.g., transferring from sitting to standing or from a bed to chair, walking, climbing stairs, or balance
	Swallowing function and symptoms	Physical functioning	Trouble swallowing food or liquids
	Sleep and related symptoms	Physical functioning	Trouble falling asleep, trouble staying asleep, changes to sleeping pattern
	Emotional and mental wellbeing	Emotional functioning/wellbeing	A person's mood, how often they worry, feel anxious, depressed or sad, how often they get angry or upset, and their self-esteem
	Cognitive function	Cognitive functioning	Problems with someone's memory, concentration, language, thinking, and ability to understand instructions
	Return to work or prior role	Role functioning	Returning to previous job (full-time or part-time), changing to a different job, doing the same thing you did before being in the ICU
	Health-related quality of life	Global quality of life	How well does a person feel about life; how much is a person's health affecting their quality of life
	Social roles, activities, or relationships	Social functioning	Connecting with others, maintaining friendships and romantic relationships, ability to join in activities with/for others
	Financial impact on patient	Personal circumstances	Dealing with hospital bills, lost income from time off work, paying for help with care at home or transportation
	Place of residence	Personal circumstances	The location where a patient is discharged to following treatment, e.g., home, acute care hospital, nursing home, specialist rehabilitation centre, assisted living
	Patient experience of physical rehabilitation	Delivery of care	What did patients think about, and how motivated were they to take part in, physical rehabilitation
Resource use	Duration of mechanical ventilation	Need for further intervention	Duration of time a patient spends being mechanically ventilated (using a breathing machine)
	Reintubation	Need for further intervention	Occasion where replacement of the breathing tube between the patient and the ventilator (breathing machine) is required
	Successful extubation	Need for further intervention	Occasion where the breathing tube between the patient and the ventilator (breathing machine) is successfully removed at a specified timepoint
	Healthcare resource utilisation	Economic	Seeing more doctors, physio/physical therapists or other healthcare clinicians, needing to be readmitted to the ICU or hospital, number of days spent in the ICU, hospital, or other healthcare setting

Legend: Thirty outcomes formed the coding framework, identified from systematic reviews of quantitative,⁸ and qualitative,⁹ literature, revised and refined by the core outcome set team; these outcomes were classified into domains and core areas according to an established taxonomy specific for core outcome set development,¹⁰ and accompanied by a brief explanatory descriptor.

Abbreviations: ICU, intensive care unit.

Table 2
Salience and frequency* of reporting of framework outcomes across participants.

Outcome	Salience and frequency* of reporting, n (%)
Muscle and/or motor nerve function	14 (100)
Physical function	14 (100)
Activities of daily living	13 (92.9)
Emotional and mental wellbeing	13 (92.9)
Healthcare resource utilisation	13 (92.9)
Patient experience of physical rehabilitation	13 (92.9)
Exercise capacity	12 (85.7)
Place of residence	12 (85.7)
Health-related quality of life	11 (78.6)
Social roles, activities, or relationships	10 (71.4)
Nutrition-related parameters	9 (64.3)
Cognitive function	8 (57.1)
Survival	8 (57.1)
Return to work or prior role	7 (50.0)
Delirium and related symptoms	5 (35.7)
Fatigue	4 (28.6)
Gastrointestinal symptoms	4 (28.6)
Pain	3 (21.4)
Respiratory (pulmonary) function and symptoms	3 (21.4)
Sleep and related symptoms	2 (14.3)
Successful extubation	2 (14.3)
Swallowing function and symptoms	2 (14.3)
Communication difficulties	1 (7.1)
Duration of mechanical ventilation	1 (7.1)
Financial impact on patient	1 (7.1)
Urinary function	1 (7.1)
Frailty	–
Reintubation	–
Sexual function	–
Joint function	–

Legend: *Frequency denotes key-word-in-context of outcome reporting across the 14 participants. Outcomes of frailty, reintubation, sexual function, and joint function were not reported by any participants.

Whilst we saw heterogeneity amongst our participants with regards to reported outcomes, there was commonality focussed around physical-based outcomes—muscle function and physical function,^{27–29} and activities of daily living,³⁰ with the former inherently needed for performance of the latter—as well as emotional and mental wellbeing,^{31–33} and healthcare resource utilisation.^{34–36} Nearly all participants also described their experience of participation in physical rehabilitation, which has previously been explored in the literature. Corner et al.³⁷ described the fundamental change in participants' sense of self as characteristic of critical illness survivor recollections of the early rehabilitation period, with that time marked by physical (weakness, fatigue, fractured sleep) and mental (impaired memory function and hallucinations) symptoms. Participants recalled dehumanisation of care and reliance on others for basic tasks, and the disconnect between perceived and real forms of themselves, but with the potential for rehabilitation to redress this imbalance and support recovery of autonomy.³⁷ Other themes around this topic have been reported by van Willigen et al.³⁸ including the importance of developing trust and rapport between patient and therapist, navigating the complex dynamic associated around the necessity of treatment (and therefore its potential value for recovery) versus the significant physical effort required, the psychological benefit that rehabilitation aligns to restoration of 'normal' function and provides a focus for recovery, and the challenges associated with setting meaningful goals to direct rehabilitation.

Even outcomes reported relatively infrequently by participants in the current study still reflect those that represent significant challenges as identified in larger populations of survivors of critical illness; for example, 'Swallowing function and symptoms'—dysphagia symptoms have been shown to continue in a third of patients and are exacerbated by increased length of ICU

stay,³⁹ 'Pain'—systematic review data demonstrate an incidence of persistent pain following ICU ranging 28%–77% of survivors,⁴⁰ and 'Sleep and related symptoms'—abnormal sleep is evident in up to approximately two-thirds of patients for more than 6 months following hospital discharge from critical illness.⁴¹

That participants did not describe any other outcomes for consideration in the list for the associated physical rehabilitation core outcome set is reflective that our existing list sufficiently captured the breadth of sequelae that survivors face and that may be relevant. This validation was methodologically valuable for the process of core outcome set development, as has been reported in previous similar studies.¹² However, the added significance of our findings is to provide *real-world* experiential meaning to those outcomes. Participants spoke to how those outcomes impacted them directly, and their narratives highlighted that their priorities centred around resumption of tasks and activities that had value to them at the personal, functional, and societal level, e.g., self-care, caring for children, returning to work, participating in social activities. Broadly, this would fit with an emphasis on 'Activity' (execution of a task or action by an individual) and 'Participation' (involvement in a life situation) categories⁴² and may have resonance for considering how outcomes are measured in the future. We observed that participants reported measurements of outcomes during their recovery and rehabilitation to be potentially extremely valuable for subjective (providing motivation, assurance, and morale regarding progression) and objective reasons (practical information to help benchmark achievement of tasks, goals, and milestones), but it was important this information was individualised and constructive for patients and delivered at appropriate times.

4.2. Strengths and limitations

Our study benefited from rigorous methods as part of a wider protocol for the development of a core outcome set for trials of physical rehabilitation interventions across the critical illness recovery continuum;⁷ our specific methods reflected the importance of patient and care partner involvement (although we recognise the limitations in having only one care partner in these interviews) in this process through eliciting their experiences as a key approach for informing potential outcomes for consideration.³ Other core outcome set developers have similarly used qualitative methods during preliminary stages of work, i.e., ahead of consensus methods, to inform generation of outcome lists.^{43–48} We removed participant familiarity as a potential source of bias by ensuring that participants were interviewed *de novo* without having seen the list of outcomes first; rather we explored what was important to them and then mapped this to the framework of outcomes to verify that we had not missed any relevant outcomes and that those that had already been identified had meaning to participants. Moving forwards, all 30 outcomes in the list will be included in the Delphi consensus process for developing the core outcome set, where patients and care partners will further contribute to rating the importance of these outcomes, in conjunction with other stakeholder groups of clinicians and researchers.

Our participant sample included only one care partner despite wide attempts to access greater numbers, and this may have influenced our findings with fewer 'voices' providing these perspectives. However, for the purposes of the current study, our final sample number was considered sufficient.^{44,49} The majority of outcomes from the framework were described by participants, no new outcomes were identified by any participant (including the single care partner), and outcomes described by the care partner did not raise any different experiences to patient participants. These findings also support that the systematic reviews of

Table 3

Exemplar narrative quotes to illustrate the ten most frequently reported outcomes by participants.

<p>Muscle and/or motor nerve function (<i>feeling weak, sore, or numb</i>)</p> <p>“... I was finally in a well-enough state to start thinking about building muscle back ...” – COS PPI 001 (female, patient, 4 years post ICU discharge)</p> <p>“... I still have tighter hamstrings than I did before, and I have very much tighter pecs that I did before, and I still have slight foot drop on my right foot ...” – COS PPI 002 (female, patient, 10 years post ICU discharge)</p> <p>“... Well the physical therapy was obviously good for developing my muscles but was very conscious that I couldn't move about easily and couldn't get out of bed by myself regularly ...” – COS PPI 006 (male, patient, 1 year post ICU discharge)</p> <p>“... I had a lot of muscle wastage, so I lost a lot of weight and a lot of muscle so I found it very difficult to walk initially ...” – COS PPI 007 (male, patient, ≤1 year post ICU discharge)</p> <p>“... my legs were just, it was just skin on bone; I mean there was just no muscle there at all, and it was quite some time before I was even able to drag myself around the ward ... Because my balance had totally gone, and my legs and feet just wouldn't work ...” – COS PPI 013 (male, patient, 5 years post ICU discharge)</p>
<p>Physical function (<i>How well a person can perform physical functional activities, e.g., transferring from sitting to standing or from a bed to chair, walking, climbing stairs, or balance</i>)</p> <p>“... So, essentially it was the same; we were doing core work and mobility, walking, trying to get me walking without the frame ...” – COS PPI 002 (female, patient, 10 years post ICU discharge)</p> <p>“... I managed to start walking just around the end of the bed, and after 5 days, again he (physio) then took me outside, and had me up and down the steps in the back garden, and then he said to me how do you think you would get on walking round the bedrooms again without any sticks? So I tried that and basically; it went from strength to strength ...” – COS PPI 004 (male, patient, ≤1 year post ICU discharge)</p> <p>“... I had to be lifted out of bed in a hoist, put into a wheelchair, and then I was wheeled to the gym, and they started off by just sitting me on the bed; they could eventually stand me up ... I started to sort of walk a bit then a lot easier. I've got to the point where I can stand unaided, I can walk, you saw me with a stick, around the home and so forth I just walk unaided because I know where the furniture is, so if I'm going to keel over, I make for the furniture, but that's not often; but outside, I certainly always use two sticks, just to be on the safe side. As far as standing still, I can stand unaided for as long as you like now. When I first started, my longest the first time it was 2 s then I started to wobble, but now it's well I could stand there as long as you want really ...” – COS PPI 008 (male, patient, 5 years post ICU discharge)</p> <p>“... I was worried about coming home because of stairs. So there wasn't any practice of going up and down stairs, and when I go home I had to do the stairs initially on my bottom because I just didn't have the strength to lift my legs up the stairs, but also to use the arms; my arms had lost their strength to pull you up the stairs ...” – COS PPI 011 (female, patient, 2 years post ICU discharge)</p> <p>“... the first step which surprised me was I was to sit on the bed ... I knew that I couldn't walk, the first exercise was to walk towards a portable device like a trolley which was far away, I'd say one metre or something like that, and I had to walk with help and I couldn't move; the weight of each foot was terrible ... And next to the stairs and leave the frame and going down the stairs and I'm going up again ...” – COS PPI 012 (male, patient, 3 years post ICU discharge)</p>
<p>Activities of daily living (<i>Being able to complete usual everyday tasks including self-care, e.g., bathing, dressing or feeding, or other activities, e.g., cooking, cleaning, managing finances, or shopping</i>)</p> <p>“... Not being reliant on people to get to the loo, to wash myself even until I was further down the line, I suppose the big one was being able to get into the bathroom on my own ... I had to walk out, I had to get in the car, I had to get out of the car ... If there was something in my locker by the side of the bed. If I got it out, I would try and put it back ...” – COS PPI 001 (female, patient, 4 years post ICU discharge)</p> <p>“... he (physio) said my ambition is to get you to walk down to your local little shop and buy something and come back up on your own ...” – COS PPI 004 (male, patient, ≤1 year post ICU discharge)</p> <p>“... Oh and also some occupational therapy which is not strictly physio but it was quite helpful because they got me doing things quiz games, discussion groups, going into the kitchen and cooking a bit, and things like that so. They made me do things, and I made cups of tea and cook some bacon and whatever, yeah just sort of household skills ...” – COS PPI 006 (male, patient, 1 year post ICU discharge)</p> <p>“... Well, I think it's hard when you're the person, when you're the actual person themselves trying to do these things, which may sometimes feel quite small compared to what you are normally used to being able to do ... Clearly my biggest aim would be to actually get out, to get back upstairs to sleep in my own bed, and also, to be able to have a shower, because my shower is upstairs, we didn't have a shower downstairs ... The exercises that you're doing are for your personal life ...” – COS PPI 010 (male, patient, 2 years post ICU discharge)</p> <p>“... It was a while before I could, I couldn't do anything, I couldn't do my normal household chores either, putting washing in the machine, I just, I had no energy at all ... Because at the time when you're going through it, you don't think you're getting any better; like, I remember thinking I'm never going to be able to walk down there and I'm never going to be able walk, I couldn't go round [supermarket] ... Using my arms to wash my hair and using, just general things like putting washing in and out of the machine ...” – COS PPI 014 (female, patient, ≤1 year post ICU discharge)</p>
<p>Emotional and mental wellbeing (<i>A person's mood, how often they worry, feel anxious, depressed or sad, how often they get angry or upset, and their self-esteem</i>)</p> <p>“... the minute I was told I could go home, my panic attacks stopped ...” – COS PPI 002 (female, patient, 10 years post ICU discharge)</p> <p>“... He was getting very depressed. He was very, very down. I tried to motivate him, but I noticed with (patient) and he was going into a big depression ... when people spoke to him (patient) wouldn't make eye contact ...” – COS PPI 005 (female, care partner, ≤1 year post ICU discharge)</p> <p>“... mentally I got very, very depressed, so mentally it was a bad time ... Well I think I got quite mentally depressed because of the swallowing business. My family said I got rather more aggressive, would react badly to things such that I started a session with talking therapies to see whether I could improve my mental well-being ...” – COS PPI 007 (male, patient, ≤1 year post ICU discharge)</p> <p>“... Part of the time, both when I was in the (name of hospital) and when I was in the other hospital ... initially I was, I didn't want to go on. I just wanted it all to end. And then that then ... I got over ... well I coped with that. Though I did feel at times that I was always suspicious, well they weren't telling me things because it wasn't going well. It was that kind of the cup ... the cup half empty or the cup three quarters empty. I kept feeling, oh I'm never going to get better ...” – COS PPI 011 (female, patient, 2 years post ICU discharge)</p> <p>“... If I have a bad day physically, it brings on all the panics and the flashbacks and vice versa. If I'm having a bad day mentally, it can lead to a bad day physically. A dreadful loss of confidence and I don't know where that is sort of instrumental in recovery. For me and the people with whom I've spoken to, that confidence never properly comes back ...” – COS PPI 013 (male, patient, 5 years post ICU discharge)</p>
<p>Healthcare resource utilisation (<i>Seeing more doctors, physio/physical therapists or other healthcare clinicians, needing to be readmitted to the ICU or hospital, number of days spent in the ICU, hospital or other healthcare setting</i>)</p>

(continued on next page)

Table 3 (continued)

<p>“... It was a 6- or 7-week total stay in hospital ... I went back for a rehabilitation period; I think it was about 8 weeks altogether; I went back there every week to see (physiotherapist name) from ITU, and she took me through an exercise programme for that period of 8 weeks ...”</p> <p>– COS PPI 003 (male, patient, 7 years post ICU discharge)</p> <p>“... there I was in intensive care for 4 weeks. I went from intensive care back to HDC, back up to intensive care ...”</p> <p>– COS PPI 004 (male, patient, ≤1 year post ICU discharge)</p> <p>“... I was in ICU for a period of 4 months, 125 days to be precise, yes ... in hospital, all told for about 10½ months ... but when I came out of hospital altogether and came home, as I said I did have a few weeks' outpatient treatment as I said, down the hospital and so forth, but when that came to an end, there didn't seem to be much chance of me having another lot; there was about a 16-week waiting list, so I went to a private physio, which is only 5 min down the road from us who have a gym and all that lot ... Then every third week apart from that I have a physio session, which is on the NHS at my local doctor's surgery ...”</p> <p>– COS PPI 008 (Male, Patient, 5 years post ICU discharge)</p> <p>“... I think I was in ICU for four and a half weeks, and then I went onto a ward ... I didn't want to go back into hospital after what I'd been through ...”</p> <p>– COS PPI 009 (female, patient, ≤1 year post ICU discharge)</p> <p>“... I was only actually in intensive care for 7 days, but I had another 4 weeks in (name of hospital) and another 5 weeks in a rehabilitation hospital ...”</p> <p>– COS PPI 011 (female, patient, 2 years post ICU discharge)</p>
<p>Patient experience of physical rehabilitation (What did patients think about, and how motivated were they to take part in, physical rehabilitation)</p> <p>“... But how easy the exercises become is an incredibly motivating as well isn't it, if you can see, it's getting easier, but it requires a certain level of dedication and a certain level of incentive. A massive incentive ... I think my mental attitude was incredibly important, and that comes from the drive to get better, to be able to look after my son again ...”</p> <p>– COS PPI 002 (female, patient, 10 years post ICU discharge)</p> <p>“... Yes, I was mad keen to get moving again, yes ... I was keen to get back to fully fit in the shortest time possible ... I was doing things at home as well. The last thing I wanted was for the person that was looking after me that particular day (when attending outpatient hospital appointment) to throw something at me that I couldn't do. That would hurt that would, so I was in want of a better phrase, trying to stay one step ahead. Not being clever or anything like that, but it was beneficial to me anyway ...”</p> <p>– COS PPI 003 (male, patient, 7 years post ICU discharge)</p> <p>“... I've been really determined the whole way through on this ... they've always been quite amazed by my determination and putting myself to make myself do things, because, you know still, I just wanted my life back ... life sometimes is hard but you've got to keep pushing yourself, because with all the work they do, if you don't push yourself as well, you're not going to get there ... I think it (receiving feedback on progress) motivated me ...”</p> <p>– COS PPI 009 (female, patient, ≤1 year post ICU discharge)</p> <p>“... I actually think if somebody had actually asked me more how I felt about doing them (rehabilitation activities). Yeah. I do think lots of it is a tick box. Because clearly, you know, the physios are doing a job, and they've got to, they're very good at their job and, you know, but they've also got to fill in their daily; they've got to justify, haven't they? But I have to say that (name of therapist) who was absolutely excellent, sometimes she would come to me when I was on the ward and she said, “How are you today?” And I was like, “I can't do anything today. I really just don't want to and I'm upset”. And she said, “Okay, well let's just sit and talk for a bit”. And she was really good. And so, she would sit and chat with me and then she'd say, “Shall we just try something now?” And I'd say, “Okay” ...”</p> <p>– COS PPI 010 (male, patient, 2 years post ICU discharge)</p> <p>“... So I was measuring myself when I got home, but I guess if they (hospital therapists) had measured how far I was walking because even though as I say I was walking up and down the corridor of the ward, it was hard work, but maybe if I'd said right let's do 10 steps one day and 20 steps the next or something like that; then at the time, I might have been a bit more positive and thinking I'm doing this whereas I thought I wasn't doing it, do you know what I mean?... When I first got home, I couldn't cope with walking around all the time, and I did spend a while in my wheelchair, and I've got a lift in my house, I've got an accessible home, but I do remember each day trying the stairs because I wanted to be able to climb stairs again; I didn't want to just give in and use the lift all the time, so I may have used it for a little while, but then I thought right I've got to do this, and I practised climbing the stairs ...”</p> <p>– COS PPI 014 (female, patient, ≤1 year post ICU discharge)</p>
<p>Exercise capacity (Ability to carry out exercise, a person's level of fitness)</p> <p>“... I had one of those little bicycles but only with the wheel. I was using that as much as I could as well ... then there were exercises like just raising my arms, so they were all quite small things, but all quite a lot of effort to start with ...”</p> <p>– COS PPI 001 (female, patient, 4 years post ICU discharge)</p> <p>“... I think measuring distance and having repetitive exercises that you slowly increase in the number of repetitions you do. So that's very easily measurable, and you can see more than you did two days ago ...”</p> <p>– COS PPI 002 (female, patient, 10 years post ICU discharge)</p> <p>“... then they said let's see if you can do sort of 20 steps you know that sort of thing, so there was a feeling that they were pushing the envelope as it were to get me to do more each time. So I'd climb up and down the steps and things just to see if I could, and then once I did that, they had be on the parallel bars to see if could walk, and then they'd say well now try walking backwards that sort of thing. So it was general exercise and that ...”</p> <p>– COS PPI 006 (male, patient, 1 year post ICU discharge)</p> <p>“... So my challenge was to get mobile walking, eventually being able to drive; then I went up to the golf driving range and hit a few balls, not many initially and then slowly built up and I could balance, hit a golf ball and started playing three holes, six holes, nine holes until I got the full round ...”</p> <p>– COS PPI 007 (male, patient, ≤1 year post ICU discharge)</p> <p>“... I couldn't obviously turn the wheel or turn the whatever it was; they had to do that just to get my legs working in a cycling motion, and that is basically all that they could do ... and sort of exercised my legs up and down and my arms and so forth, and then as I progressed, I was then put on the tilt table again ... And they also had MOTomed machines, the cycle, I was strapped to those, and I did a lot of MOTomed work ... I used their pool there, the hydrotherapy pool, and that was absolutely brilliant ... I feel as though I've got to the stage now I do weightlifting with the personal trainer and on a walking machine and on a treadmill ...”</p> <p>– COS PPI 008 (male, patient, 5 years post ICU discharge)</p>
<p>Place of residence (The location where a patient is discharged to following treatment, e.g., home, acute care hospital, nursing home, specialist rehabilitation centre, assisted living)</p> <p>“... But they sent me home because we had the right care in place at home, so I was able to be allowed to go home ...”</p> <p>– COS PPI 002 (female, patient, 10 years post ICU discharge)</p> <p>“... we lived in a house, we still do, and I had stairs to climb ... So they sent me for 2 days to a recovery hospital, a very small hospital, but I didn't like it there, so I asked if I could go home earlier ...”</p> <p>– COS PPI 003 (male, patient, 7 years post ICU discharge)</p> <p>“... I managed that exercise OK, and at the end of it, they said yeah you're fit enough to go home ...”</p> <p>– COS PPI 004 (male, patient, ≤1 year post ICU discharge)</p> <p>“... and when I came out of hospital, so then I had 2 months on the ward, 2 months in a rehab hospital, and then came home ...”</p> <p>– COS PPI 010 (male, patient, 2 years post ICU discharge)</p>
<p>Health-related quality of life (How well does a person feel about life; how much is a person's health affecting their quality of life)</p>

Table 3 (continued)

“... Yeah when I came out of Hospital, I thought at least I can go home and sleep in my bed, but for 12 days, they said well don't go up the stairs or anything, so I had to have a bed downstairs. Yeah, so although I could get up the stairs, they said we'd rather you didn't until you got used to it or fit in more roles and things. So they did the trials and eventually did go upstairs, but I was longing to get in the bath and things which I hadn't had for months and just be able to go back to normal life and sleep in my own bed and watch TV, and, I mean, I had watched some in the ward, but it wasn't that good, but I mean I couldn't really pick and choose like I can at home. So I was very keen to get back into sort of pretty well normal life ...”
– COS PPI 006 (male, patient, 1 year post ICU discharge)

“... thinking that is this how my life is going to be without being able to eat properly ...”
– COS PPI 007 (male, patient, ≤1 year post ICU discharge)

“... Because the wound hadn't healed I couldn't shower for a year ...”
– COS PPI 011 (female, patient, 2 years post ICU discharge)

“... But in the event, I never really recovered my mobility from that. So whether it was the sepsis that did a lot of nerve damage or quite what I don't know, but where I was as fit as a fiddle before I went in, now my mobility is incredibly bad, my balance is incredibly bad, and yeah so I go to a, visit a gymnasium around the corner, which is run by the local authority, and it's for people with long-term mobility problems, and that helps me a little bit now, but I don't think will ever, I think all of that really does it stops it getting worse I think ... So that loss of confidence has a huge impact as well on everything ...”
– COS PPI 013 (male, patient, 5 years post ICU discharge)

Social roles, activities, or relationships (Connecting with others, maintaining friendships and romantic relationships, ability to join in activities with/for others)

“... I couldn't really be left alone with him unless I could get him out of his cot and pick him up ...”
– COS PPI 002 (female, patient, 10 years post ICU discharge)

“... So, at the moment, he had a first day out yesterday with his camera because he's a very, very keen photographer. Yeah, he goes with his friend. Unfortunately, he hasn't been able to. Yesterday, he put his trainers on and was going with his friend because he's got a friend who's not been well, but they keep each other company, and he's said, “I've got my shoes on and I'm going out”. And he hasn't been out for months like that ...”
– COS PPI 005 (female, care Partner, ≤1 year post ICU discharge)

“... I mean progressively I went out, and we went on trips and my wife driving, and I went shopping in (local town) you know and things ...”
– COS PPI 006 (male, patient, 1 year post ICU discharge)

“... So yes, I am able ... at the beginning I was going to the town centre, long walks, I couldn't do because I was bad, but with time, after 6 months, for example, I got a relative coming from (another country) here to ... and I was able to go with them to (city), and we've been walking in (city) which took effort ...”
– COS PPI 012 (male, patient, 3 years post ICU discharge)

Abbreviation: ICU, intensive care unit.

Table 4

Exemplar narrative quotes to illustrate lesser frequently reported (≤9 participants) outcomes.

Nutrition-related parameters (weight change, changes to appetite, changes to taste)

“... Because obviously, I needed to do a lot of muscle rebuilding and immune system rebuilding, and I had a certain amount of knowledge, but I needed someone that had intense knowledge about how I could achieve that with my diet ... We were bringing food in, actually, because my calorie intake was the biggest concern ...”
– COS PPI 002 (female, patient, 10 years post ICU discharge)

“... I went from 18 stone whilst in hospital down to about 14, and obviously on discharge, I lost another stone as well. I lost five stone in total. So I wasn't very strong ... I felt, I didn't feel ashamed of myself, but I felt so self conscious; I'd lost so much weight, I looked like a POW, I looked terrible ... He said the only reason you feel like that is because of your muscle wastage ...”
– COS PPI 004 (male, patient, ≤1 year post ICU discharge)

“... Well for one thing, I couldn't eat very well when I first came out of the first two wards, first three wards, but when I got to rehab, I did actually start eating and enjoying food a bit more ... then I got onto normal food, and I sort of developed more of an appetite, but by then, of course, I wasn't used to eating, so I had to get back used to eating Again, and that's the more you eat the stronger you get so ...”
– COS PPI 006 (male, patient, 1 year post ICU discharge)

“... That gradually improved once I got home, and I was eating because I wasn't eating at all at the time and I had different medications; I was on a nasal gastric tube to start with ...”
– COS PPI 014 (female, patient, ≤1 year post ICU discharge)

Cognitive function (Problems with someone's memory, concentration, language, thinking, and ability to understand instructions)

“... And I said, “No, it's strange because my grandson obviously came up”. He's 18 now, and he was 17 at the time and (grandson) doesn't remember a thing about that ...”
– COS PPI 005 (female, care partner, ≤1 year post ICU discharge)

“... Ok, well I don't remember too much about intensive care, but I was sort of half-conscious, but I don't really honestly remember that much ... I was fairly confused; I'd lost most of my memory by then, and so I was trying to rebuild my memory. So I'd forgotten where I lived and things like that ... so that was more of a concern to me than my physical state ...”
– COS PPI 006 (male, patient, 1 year post ICU discharge)

“... I couldn't remember anything, and I just felt like I was losing my mind ...”
– COS PPI 009 (female, patient, ≤1 year post ICU discharge)

“... Well yes, and there is something which is what I felt, a lot is my capacity of concentration. So when I came the first time, when I came home, I didn't remember my home. The capacity of concentration, it wasn't there ... the capacity of concentration and then my ability for learning which was affected, still it is ...”
– COS PPI 012 (male, patient, 3 years post ICU discharge)

Survival (Surviving [being alive] after ICU admission, hospital admission, or after hospital discharge)

“... So, there's physical stuff, but I'm alive. It's not stuff I'm going to complain about ...”
– COS PPI 002 (female, patient, 10 years post ICU discharge)

“... and just said, “We don't really know if (patient) will come through this”, and of course, obviously I don't need to tell you how you feel ...”
– COS PPI 005 (female, care partner, ≤1 year post ICU discharge)

“... I was more concerned with just staying alive at that point ...”
– COS PPI 006 (male, patient, 1 year post ICU discharge)

“... I was close to death the first time, and I thought I'm not going to cope with another lot ...”
– COS PPI 013 (male, patient, 5 years post ICU discharge)

Return to work or prior role (Returning to previous job (full-time or part-time), changing to a different job, doing the same thing you did before being in the ICU)

(continued on next page)

Table 4 (continued)

<p>“... It was really because I got home at the end of February in the end, and I didn't want to be off work for too long ...” – COS PPI 001 (female, patient, 4 years post ICU discharge)</p> <p>“... Well, being self-employed is a target itself isn't it. You've got to get back into some sort of normality in sickness because when you work for yourself you know, well I don't know whether you do, but you just don't have time off do you, and I'd spent 3 months in hospital, and I was pretty anxious to get back to work ...” – COS PPI 003 (male, patient, 7 years post ICU discharge)</p> <p>“... So consequently, 11 or 12 months down the line, I've still been off work, they said I'm not well enough to go to work ... I came out of hospital in June, and I thought I was going back to work in July, and that's how I've been every month. I'm going back now, I'm going back now ...” – COS PPI 009 (female, patient, ≤1 year post ICU discharge)</p>
<p>Delirium and related symptoms (Having an episode of acute confusion, hallucinations, delusions, or nightmares)</p> <p>“... I've got flashbacks and hallucinations that I remember ...” – COS PPI 001 (female, patient, 4 years post ICU discharge)</p> <p>“... I'm still having problems with that and hallucinations, and the whole experience, you know, they'd say “Oh, she's always smiling”, but I had lots of problems with bad dreams and being frightened and things like that ...” – COS PPI 009 (female, patient, ≤1 year post ICU discharge)</p> <p>“... I was having severe mental problems as well which were, the flashbacks and the panic attacks which all stemmed back from the hallucinations I had during that short time in ICU ...” – COS PPI 013 (male, patient, 5 years post ICU discharge)</p>
<p>Fatigue (An overwhelming, sustained feeling of exhaustion, mental or physical tiredness, having little energy for physical and mental work)</p> <p>“... And the feeling of being so almost worn out with the physios tucking everything in and strapping them on. By the time all that was done, that to me was like a day's exercise before they even say to me right, now (patient name) can you stand up? ...” – COS PPI 010 (male, patient, 2 years post ICU discharge) what I tried to do ... I did some, but not ... I have a static bike at home, but I was ... I got tired. – COS PPI 012 (male, patient, 3 years post ICU discharge)</p> <p>“... but I had no energy to do anything, and I was relying on people, and I do remember thinking at one point I'm never going to be able to cook a Christmas dinner this year, but I did it with the help of my family ...” – COS PPI 014 (female, patient, ≤1 year post ICU discharge)</p>
<p>Gastrointestinal symptoms (Nausea, vomiting, constipation)</p> <p>“... And also, the difficulty is also at that particular point I had, I mean at one point, I had I think two, four, five, I probably had, at one time I had seven bags collecting my waste ...” – COS PPI 010 (male, patient, 2 years post ICU discharge)</p> <p>“... The other thing that I was affected with were my bowels ... and gave the doctors and nurses cause for concern, but it certainly worried me ...” – COS PPI 014 (female, patient, ≤1 year post ICU discharge)</p>
<p>Pain (Any bodily pain)</p> <p>“... the legs, oh they really swelled up, swoll up, whatever the correct terminology is, and they were really very, very painful ...” – COS PPI 011 (female, patient, 2 years post ICU discharge)</p> <p>“... but hugely, in constant pain at the time, so it was a bit of an ordeal ...” – COS PPI 014 (female, patient, ≤1 year post ICU discharge)</p>
<p>Respiratory (pulmonary) function and symptoms (Trouble breathing, shortness of breath, coughing)</p> <p>“... it was more of a stamina thing because the pneumonia hit my breathing for six basically ...” – COS PPI 003 (male, patient, 7 years post ICU discharge)</p> <p>“... I remember being scared thinking I can't even breathe, and you do genuinely think oh I'm not going to be able to breathe properly and I'm going to be like this forever, but it takes a long time for your lungs to improve after pneumonia ...” – COS PPI 014 (female, patient, ≤1 year post ICU discharge)</p>
<p>Sleep and related symptoms (Trouble falling asleep, trouble staying asleep, changes to sleeping pattern)</p> <p>“... The minute I got home, I could sleep ...” – COS PPI 002 (female, patient, 10 years post ICU discharge)</p> <p>“... By the time I came home, I still was very weak, I still spent a lot of time sleeping ...” – COS PPI 014 (female, patient, ≤1 year post ICU discharge)</p>
<p>Successful extubation (Occasion where the breathing tube between the patient and the ventilator [breathing machine] is successfully removed at a specified timepoint)</p> <p>“... I weaned off the ventilator fairly quickly, and I was then transferred ...” – COS PPI 002 (female, patient, 10 years post ICU discharge)</p> <p>“... although I had been taken off the life support machine ...” – COS PPI 008 (mle, patient, 5 years post ICU discharge)</p>
<p>Swallowing function and symptoms (Trouble swallowing food or liquids)</p> <p>“... Because it affected me in that I didn't want to go out for a meal with my wife; I was taking about three times as long to eat a meal as the rest of my family would, so I'd still be chewing away whilst they'd gone away and washed up, dried up, and I was still chewing, so mentally it was a bad time ...” – COS PPI 007 (male, patient, ≤1 year post ICU discharge)</p> <p>“... and I also saw a speech and language therapist because my swallowing was not very good to start with either that seemed to be affected a bit. I was eating, but I felt like I couldn't swallow water even. I'd have a couple of gulps of water, and I couldn't breathe afterwards ...” – COS PPI 014 (female, patient, ≤1 year post ICU discharge)</p>
<p>Communication difficulties (Problems communicating with others, e.g., by speech, writing, or gesture)</p> <p>“... I do remember that when I had my tracheotomy, I couldn't talk, and I was trying to communicate with people, and my arms were still so full of fluid that I couldn't lift them up very easily they were that heavy, and in the end, even though I'm right-handed, for some bizarre reason, I was actually able to write left-handed perfectly, so people could read what I was writing, and that was my way of telling people what I needed or whatever that might have been ...” – COS PPI 001 (female, patient, 4 years post ICU discharge)</p>
<p>Duration of mechanical ventilation (Duration of time a patient spends being mechanically ventilated [using a breathing machine])</p>

Table 4 (continued)

“... and I was still paralysed at the time, although I had been taken off the life-support machine I was on that for about 3 months, three-and-a-half months, something like that ...”
 – COS PPI 008 (male, patient, 5 years post ICU discharge)

Financial impact on patient (Dealing with hospital bills, lost income from time off work, paying for help with care at home or transportation)

“... And the impact on us financially, obviously was that by this point, I'd lost my job, so we had to employ an au pair to come and look after my little boy because there was no way I could do it ...”
 – COS PPI 003 (male, patient, 7 years post ICU discharge)

Urinary function (Incontinence [frequency or urge])

“... whenever I wanted to sort of use the toilet, I was asking for a bed pan, and it wasn't forthcoming you know, and of course I had, not of course, I did at the time have quite a nasty urine infection ...”
 – COS PPI 003 (male, patient, 7 years post ICU discharge)

Abbreviation: ICU = intensive care unit.

Table 5

Matrix depicting outcome reporting across individual participants.

Outcome	Participant													
	001	002	003	004	005	006	007	008	009	010	011	012	013	014
Muscle function ^a	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Physical function	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Activities of daily living	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Emotional and mental wellbeing		X	X	X	X	X	X	X	X	X	X	X	X	X
Healthcare resource utilisation	X	X	X	X		X	X	X	X	X	X	X	X	X
Patient experience ^a	X	X	X	X		X	X	X	X	X	X	X	X	X
Exercise capacity	X	X	X	X		X	X	X	X	X	X	X	X	X
Place of residence	X	X	X	X		X	X	X	X	X	X	X	X	X
HRQL		X		X	X	X	X	X	X	X	X	X	X	X
Social roles ^a		X	X	X	X	X	X	X	X	X	X	X	X	X
Nutrition-related parameters	X	X		X	X	X	X			X			X	X
Cognitive function					X	X	X		X		X	X	X	X
Survival					X	X		X	X			X	X	X
Return to work or prior role	X	X	X			X	X		X			X		
Delirium and related symptoms	X				X				X				X	X
Fatigue									X	X		X		X
GI symptoms				X	X					X				X
Pain									X		X		X	
Respiratory function ^a			X						X					X
Sleep and related symptoms		X												X
Successful extubation		X						X						X
Swallowing function and symptoms							X							X
Communication difficulties	X													
Duration MV								X						
Financial impact		X												
Urinary function			X											

Abbreviations: GI, gastrointestinal; HRQL, health-related quality of life; MV, mechanical ventilation.

Note: Outcomes of Frailty, Reintubation, Sexual function, and Joint function were not reported by any participants and are not listed.

^a **Full outcome names:** Muscle and/or motor nerve function; Patient experience of physical rehabilitation; Social roles, activities, or relationships; Respiratory (pulmonary) function and symptoms.

quantitative⁸ and qualitative⁹ literature undertaken to generate the pre-existing list of outcomes were efficient and effective approaches to capturing relevant trial outcomes—this is important for streamlining patient and care partner involvement in core outcome set development to minimise potential burden.

The salience and frequency (within context, not solely based on word count, as per Weber²³) with which outcomes from the framework were described by participants varied notably, with an emphasis on outcomes of a physical and practical nature (e.g., muscle function, physical function, and activities of daily living) and including four outcomes not mentioned at all. These findings may be related to the content of the interview guide, focussing on experience of recovery across the recovery continuum after critical illness with specific reference to physical rehabilitation, given the scope of the associated core outcome set;⁷ had participants been asked specific questions related to each outcome, this might have confirmed their experience of them, albeit this may also have resulted in a more closed style of

questioning and discussion. For some unreported outcomes such as reintubation, poor recall may have been an influencing factor—patients may not remember this occurring at the time and/or may not have been advised by others during their recovery of its occurrence; for others, such as joint function, this may have been implicit during participants' recollections of experiencing muscle weakness and difficulty in performance of functional tasks but was not explicitly described. Descriptions of other outcomes may be secondary to the demographics of our sample; for example, only half of our respondents reported detail related to returning to work, known to be significantly impacted in survivors of critical illness;⁵⁰ however, eight of our participants were already retired at the time of interview such that this will have been less applicable. That four participants were back at work and that two participants' employment status was affected by their health status, speaks to the need to appreciate the individual circumstances around this event,⁵¹ but it was beyond the remit of this study.

We adopted a framework analysis approach to our findings following established methods,^{18–22} albeit revised from our original plan of thematic analysis.⁵² We used the existing list of outcomes as the coding framework; the advantages of this were two-fold: firstly, that we were able to verify the relevance of our known outcomes and secondly, allowing us to identify any new outcomes that could be considered for potential inclusion in the core set.

5. Conclusion

In conclusion, patient and care partner experiences confirmed the relevance of a pre-existing list of outcomes for potential inclusion in a core outcome set for trials of physical rehabilitation interventions across the critical illness recovery continuum. This suggests that prior systematic literature searches were sufficient for identifying outcomes to propose in the core outcome set. This was verified through participant reporting of nearly all outcomes in the pre-existing list, and the absence of reporting any new content for consideration. Importantly, the narratives described in this study further elucidate our understanding of the true real-life impact of these outcomes for participants.

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CRedit authorship contribution statement

Bronwen Connolly: Conceptualisation, Methodology, Formal analysis, Investigation, Data curation, Writing—original draft, Writing - review and editing, Project administration, Funding acquisition, Supervision.

Rhian Milton-Cole: Formal analysis, Data curation, Writing—review and editing.

Bronagh Blackwood: Writing—review and editing.

Natalie Pattison: Methodology, Validation, Writing—review and editing, Supervision.

Conflict of interest

The authors declare no potential conflicts of interest.

Data availability

Due to the nature of this research, participants of this study did not agree for their data to be shared publicly, so supporting data are not available. All findings are reported in this manuscript.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.aucc.2024.05.005>.

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