

Novel digitally enabled care pathway to support postintensive care recovery and goal attainment following critical illness

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INTRODUCTION

Intensive care unit (ICU) survivors, particularly with a protracted length of stay such as those mechanically ventilated for COVID-19 pneumonitis, experience lasting physical, cognitive and psychological challenges that impede their recovery and functional capability.¹ Survivors also experience substantial symptom burden including breathlessness, extreme fatigue and pain.² Together, the healthcare issues faced by ICU survivors are frequently referred to as postintensive care syndrome (PICS). Family members acting as informal caregivers experience substantial psychosocial burden and in some cases loss of employment and financial difficulties due to their informal caregiver commitments.³ Unfortunately, fragmentation in healthcare delivery following transfer from the ICU to an in-patient ward location, and following hospital discharge, is all too common.⁴ This fragmentation results in mismatches in the healthcare services needed and those received, information loss, treatment omissions, hospital readmission, and poor patient and family experience, all of which may interfere with recovery.^{5–7}

Despite the well-established recovery challenges faced by ICU survivors and their family members, development of a recovery plan and provision of follow-up recovery services are highly variable, and in some jurisdictions extremely limited.⁸ Individualised recovery goal setting, although the standard of care across many areas of rehabilitation⁹ is not routine for ICU survivors. Virtual care and telemedicine may provide a solution to bridge the

Summary box

What are the new findings?

- ▶ We present an innovative digital recovery pathway incorporating individualised goal setting, goal attainment scaling monitoring, symptom monitoring and tailored informational e-resources for intensive care unit (ICU) survivors and their families.

How might it impact on healthcare in the future?

- ▶ Immediate healthcare and rehabilitation needs of ICU survivors following hospital discharge are better met.
- ▶ Healthcare literacy needs of ICU survivors and their family members are addressed and tailored to individual need.
- ▶ Reduced unscheduled utilisation of existing acute and community healthcare services by ICU survivors.

fragmentation prevalent across arbitrary healthcare system boundaries and thus enable individualised patient and family-centred recovery for ICU survivors. Although telemedicine is commonly used in the management of chronic diseases such as Chronic Obstructive Pulmonary Disease (COPD) and congestive heart failure,¹⁰ only a few examples exist that facilitate rehabilitation and recovery of ICU survivors such as the virtual Sepsis Transition and Recovery (STAR) programme for sepsis survivors in the USA.¹¹

Therefore, as a clinical service innovation, we aimed to create a digital recovery pathway delivered via an e-health platform (aTouchAway, Aetonix, Canada)

incorporating individualised goal setting, Goal Attainment Scaling (GAS) monitoring, symptom monitoring and tailored informational e-resources for ICU survivors and their families. Our objective of this clinical innovation to restore continuity of information and healthcare delivery across the two key care transitions—from ICU to the ward and from hospital to home—that is individualised and responsive to the currently unmet healthcare and education recovery needs of ICU survivors and their families.

METHODS

Intervention design

The ICU digital recovery pathway has been coproduced by healthcare professionals, clinical academics, patients and family members, in collaboration with our e-health partner Aetonix. Intervention design involved iterative development of clinical workflows (similar to automated protocols) for both the in-hospital and at-home phases of recovery. These workflows were then programmed into the virtual care platform aTouchAway. The central component of the pathway is individualised recovery goal-setting by the patient in collaboration with a dedicated ICU recovery coordinator.

The ICU digital recovery pathway comprises the following elements: (1) e-forms for the assessment of baseline status and barriers to recovery; (2) setting of individualised recovery goals; (3) patient self-reported e-monitoring of goal achievement with automated reminders; (4) provision of e-resources tailored to recovery barriers; (5) patient recovery e-diary; (6) tailored activity reminders; (7) note function enabling the recovery coordinator to document patient encounters with optional electronic medical record upload and (8) two-way digitally secure text, audio and video communication between the patient, nominated family members and the recovery coordinator (figure 1). These eight elements are present in both the in-hospital and at-home stages of the pathway. Elements 1–4 are performed on enrolment for the in-hospital phase and repeated prior to home discharge. The at home version of the pathway also includes weekly check-in and symptom management e-forms that notifies the recovery coordinator of any ongoing or new physical, cognitive and psychological issues and ongoing or new symptoms as well as a 6-week home recovery assessment e-form.

ICU patients enrolled onto the pathway by the recovery coordinator are those who received mechanical ventilation for three or more days; and are (1) haemodynamically stable; (2) conscious and cooperative; (3) not considered at end of life and (4) considered able to participate in the recovery process. These are the same criteria used for referral to the ICU recovery clinic. For pragmatic reasons, we included only patients who can communicate in English, or has a family member that can communicate for them.

ICU patients are regularly screened for inclusion on the pathway once clinically improving following ICU discharge. There are no specific exclusions to enrolment on the pathway.

Personalised recovery goals are set by the patient in discussion with the recovery coordinator with short-term, medium-term and long-term attainment horizons. In-hospital these are defined as 3, 7 and 14 days; at home these are defined as 1, 4 and 8 weeks. Goal-setting is based on GAS and includes discussion between the patient and the recovery coordinator and then documentation on the digital ICU recovery pathway of (1) what goal achievement would look like; (2) goal importance; (3) perceived goal difficulty and (4) perceived ability to attain the goal.^{12 13}

Monitoring of goals is also based on GAS, with patients rating the goal as achieved better than expected, achieved as expected or not achieved. The recovery pathway workflow codes patients as status green, yellow or red based on their responses, which are then reviewed by the recovery coordinator. Once goals are rated, new goals can be set within the digital ICU recovery pathway if considered appropriate by the patient and recovery coordinator.

The e-resources available via the patient's aTouchAway account are tailored to the patient's unique recovery barriers assessed on enrolment to the pathway and prior to home discharge. We developed a library of very brief information sheets (see figure 1, panel 6 as an example) for managing commonly experienced symptoms such as fatigue, nausea, breathlessness; issues affecting recovery such as difficulty swallowing, reduced balance; and strengthening exercises. These e-resources are suited to the early phases of recovery when patients struggle with large amounts of information. Brief e-resources are complemented by a comprehensive library of in-depth patient information resources covering physical, psychological, cognitive and social domains of ICU recovery. The library includes hospital information leaflets, tailored guidance from expert groups and links to specialist recovery websites and key National Health Service (NHS) approved apps.

Following hospital discharge, patients are asked to complete the weekly check-in e-form. Patients are contacted by the recovery coordinator via the secure aTouchAway platform on a weekly basis to discuss recovery goals, as well as new and ongoing issues related to recovery and symptom management. The recovery coordinator also organises appropriate specialist or community referrals to address unmet or new recovery needs. Weekly check-ins are done for 4 weeks following discharge, every 2 weeks for a month, and then monthly until the patient attends an appointment at the ICU recovery clinic –12 weeks after hospital discharge. Prior to this clinic appointment, the recovery coordinator prepares a summary for the clinic team of recovery goal achievement, referrals

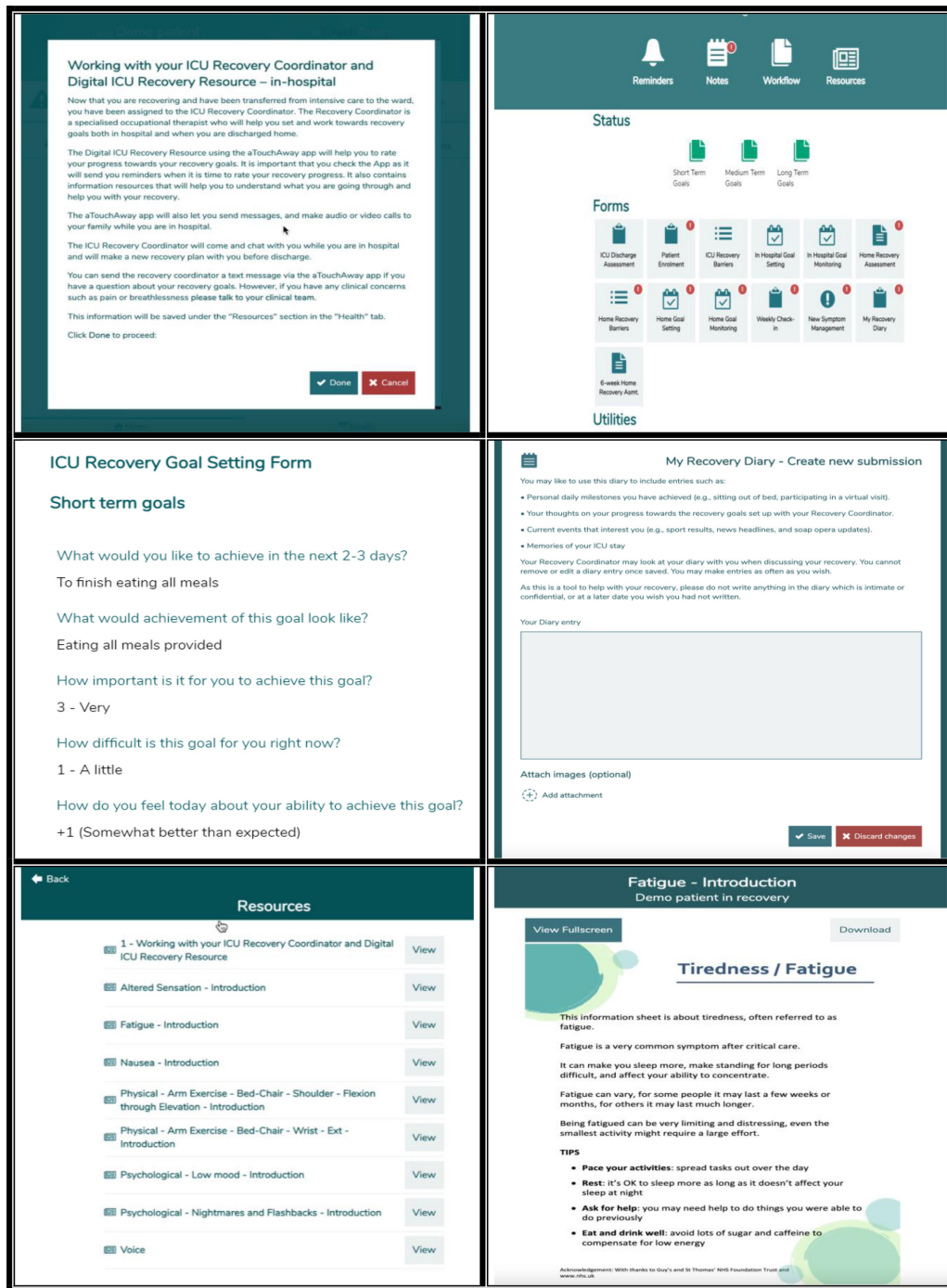


Figure 1 Screenshots of elements of the digital ICU recovery pathway. ICU, intensive care unit.

made and ongoing recovery barriers. After this time, check-ins are done every 4 weeks or on an as needed basis until 6 months after discharge.

Implementation

Implementation steps for the ICU recovery pathway included obtaining relevant approvals from information governance, privacy and security; onboarding of the recovery coordinator—an occupational therapist experienced in ICU recovery; configuration of dedicated tablets and purchase of tablet stands for patients in the hospital recovery pathway; and communication

with the relevant ICU and therapist teams. Dedicated 4G enabled tablets were configured to the recovery pathway and with access to websites and apps related to ICU recovery as well as activities such as news sites, games (eg, sudoku; crosswords), e-books and music.

In the first 3 months, we have worked with the recovery coordinator, programming team and patients to refine our processes in terms of identifying appropriate patients, debugging programming issues and integrating the recovery coordinator role and pathway in the in-hospital and ICU recovery clinical teams.

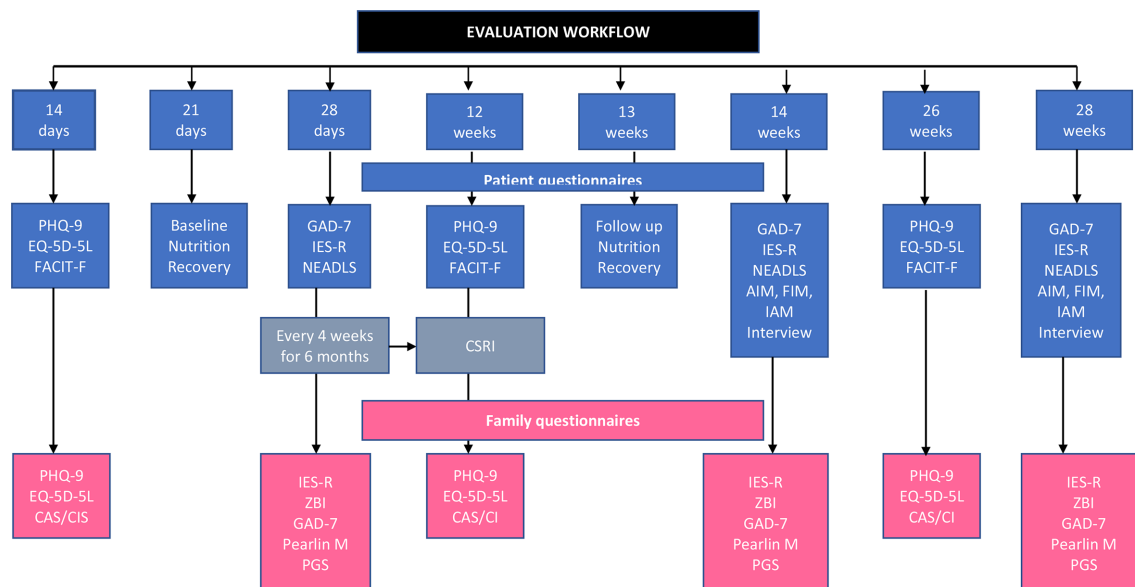


Figure 2 Evaluation workflow. AIM, Acceptability of Intervention Measure; CAS, Caregiving Impact Scale; CIS, Caregiving Assistance Scale;^{22,23} CSRI, Client Services Receipt Inventory;¹⁵ EQ-5D-5L, EuroquoL–5 Dimensions–5 Levels;²⁴ FACIT-F, Functional Assessment of Chronic Illness Therapy-Fatigue;²⁵ FIM, Feasibility of Intervention Measure;¹⁴ GAD-7, General anxiety Disorder-7;²⁶ IAM, Intervention Appropriateness Measure; IES-R, Impact of events Scale-Revised;²⁷ NEADLS, Nottingham Extended Activities of Daily Living Scale;²⁸ Pearlín M, Pearlín Mastery;²⁹ PGS, Personal Gain Scale;³⁰ PHQ-9, Patient Health Questionnaire-9;³¹ ZBI, Zarit Burden Interview.³²

Evaluation

At 14 and 28 weeks, as part of our service evaluation assessing acceptability and feasibility of the recovery pathway, we have incorporated the Acceptability of Intervention Measure, Intervention Appropriateness Measure and Feasibility of Intervention Measure.¹⁴ We also offer the opportunity to participate in a qualitative interview exploring perceptions of pathway acceptability and barriers and facilitators to its use.

In addition to the ICU recovery pathway workflow, we have also developed a recovery outcomes workflow. This provides the patient with validated questionnaires via their secure aTouchAway account that are then used by the ICU Recovery Clinic to assess important elements of physical and emotional recovery and health related quality of life and make appropriate referrals (see figure 2). We have also included a nutritional recovery questionnaire developed in consultation with clinical experts and end-users to measure nutritional needs at 3 and 13 weeks. Completion reminders are sent via the e-platform at 7 days with alert sent to the recovery coordinator’s aTouchAway account. We purposefully staggered questionnaires over 2–4 week periods at baseline, 3 months and 6 months intervals to reduce questionnaire fatigue. Every 4 weeks patients are also presented with the Client Services Receipt Inventory¹⁵ to capture healthcare utilisation following hospital discharge.

Family members are also linked to the patient’s aTouchAway account during hospital admission as a contact with the patient’s permission. This enables patients and family to communicate via text messages

or audio/video calls. For family members we are also collecting validated questionnaires to evaluate family member psychological and caregiver outcomes as well as health related quality of life (see figure 2).

RESULTS

The digital ICU recovery pathway was implemented as a service innovation in June 2021. Over the first 12 weeks of implementation, 87 patients were screened. Fifty-one were eligible and 19 were enrolled. Of those 31 who were not enrolled, five declined as not able to engage with the technology and 26 were discharged before review for participation. Reasons for ineligibility were cognitive impairment, death in hospital, less than 72 hours of invasive mechanical ventilation and non-English speaker. The first five patients (three female, two male; median age 57) using the pathway for 2 months had a median (IQR) ICU length of stay of 14 (9–30) days with two out of the five admitted for COVID-19 pneumonitis. One patient was commenced on the pathway in hospital, the remainder on transition to home due to being discharge ready. All five patients identified anxiety, difficulty sleeping, fatigue and global weakness as barriers to recovery; barriers such as problems with swallowing, dizziness, nausea and altered sensation were uncommon. The following educational resources were assigned to four or more patients; Returning to Driving, Coping with Fatigue Following a Critical Care Admission, Nutrition at Home After Critical illness, Pain Support, Difficulty Sleeping.

The short-term goals set by patients on pathway commencement have primarily focused on ability to walk independently with distance, time and amount of support personalised to the patient's ability. Medium term goals have also focused on mobility with others related to activities of daily living such as preparing a meal and shopping. Two patients reported achieving their initial short-term goals, two partially achieved, and one did not achieve. During completion of the first weekly check-in, four (80%) patients identified new or ongoing issues related to recovery. All four identified issues with mood, three identified issues with memory, one patient identified issues with eating and drinking and another with activities of daily living.

DISCUSSION

In this paper, we outline the design and the early implementation phase of a novel digital recovery pathway introduced as a clinical innovation for ICU survivors. Although we designed the pathway to be commenced in-hospital, early experience suggests patients may be not ready to engage in recovery goal setting in the immediate post-ICU period or in some cases, the time frame from ICU to hospital discharge is relatively short. Language, cognition and familiarity with or access to technology, particularly in the older generation (<https://www.goodthingsfoundation.org/the-digital-divide/>), do pose barriers in terms of ability to enrol patients onto the pathway. When language is a barrier for a patient, we have been able to work with a family member who can help their relative interact with the digital pathway at home. We do have the potential to loan tablets to patients lacking their own device, however their lack of technology familiarity likely makes this option infeasible. In both phases of the digital pathway, it is important to have good inter-professional relationships and interworking with the existing therapy teams, outpatient clinics and community services to facilitate integration of the digital recovery pathway within existing services.

At present, other contemporary solutions to ameliorating fragmentation at key transition points include ICU to ward discharge summaries, rehabilitation prescriptions and ICU recovery/follow-up clinics. However, ICU to ward discharge summaries are designed primarily for healthcare team members and do not provide resources needed to promote patient and family engagement in recovery.¹⁶ Rehabilitation prescriptions are used only in a small number of critical care services and are generally therapist as opposed to patient-led.¹⁷ ICU recovery/follow-up clinics generally provide appointments 6–12 weeks after discharge.¹⁸ During the intervening period, patients receive limited support to address the complex issues faced by ICU survivors and their family members in the immediate return to home.¹⁹ Our digital recovery pathway aims to address this service gap. Unmet needs during this highly vulnerable period include provision of assistive

devices for function and breathing support; coordination with government assistance and community health and social care programmes; rehabilitation therapy; medication management and services to support mental health.¹⁹ Other unmet needs crucial to hospital and early post-discharge recovery include provision of tailored informational resources on critical illness recovery for patients and family members as well as assessment of recovery needs and individualised setting of recovery goals.^{20 21}

CONCLUSIONS

We have successfully designed and report on early implementation of a digital recovery pathway incorporating individualised goal setting, GAS monitoring, symptom monitoring and tailored informational e-resources for ICU survivors and their families. At present, we continue to make iterative changes based on patient and clinician feedback while collecting data to demonstrate feasibility and acceptability of the pathway as well exploratory data on whether the pathway addresses healthcare needs in the immediate post-hospital discharge period and promotes recovery. Future research will explore feasibility of a multicentre trial to determine whether the pathway improves patient recovery outcomes compared with the standard of care.

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Competing interests None declared.

Patient consent for publication Not required.

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