**Development of a Menu of Recovery Goals to Facilitate Goal Setting after Critical Illness**

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**Keywords:** critical care; post-intensive care syndrome; recovery; goal-setting; rehabilitation

**Funding statement**

This work was supported by a grant to develop the digital ICU recovery pathway from the Guys’ and St Thomas’ NHS Foundation Trust Charity.

**Competing interest statement**

No competing interests

**Institutional Review Board statement**

Study title: Development of a Menu of Recovery Goals to Facilitate Goal Setting after Critical Illness

Approved by the King’s College London Research Ethics Board as a minimal risk study MRA-20/21-22697 on 4th May 2021.

All procedures were in accordance with the ethical standards of the responsible committee on human experimentation and with the Helsinki Declaration of 1975. Informed consent was obtained from all participants.

**ABSTRACT**

**Objective**

To develop an expert-informed (including end users) recovery goal menu for adult survivors of critical illness applicable to the community/home setting.

**Design**

Stage 1 Item generation: iterative development of domains, sub-domains, and goals in consultation with intensive care survivors, family members and expert clinicians. Stage 2 Content validity assessment: cognitive interviews and the content validity index.

**Setting**

Virtual consultation meetings facilitated by the research team at King’s College London and Guy’s St Thomas’ NHS Foundation Trust.

**Subjects**

Adult ICU survivors and relatives, and ICU healthcare professionals specialised in critical illness recovery

**Interventions**

None

**Measurements and Main Results**

Item generation resulted in a goal menu comprising 4 domains, 22 sub-domains and 95 goals assigned as follows: Self-care: 9 sub-domains with 37 goals, Productivity: 7 sub-domains with 13 goals, Leisure: 3 sub-domains with 25 goals, and Person domain 3 sub-domains with 20 goals. Cognitive interviews resulted in addition of 79 goals and modification of 7, addition of 4 new sub-domains and modification of 4, thus resulting in 4 domains, 26 sub-domains with a total of 174 goals. Twenty-four sub-domains (169 goals) were deemed relevant with Item-Content Validity Index (I-CVI) scores ranging from 0.72 to 1. Two sub-domains (5 goals) did not meet the 0.7 cut-off and were removed. The Scale Level-Content Validity Index/Universal Agreement (S-CVI/UA) score was 0.46; the Scale Level-Content Validity Index/Average (S-CVI/Ave) 0.91. Average Content Validity Ratio (CVR) was 0.93.

**Conclusion**

An expert informed recovery goal menu for intensive care survivors has been developed with excellent content validity.

**KEY POINTS**

**Question:** To develop a recovery goal menu for adult survivors of critical illness applicable to the community/home setting.

**Findings:** The final goal menu comprises 169 goals within 24 sub-domains grouped under 4 domains.

**Meaning:** This menu will help patients to set goals and increase our understanding of how individuals recover from critical illness.

**Introduction**

Survivors of critical illness experience a myriad of health problems that persist following hospital discharge. Post Intensive Care Syndrome (PICS) comprising new or worsening physical, psychological and/or cognitive impairments affects more than 50% of adults surviving critical illness (Harvey and Davidson, 2016, Geense et al., 2021, Marra et al., 2018). Impairments associated with PICS negatively affect individual and caregiver health-related quality of life (HrQoL) as well as impeding return to work or other occupational roles (Mehlhorn et al., 2014, Hofhuis et al., 2021, Kamdar et al., 2020).

In the UK, provision of recovery services to support survivors of critical illness has expanded over recent years (Connolly et al., 2021) with patient-centred rehabilitation and individualised recovery goal setting advocated (National Institute of Health and Care Excellence, 2017, The Faculty of Intensive Care Medicine, 2021, National Institute of Health and Care Excellence, 2009). Structured and personalised goal setting during rehabilitation can result in higher levels of self-efficacy and improved HrQoL when compared to rehabilitation without goal setting (Levack et al., 2015). When goals are clearly defined and consistent with personally meaningful aspirations, patients are more motivated towards achievement (Sivaraman Nair, 2003, Levack et al., 2015). Goal setting after critical illness is important for motivation and self-efficacy (McPeake et al., 2020). However, goal setting in the immediate phase of recovery from critical illness can be difficult for patients to engage in. Previous research suggests a more paternalistic approach from the multidisciplinary team is preferred by patients in the early stages of recovery (Corner et al., 2019, van Willigen et al., 2020). As recovery progresses, goal setting becomes more collaborative with patients engaging more readily with the rehabilitation team in their recovery process (Corner et al., 2019).

Goal Attainment Scaling (GAS) is a method of scoring individualised goals after a rehabilitation intervention that is a valid, reliable, and sensitive patient-reported outcome measure (Stolee et al., 2012, Hurn et al., 2006, Rockwood et al., 2003). First utilised in the mental health field, GAS has now been applied to a variety of clinical settings including care of the older person (Stolee et al., 2012, Toto et al., 2015), neurology (Rannisto et al., 2015, Jung et al., 2020), , musculoskeletal pain management (Haladay et al., 2021), and paediatrics (Harpster et al., 2019).

GAS offers a number of advantages over comparable measures as goals are individually identified as a collaborative process between the patient and multi-professional team. Achievement levels are set with reference to current function and expected levels of attainment. Essentially each patient has their own individualised outcome which is scored in a standardised way (Turner-Stokes, 2009). GAS has been shown to be more responsive to change when compared to the Barthel Index, United Kingdom Functional Independence Measure and Functional Assessment Measure, Physical Self-Maintenance Scale, Katz Activities of Daily Living Index and the Spitzer Quality of Life Index in older adults (Rockwood et al., 1993, Turner-Stokes et al., 2009, Khan et al., 2008). However, GAS can be time consuming as bespoke goals need to be developed, along with definitional criteria for achievement of these goals (Hale, 2010, Stolee et al., 2012). To address this challenge, condition-specific goal menus have been developed. Examples of clinical domains with established goal menus include Down’s syndrome, haemophilia, bladder/bowel dysfunction, and care of the older person (Knox et al., 2021, Goldstine et al., 2021, Roberts et al., 2018, Yip et al., 1998). At present, there is no goal setting menu for adults recovering from critical illness.

Our group developed a digital intensive care unit (ICU) recovery pathway to bridge existing gaps in recovery support during transitions from the ICU to the ward and on discharge to home (Rose et al., 2022). Central to this pathway is the setting and monitoring of patient-centred recovery goals. These are developed collaboratively by the patient and a dedicated recovery coordinator using the e-platform aTouchAway™ (Aetonix Canada). This commercially available product is a virtual care platform that uses clinician/researcher developed care pathways to support patients in care transition or disease management (<https://aetonix.com/>). We anticipate formulation of a recovery goal menu will promote former ICU patient engagement and independence with goal setting via the digital ICU recovery e-platform.

**Primary Objective**

To develop an expert-informed (including end users) recovery goal menu for adults recovering from critical illness applicable to the community/home setting.

**Methods**

We modelled our methods on previous studies outlining goal setting menu development in other health conditions (Goldstine et al., 2021, Knox et al., 2021, Roberts et al., 2018, Yip et al., 1998).

*Participants*

For item generation and content validity assessment using the CVI we used purposive sampling to recruit clinical experts, ensuring representation of all members of the multi-professional team involved in ICU recovery and rehabilitation. Expert clinicians were recruited through existing ICU professional (e.g., professional societies such as the Intensive Care Society), our own personal networks, and snowballing methods. We used convenience sampling via a multi-modal strategy to recruit former ICU patients, caregivers, and relatives. This strategy included Twitter, patient, and family advocacy groups (e.g., ICUsteps) and snowballing methods.

Our inclusion criteria for clinicians/clinical academics were: 1) at least 3 years’ experience of working with former ICU patients; and 2) English speaking. Our inclusion criteria for former ICU patients, caregivers and relatives were: 1) adults aged over 18 years; 2) mechanically ventilated in an ICU for three days or more in the previous 3 years (patients only); and 3) English speaking.

The study was approved by the King’s College London Research Ethics Board as a minimal risk study MRA-20/21-22697. Informed consent was obtained from all participants. Patient and family member expert panel participants were provided a voucher in lieu of the time commitment involved. No payments were made to patient or family member participants of cognitive interviews.

*Stage 1 – Item generation and refinement*

To inform the selection of a theoretical model to underpin the recovery goal menu, we held iterative discussion within the research team, and reviewed the evidence base including existing models (e.g., Canadian Model of Occupational Performance Engagement (CMOP-E)) (Polatajko, 2007) and functional measures (e.g., Barthel Index) (Mahoney and Barthel, 1965). As such selection of a theoretical framework informed the subsequent generation of menu domains and sub-domains providing a structure for classification of goals.

We subsequently convened our expert panel comprising former ICU patients, relatives, and ICU healthcare professionals representing medicine, nursing, physiotherapy, occupational therapy, speech and language therapy, nutrition and dietetics, pharmacy, and psychology. Three virtual (via Microsoft Teams) consultation meetings were held with the panel. The purpose of the first meeting was to discuss the theoretical frameworks to underpin the menu and to identify potential menu domains and sub-domains. In the second meeting, we elicited input to generate and refine the domains and sub-domains. After the second meeting we generated a list of recovery goals set by former ICU patients using our digital ICU recovery e-platform pathway to create an initial list of recovery goals within these sub-domains. In the third meeting, menu domains, sub-domains and goals were presented and discussed. Post-meeting research team actions included: goal review, goal assignment to the most appropriate domain and sub-domain, goal wording standardisation, and removal of redundant goals.

*Stage 2 - Content Validity*

*Cognitive Interviews*

We conducted an initial assessment of content validity using the cognitive interview method (Terwee, 2017). We conducted small group or one-on-one virtual (via Microsoft Teams) cognitive interviews with former ICU patients to determine: i) goal menu comprehensiveness; ii) goal relevance; and iii) goal comprehensibility (Terwee, 2017). Participants were emailed the goal menu as an Microsoft Excel file in advance of the meeting with a request to undertake an initial review prior to the interview. During the cognitive interviews facilitated by the research team, participants were asked to review goals within each domain and sub-domain and verbalise their opinions on comprehensiveness, suitability, and comprehensibility. At the start of each interaction we advised former ICU patients to contact the research team, all of whom are clinicians experienced in ICU recovery, for support if they experienced any distress. Interviews were digitally recorded and transcribed using Microsoft Teams transcription. Menu items were added, refined, or removed based on participant consensus during the cognitive interviews.

*Content Validity Index and Content Validity Ratio*

We asked ICU recovery and rehabilitation experts to assess content validity using the content validity index (CVI) (Yusoff, 2019). Expert participants rated each of the 26 menu sub-domains for relevance, essentiality, and clarity using the CVI. Given the large number of individual recovery goals in the menu, we requested participants provide one score for each sub-domain and the associated goals as opposed to rating each goal individually. Using the CVI, relevance was rated as: not relevant, somewhat relevant, quite relevant, very relevant; clarity was rated as: not clear, needs some revision, very clear; essentiality was rated as: not essential, useful but not essential, essential.

For each sub-domain we subsequently calculated the Item-CVI (I-CVI) dividing the number of content validity assessments assigned a rating of very relevant, by the total number of participants. I-CVI scores range from 0 to 1; an I-CVI > 0.79 was deemed relevant, between 0.7 and 0.79 needs revision and below 0.70 the sub-domain was eliminated (Zamanzadeh et al., 2015). We calculated the Scale Level-CVI (S-CVI) using both the S-CVI/Universal Agreement (S-CVI/UA) and Average (S-CVI/Ave) methods. The S-CVI/UA was calculated by adding all sub-domains with an I-CVI equal to 1 divided by the total number of sub-domains. The S-CVI/Ave was calculated by dividing the sum of all sub-domain I-CVIs by the total number of sub-domains (Shrotryia and Dhanda, 2019). Scores of S-CVI/UA ≥ 0.8 or S-CVI/Ave ≥ 0.9 demonstrate excellent content validity (Polit and Beck, 2006, Rubio et al., 2003).

We calculated the content validity ratio (CVR) to determine if a sub-domain was necessary for inclusion. We used the formula: (Ne – N/2)/(N/2) in which Ne was the number of participants indicating the sub-domain was essential and N is the total participant number (Shrotryia and Dhanda, 2019). CVR scores range from -1 to +1 with higher scores indicating greater agreement among panel members (Ayre and Scally, 2014).

**Results**

*Stage 1 - Item generation and refinement*

Initial item generation by the research team identified seven potential domains and 35 sub-domains which were underpinned by the CMOP-E and UK FIM+FAM (Polatajko, 2007, Turner-Stokes and Siegert, 2013). These were presented at the first expert consultation meeting comprising seven ICU recovery experts for discussion. Participants confirmed the CMOP-E and UK FIM+FAM were appropriate theoretical underpinnings to inform domain and subdomain selection.

The CMOP-E was selected to underpin the goal menu as it promotes patient-centred holistic interventions ensuring the physical, cognitive, and psychological impairments associated with PICS are addressed. It is also an occupational performance model widely used by occupational therapists across clinical settings. The theories informing the CMOP-E model include humanistic, developmental and learning, and environmental, creating an interdisciplinary foundation for the model (Polatajko, 2007). The CMOP-E comprises three components; Person, Environment and Occupation. The Occupation component includes Self-care, Productivity and Leisure (Polatajko, 2007). These terms, alongside the Person component of the CMOP-E, resonated with our former ICU patients and as such, were used as the final domains. The UK FIM+FAM informed selection of sub-domains. The UK FIM+FAM is a valid, reliable measure of functional independence incorporating items on physical functioning, activities of daily living, cognition and psychosocial functioning (Turner-Stokes and Siegert, 2013). Patients recovering from critical illness often experience impairment in these areas thus the UK FIM+FAM provided the initial founding on which to base the goal menu sub-domains.

Following this meeting, the research team modified and added to the initial list of domains and sub-domains to form eight domains and 51 sub-domains. This classification was presented at meeting two, attended by one former ICU patient and one relative. Following discussion, participants recommended amalgamating the eight domains to four overall domains (Self-care, Productivity, Leisure, Person) and to revise and reallocate sub-domains resulting in 23 sub-domains. Review of goals set by patients using the ICU digital recovery pathway identified 74 goals to include in the menu. The menu structure and content were presented at meeting three attended by a further one former ICU patient and one relative. Recommendations from this meeting resulted in modification of 2 sub-domains and 6 goals, and addition of 21 goals (Table 1). These item generation and revision processes resulted in a goal menu comprising 4 domains, 22 sub-domains and 95 goals assigned as follows: Self-care: 9 sub-domains with 37 goals, Productivity: 7 sub-domains with 13 goals, Leisure: 3 sub-domains with 25 goals, and Person domain 3 sub-domains with 20 goals.

*Stage 2 - Content validity*

*Cognitive Interviews*

Seven former ICU patients participated in cognitive interviews via Microsoft teams. Participant demographics are shown in Table 2. All goals generated in Stage 1 were deemed relevant. Participants suggested addition of a further 79 goals and modification of 7, and additional 4 new sub-domains and modification of 4 (Table 1). This resulted in 4 domains, 26 sub-domains with a total of 174 goals.

*Content Validity Index and Content Validity Ratio*

Participants comprised one physician, one speech and language therapist, two ICU nurses, two dieticians, two physiotherapists and three occupational therapists.

Twenty-four sub-domains comprising 169 goals were deemed relevant with I-CVI scores ranging from 0.72 to 1; 11 sub-domains (115 goals) had a I-CVI score of 1, five sub-domains (35 goals) I-CVI 0.91, six sub-domains (16 goals) had I-CVI 0.82, two sub-domains (3 goals) I-CVI 0.73. The two sub-domains (5 goals) of 'caring for others’ and ‘volunteering’ scored <0.7 and therefore were considered not relevant. We removed these sub-domains prior to calculation of the S-CVI.

The S-CVI/UA and S-CVI/Ave scores were 0.46 and 0.91 respectively. The S-CVI/UA did not reach 0.8, yet the S-CVI/Ave exceeded the required score of 0.9 indicating excellent content validity.

Eighteen sub-domains (150 goals) had a CVR score of 1, two sub-domains (11 goals) 0.81, one sub-domain (4 goals) 0.8, two sub-domains (3 goals) a score of 0.63, and one sub-domain (1 goal) a score of 0.6. Mean CVR was 0.93 indicating a high agreement on essentiality.

The final goal menu comprises 169 goals within 24 sub-domains grouped under 4 domains. Supplementary material includes all calculations and scores for I-CVI, S-CVI/UA, S-CVI/Ave, CVR and how the menu may appear on the digital platform.

**Discussion**

In this study, through extensive and iterative consultation with former ICU patients, their relatives, and an expert panel of ICU healthcare professionals, we developed a patient-centred recovery goal menu comprising 4 domains, 24 subdomains and 169 goals that demonstrated excellent content validity. Former ICU patients and clinicians involved in recovery and rehabilitation planning can use this menu collaboratively to easily select those goals most meaningful to them, thereby informing the development of a bespoke recovery/rehabilitation plan.

. Patient centred goal setting as part of recovery can have beneficial outcomes for patients including improving motivation, occupational performance, engagement in rehabilitation and goal achievement (Sugavanam et al., 2013, Levack et al., 2006). In the UK, this is advocated in a recent quality standard and guideline (National Institute of Health and Care Excellence, 2017, The Faculty of Intensive Care Medicine, 2021). Using methods to support patients to achieve their individualised goals is a key component of this guidance (The Faculty of Intensive Care Medicine, 2021). However, patient-centred goal setting can be challenging to achieve in practice owing to the time needed to identify bespoke goals, the staffing resource required, and a patient’s ability to engage in this process during the immediate phase of recovery. Disparate information systems can lead to goal documentation not being readily accessible across services resulting in a loss of care continuity as there is no live, updateable record of goals that have been set. This recovery goal menu may help to address these existing barriers by reducing the burden of goal setting in the initial period of recovery at home and helping to assist goal setting independence and patient engagement as recovery progresses. Sharing of the goal menu provides an opportunity for this information to be accessed across different services which has the potential to overcome discrete information systems.

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Notably, the menu contains a large number of goals related to Self-care. This domain encompasses daily occupations including movement, personal care, bladder and bowel care, nutrition, and sleep. Reported experiences of former ICU patients in the early discharge home period highlight physical, cognitive, and psychological difficulties which impair ability to participate in activities of daily living and thus impede independence (King et al., 2019, Ågård et al., 2012). Struggling to return to independence can adversely affect HrQoL (Auriemma et al., 2021). Therefore, the large number of goals in the Self-care domain of our menu reflects the needs of former ICU patients and emphasises the importance of recovery in this area. The number and range of goals also highlights the wide ranging functional deficits of former ICU patients on hospital discharge and the need for robust support mechanisms to be in place during this transition.

Our digital ICU recovery pathway incorporates goal setting, GAS monitoring, symptom monitoring, and tailored information e-resources with a view to ensuring information and support are provided across key care transitions for former ICU patients and their families. This newly created menu of recovery goals will enhance personalised goal setting which is central to the pathway. In many countries, including the UK, Canada, Australia and the US, follow-up recovery services are highly variable in the type of services delivered and the personnel that deliver them. This is frequently due to lack of funding and resources available to support patients' recovery after discharge (Stapleton et al., 2020, Cook et al., 2020, Kuehn, 2019, Wilbur et al., 2021, Connolly et al., 2021, Danesh et al., 2022). Most ICU recovery services in the UK comprise follow up clinic consultations with limited availability of community rehabilitation programmes (Connolly et al., 2021). A recent guide produced by the Faculty of Intensive Care Medicine in the UK titled ‘Life after Critical Illness’ outlined that rehabilitation should be patient-centred, supporting patients to achieve their individualised goals to improve quality of life (The Faculty of Intensive Care Medicine, 2021). This suggests that an intervention built on goal setting is more appropriate and likely to complement follow-up recovery services as well as improve patient outcomes. Further evaluative work once the menu has been programmed onto our digital platform is warranted to assess patient engagement and acceptability of the menu in this format.

In relation to future practice, our recovery goal menu has the potential for adaption and scalability to other contexts such as ICU recovery prior to hospital discharge, community rehabilitation services, and critical care recovery clinics. Transfer of the record of patient-centred goals between clinicians and services supports continual goal setting/achievement. Use of the goal menu and mapping of recovery goals may also help clinicians better understand and phenotype critical illness recovery progression. This may influence the structure of existing clinical services or inform the development of new rehabilitation pathways for these patients. There is also potential for the menu to complement The Post-ICU Presentation Screen – Community version (PICUPS-Community) (Turner-Stokes et al., 2022, UK Rehabilitation Outcomes Collaborative et al., 2020) as there are similar domains in both. The PICUPS-Community screening tool informs understanding of the rehabilitation and support needs of patients recovering from critical illness, thereby informing the basis of a rehabilitation prescription. Once rehabilitation needs are identified, the goal menu could be utilised to set recovery goals within these areas. Another interesting area of future research is to explore whether availability of the menu is associated with improved engagement in goal setting as compared to patients having to come up with their own goals without the aid of a menu.

**Limitations**

We recognise that despite extensive consultation, the menu may not reflect all goals former ICU patients may wish to set for their recovery. Additional personalised goals can be added to a recovery plan. Evaluation of the menu embedded into our digital ICU recovery platform will enable us to understand if common goals have been omitted and need to be added to future iterations. We endeavoured to include all the professional groups involved in critical illness recovery during the consultation process and assessment of content validity, however we recognise that Psychology and Neuropsychiatry were not represented. This may have impacted on the goals included within the menu. Due to the number of goals to be rated with the content validity index we did not invite former ICU patients to participate in this phase of the content validity assessment. We recognise that this as a limitation of our results. With the inclusion of more goals, the menu is now longer than originally anticipated. We recognise this may affect patient engagement with the menu and overall usability. We will evaluate this once the menu is programmed into our ICU digital recovery pathway.

**Conclusion**

Through an extensive iterative approach with ICU healthcare professionals with expertise in ICU recovery and end-users we have developed a recovery goal menu for former ICU patients. We anticipate this menu will not only help patients to set their own goals to enhance recovery but will also enable mapping of recovery goals that will increase our understanding of the interventions needed and of how individuals recover from critical illness. This may help inform the provision of rehabilitation services in the future. Our next step in our research programme is to evaluate the menu in terms of acceptability and usability once it is programmed into our digital ICU recovery pathway.

**Abbreviations**

CMOP-E - Canadian Model of Occupational Performance and Engagement

CVR - Content Validity Ratio

FIM – Functional Independence Measure

FAM – Functional Assessment Measure

GAS – Goal Attainment Scaling

HrQoL - Health-related quality of life

ICU – Intensive Care Unit

I-CVI - Item-Content Validity Index

PICS – Post-intensive care syndrome

PICUPS-Community - Post-ICU Presentation Screen – Community version

S-CVI/Ave - Scale Level-Content Validity Index/Average

S-CVI/UA - Scale Level-Content Validity Index/Universal Agreement

UK – United Kingdom

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Table 1: Characteristics of participants in Stage 2 cognitive interviews

|  |  |
| --- | --- |
| Demographics | Median (IQR) |
| Age – years | 48 (12.5) |
| Sex – n (%) |  |
| Male | 4 (57) |
| Female | 3 (43) |
| Ethnicity – n (%) |  |
| White | 7 (100) |
| ICU LOS - days | 16 (20) |
| MV duration - days | 12 (19) |
| Hospital LOS - days | 37 (20) |

All figures are median (IQR) unless otherwise specified.

Abbreviations: ICU: Intensive Care Unit, LOS: Length of stay, MV: Mechanical ventilation