Rehabilitation following Critical Illness

Study Protocol

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Introduction

Increasingly patients admitted to critical care are more likely to survive to hospital discharge. This survival is not without cost, as these patients (who are increasingly older and have chronic co-morbidities) are often left with significant physical, psychological, and cognitive morbidity collectively termed 'post intensive care syndrome'. As a result, survivors of critical illness have complex rehabilitation needs, both within the short and long term, impacting on return to pre-illness quality of life and function [1-3]. In 2009 NICE advocated the requirement for early and structured programmes of rehabilitation for patients admitted to critical care, though there remains poor uptake and implementation. This guideline touches on several key measures of quality throughout the patient pathway [4].

From the moment of admission, critically ill patients experience both physical and non-physical decline. Muscle mass reduces at a rate of 2-3% every day. Delirium is common, affecting up to 70% of patients who require mechanical ventilation, and associated with long-term cognitive impairment. Critically ill patients frequently experience nutritional morbidity on discharge from ICU, with hospital-acquired malnutrition and an inability to eat and drink all too common. Those discharged from ICU often require expert laryngeal management due to the impact of artificial airways affecting swallowing, secretion management and communication. Failure to address these issues in a timely and efficient manner, leads to further worsening of patient outcomes and distress [1-3].

Patients stepping down from critical care to general wards have complex rehabilitation needs. As patients move to areas responsible for treating their primary condition, ongoing post intensive care problems often go unrecognised or are sub-optimally managed. This leads to variations and inequality in post critical care rehabilitation. A lack of access to the multidisciplinary team further exacerbates this issue, meaning rehabilitation may be focused solely on mobility to facilitate hospital discharge rather than supporting complete recovery [4-5].

Following discharge from hospital patients are often left with significant ongoing physical, functional, and psychological morbidity. Recovery can take months or even years and is often incomplete. A lack of structured and formal follow up means patients are often left to fend for themselves following hospital discharge, creating feelings of social isolation, abandonment, vulnerability and reduced physical activity. Consequently, this results in an inability to return to work, functional disability, financial burdens, and reduced quality of life. Due to a lack of national investment, where present, rehabilitation services have been commissioned at a local level. As a result, and as highlighted by the GIRFT report, overall recovery and outcome becomes dependent on where a patient lives, rather than solely related to the severity of critical illness impairments. This is also the stark reality for patients following discharge from hospital. Despite the significant ongoing physical and non-physical morbidity, only 27.3% of organisations reported any form of post-critical care follow-up of patients, and 6.8% reported availability of a rehabilitation programme [6].

Specialist rehabilitation programs addressing subsets of patients admitted to intensive care (e.g., trauma, stroke, cardiac disease) have repeatedly been shown to be cost-effective, recouping cost early, and generating significant savings (e.g., lifetime savings of £700k per patient in traumatic brain injury). However, the majority of patients admitted to intensive care units fall outside these strict criteria (e.g., sepsis or emergency surgery) and no such provisions exist. The inadequacies in current service provision were especially evident and completely unprepared for the 35,000 extra patients admitted to ICUs in the first two waves of the COVID-19 pandemic, for whom no rehabilitation and restitution plans exist [7].

References

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Guidelines and standards

- E10/S/a NHS Standard Contract for Complex Gynaecology - Severe endometriosis. 2013. Gateway Reference 01369. https://www.england.nhs.uk/wp-content/uploads/2018/08/Complex-gynaecology-severe-endometriosis.pdf
- Faculty of Intensive Care Medicine - Guidance for recovery and rehabilitation for patients following the pandemic – May 2020. https://www.medscape.co.uk/viewarticle/faculty-intensive-care-medicine-guidance-covid-19-recovery-2020a10010so
- Guideline for the Provision of Intensive Care Services (Vol 2) – Provides an overview around the process and pathway of rehabilitation service delivery, including screening for new morbidity and the need for multi-professional input and intensive care follow up clinics https://www.ficm.ac.uk/standardssafetyguidelinesstandards/guidelines-for-the-provision-of-intensive-care-services
- Intensive Care Society – Rehabilitation Framework and Framework for assessing early rehabilitation needs following treatment in intensive care. https://ics.ac.uk/guidance/rehabilitation.html
- Public Health Outcomes Framework 2019/20: a consultation. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/822149/Government_response_to_proposed_changes_to_PHOF_2019_to_2020.pdf
    - E- Healthcare and premature mortality **–** reduce mortality from causes considered preventable and emergency hospital readmissions within 30 days of hospital discharge.
- NICE Guideline CG83 Rehabilitation after critical illness in adults - This guidance covers rehabilitation strategies for adults admitted to intensive care. https://www.nice.org.uk/guidance/cg83
- NICE Quality Standard 158 – Describes high priority areas for quality improvement and provides quality statements on initiating rehabilitation, handover, and patient information. https://www.nice.org.uk/guidance/qs158/chapter/About-this-quality-standard
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    - Domain 2 - Enhancing quality of life for people with long term conditions**,** ensuring people feel supported to manage their condition. Maximise functional ability to support return to work. Improve quality of life of carers.
    - Domain 3 – Helping people to recover from episodes of ill health or following injury.
    - Domain 4 – Ensuring that people have a positive experience of care
- The Adult Social Care Outcomes Framework 2018/19. https://www.gov.uk/government/publications/adult-social-care-outcomes-framework-handbook-of-definitions
    - Domain 1 - Enhancing quality of life for people with care and support needs, giving people control and providing access to support which matches their needs.

Aims and Objectives

Overall aim:

This study aims to evaluate the rehabilitation provided to critically ill adults within intensive care units, as well as throughout the recovery pathway to encompass both ward based and community care.

Objectives

Clinical

To identify:

- how physical, psychological, and cognitive rehabilitation needs are identified within the ICU.
- when rehabilitation needs are identified, and what access to the multidisciplinary team is available.
- whether rehabilitation was initiated at the appropriate time in ICU.
- whether rehabilitation was delivered with an appropriate level of consistency.
- what governance processes are in place to ensure a robust structure for rehabilitation delivery.
    - e.g., MDT ward round, Goal-setting meetings, individualised treatment plans
- what measures of quality are used for rehabilitation delivery and patient outcomes.
    - e.g., which Patient Reported Outcome Measures (PROMs)?
- what processes are in place for assessment of rehabilitation need at ICU discharge and how are these identified needs handed over to ward teams on step down.
- whether patients' physical, psychological, and cognitive rehabilitation needs are being met in the ward environment.
    - whether there is follow-up from ICU/ ICU after care services on to the ward with continuity and consistency of delivery.
    - whether there is access to the MDT on the ward.
- whether there is an assessment of rehabilitation needs on hospital discharge.
- what follow up provision exists following hospital discharge and do patients receive ongoing rehabilitation as required, following hospital discharge.
- who is responsible for coordinating rehabilitation throughout the recovery pathway.
- what opportunity has the patient had to engage in discussion about their critical illness and their wishes and preferences.
- to what extent are the patients views and wishes considered when developing treatment goals.
- what information is provided to patients, relatives and carers within hospital and following discharge regarding critical illness, rehabilitation, and recovery and information on how to access support.
- how is information regarding the patients ongoing rehabilitation needs handed over to community services (where required)?
- Who is responsible for the patient's rehabilitation needs following discharge from hospital
- If the patient's is GP provided with an appropriate summary of the patient's hospital stay AND any ongoing rehabilitation needs.

Organisational

To identify:

- the type of service available at hospital and arrangements for the provision of the service being investigated.

- the governance arrangements, policies, and protocols on assessment of rehabilitation need and subsequent provision.
- the access and availability to members of the multidisciplinary team to provide rehabilitation services to patients.
- The employment of MDT members, WTEs dedicated and ring-fenced for ICU rehabilitation.
- If there exists a hospital lead for ICU rehabilitation, and if so their training and experience.
- the access to specialist services.
- organisational structures in place to deliver the highest quality rehabilitation care and ensure seamless transition between ICU, the ward, and the community.
- the access to specialist equipment e.g. specialist seating, mobility aids, access to gym space

- is there a programme of education for step down wards on ICU recovery?
- availability of rehabilitation teams in the community for primary care to refer to if long term issues are identified?
- how hospitals are aligning critical care rehabilitation work programmes for service improvement.
    - Including participation in national work programmes

Methods

Early patient involvement

As part of the early scoping of this study, we have worked with patients to identify the areas of care that are important to review, and to ensure a patient-centred study. This was done by undertaking a series of four focus groups with patients who had experienced a stay of 4 or more consecutive days on ICU.

The results of these have fed into the development of the study aims and objectives, and a summary is included in Appendix 1.

Participating hospitals

Data will be collected from hospitals in England, Wales, and Northern Ireland, in which patients can be admitted to intensive (level 3) care and hospitals where rehabilitation care is provided to inpatients as well as from primary care and community providers.

Population

Patients aged 18 and over, who were admitted to hospital as an emergency and who survived to hospital discharge, following a stay for 4 or more consecutive days on a level 3 unit.

Exclusions

Neurology/ trauma patients will be excluded from the study

Incidence and prevalence

ICNARC data from 197 Adult critical care units (including ICUs and ICU/HDUs)			
	2019	**2020**	**2021**
Total admissions	**150,089**	**130,917**	**127,628**
Survivors	**141,320**	**120,124**	**114,4449**
Mean length of stay on ICU (days)	**5.4**	**6.4**	**7.2**

Case identification

Patients will be identified retrospectively via a patient identifier spreadsheet, which will be disseminated to Local Reporters to populate with basic data (hospital details, NHS number, age, admission/ discharge dates, primary ICD10 and OPCS codes, source of admission and discharge destination and named GP) for patients who received ICU (level 3) care for four or more consecutive days during the sampling period:1st October 2022 to 31st December 2022 (NB patients' care will reviewed for up to 1-year post-discharge from the ICU). From this pool of data, a maximum of 15 patients will be sampled from each ICU for inclusion in the detailed review process. In addition, the local reporter will be asked to provide details for this smaller sample of any community-based rehabilitation care, so that the complete case information can be sought.

Method of data collection

In-hospital clinician questionnaire

A questionnaire will be sent to the named consultant intensivist for each patient in the study. We will limit the number of questionnaires to 4 per consultant to minimise the burden on individual clinicians. Questionnaires can be completed by the named intensivist with input from the MDT. We will ask that the named rehabilitation lead/ coordinator at each hospital act as a 'study contact', to facilitate the process and to support the Local Reporter to collect the required data.

Data collected will include information on the assessment of rehabilitation needs and access to rehabilitation throughout the inpatient hospital stay and following discharge from hospital at follow-up appointment(s) for up to 1-year post-discharge.

The questionnaires will be disseminated via the NCEPOD online questionnaire system which is accessed by NCEPOD Local Reporters. The Local Reporters will then be able email the relevant clinician, granting them access to the online questionnaire. Reminder emails will be sent at six weeks and ten weeks where the data are outstanding. The Local Reporter will be asked to return copied extracts of the patient's case notes to NCEPOD alongside the completed questionnaires.
The study will be promoted through the Intensive Care Society and the Rehabilitation CRG.

GP and community clinical questionnaire

A short questionnaire will be disseminated to the patient's GP to identify the provision for assessment of rehabilitation needs and delivery of rehabilitation in the community, including routine follow-up appointments for up to 1-year following discharge from hospital (following the ICU stay of 4 or more consecutive days).

Hospital organisational questionnaire

An organisational questionnaire will be disseminated to all participating hospitals that will collect data on the organisational structures, policies and staffing required to deliver a high-quality rehabilitation service (as outlined in the organisational objectives)

Case note review

Case notes including, but not limited to:

- ICU notes, ICU discharge documentation, post-ICU step-down, ward notes, rehabilitation care pathway documentation, rehabilitation prescription/ passport discharge from hospital documentation, GP letters, details of follow-up appointment/s (up to 12 months post-discharge)
- Community/ rehabilitation hospital in-patient notes (if applicable)
- GP notes (if applicable, up to 12 months post-discharge)

- Community services notes (if applicable, up to 12 months post-discharge)

Photocopies/ digital scans of the case notes of each included patient will be requested at the time of questionnaire dissemination. A list detailing the required case note extracts will be circulated to Local Reporters. Upon receipt at NCEPOD the case notes will be made anonymous for all patient identifiable information.

Reviewer assessment form
A multidisciplinary group of reviewers (details below) will be recruited to assess the case notes and questionnaires and give their opinions on the quality of the rehabilitation care provided across the pathway via completion the reviewer assessment form.

Anonymous on-line patient and carer survey
This will be an anonymous online questionnaire for patients who have had a stay of 4 or more consecutive days on ICU (level 3 care) and their carers collecting their views of the services available to them. The data will not be linked to any other aspects of data collection.

Anonymous on-line Clinician survey
This will be an anonymous online questionnaire for healthcare professionals in the MDT involved in the care of patients' rehabilitation and collect their views on the service they provide, including training, experience, and competencies to deliver rehabilitation.

Data source	**Target number**
Organisational questionnaire	~200
Clinician questionnaires	~500
Case note review	~500
Patient survey	~100

Study method test
The data collection methods and data collection tools will be tested to ensure they are robust.

Analysis and Review of Data

Reviewers
A multidisciplinary group of reviewers will be recruited to assess the case notes and questionnaires and provide their opinion on the care the patients received.

An advertisement will be sent to Local Reporters to disseminate throughout the relevant departments. It will also be placed on the NCEPOD website. Successful applicants will be asked to attend a training day where they will work through anonymised case notes with the case reviewer form.

A number of meeting dates will be arranged, and each reviewer will then be asked to attend a further 4 meetings. NCEPOD staff will ensure there is a mix of specialties at each meeting from across England Wales and Northern Ireland. The group will include ICU consultants, physiotherapists, speech and language therapists, occupational therapists, dietitians, ICU nursing staff, general nurses, rehabilitation consultants, general surgical and medical consultants.

Each meeting will be chaired by an NCEPOD clinical coordinator who will lead discussion around the cases under review.

Towards the end of the study the reviewers will be invited to attend a meeting where the data will be presented to and discussed with them and the Study Advisory Group. The reviewers will also be sent two copies of the draft report for their comment as this is developed.

Confidentiality and data protection
All electronic data are held in password protected files and all paper documents in locked filing cabinets. As soon as possible after receipt of data NCEPOD will encrypt electronic identifiers and anonymise paper documents. Section 251 approval has been obtained to perform this study without the use of patient consent in England and Wales. Public Benefit Privacy Panel approval has been received for Scotland.

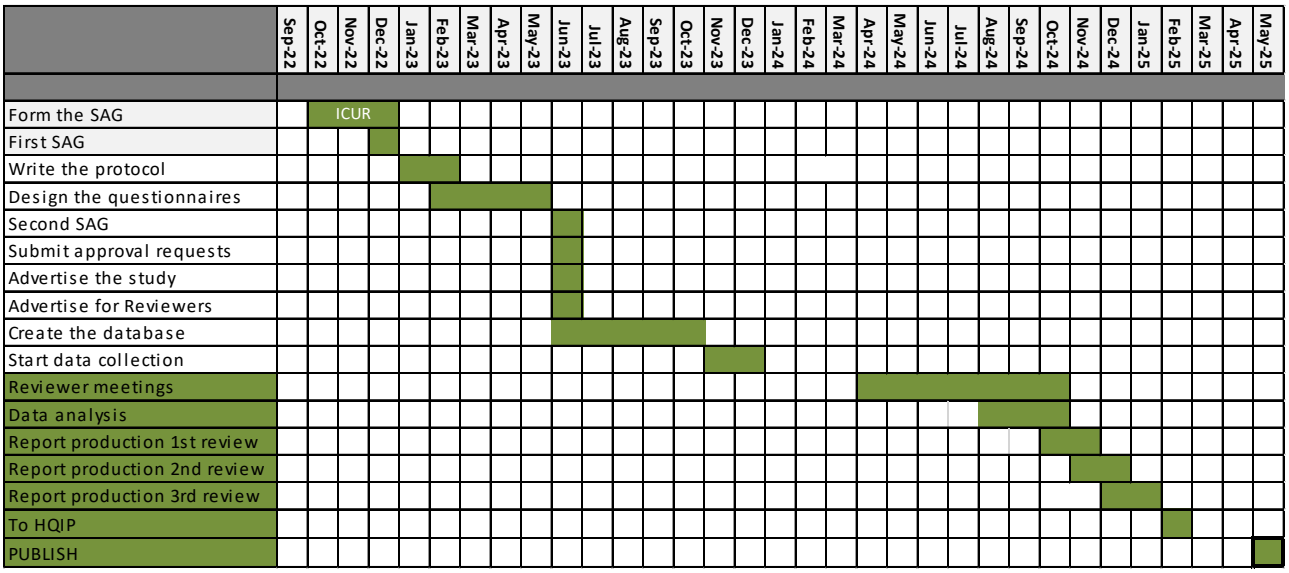
Study promotion
Prior to data collection, NCEPOD will contact all hospitals that have a (level 3) Intensive care unit to promote the study. The study will also be promoted to patients via patient groups, e.g., ICU Steps, NCEPOD Local Reporters (sending the study poster on to the relevant departments), via study contacts recruited as part of the case identification strategy, and via the relevant Colleges and Associations

Dissemination
On completion of the study a report will be published and widely disseminated.

Data sharing
Post publication of the study there is the potential to share anonymised data sets with interested parties working in the same field. This will be undertaken following a strict process and will ensure the data does not become identifiable in their nature due to small numbers.

Timeline - old

Timeline - new



Appendix 1

Scoping focus group summary

At the study outset, four focus groups were undertaken to gather the views of patients on what went well, and what did not go well with their rehabilitation care post ICU stay to inform the direction of the study.

Participants were recruited via social media and with the help of ICU steps.
15 people participated in these sessions, with representation from across the UK.

The areas the focus group participants indicated it was important to include in the study are listed below. These will feed into the development of the study aims and objectives.

Areas to review:

- Communication within the ICU
    - Communication can be blunt with families/partners, lacking bedside manner and more compassion on procedures - need for online resources.
    - Maintaining ICU diaries for patients
    - Some patients had a lack of counselling support, or mental health support in general – need to talk through ICU stay not met without proper counselling.
    - Communication between doctors and nurses

    - Communication is needed between the nursing staff and patients to assist in the routines, comfort, and in easing delirium for patients.

- Education of staff to understand the severity of how much rehabilitation patients need, difficulties communicating with them and the journey that lies ahead.
- Consistency of care for patients stepped down from ICU to General wards
- Transition from ICU to general ward was generally inadequate and a bad experience for patients. Lack of ICU to ward understanding and step-down from ICU identified.
- Lack of support in the community once patients have been discharged from hospital seemed hit and miss, but mostly negative.
- Delay in assessments and follow-up after discharge from hospitals can be as long as 6 weeks after, without having any support.
- Little input from other allied health professional e.g., occupational health, are available on occasion only, and long waiting lists for services.
- More training for staff in ICU to handle patient deliriums
    - The majority of patients still have PTSD after their episodes of delirium at ICU – need for help in recovery from this and support.
    - More resources to inform staff on the states of delirium and patient experiences.