

Commissioner's Guide to the NCEPOD Report 'Recovery Beyond Survival'

INTRODUCTION

Critical care provides specialised hospital treatment and constant monitoring for people who are seriously ill, often for patients who have a serious problem with one or more organs. They may receive critical care due to a short-term condition such as an infection, heart attack or stroke, or following a serious accident or major surgery. The NHS has different levels of critical care depending on a patient's needs. This report focuses on the rehabilitation of patients who had an admission to an intensive care unit (ICU). ICUs provide level 3 critical care for patients who require advanced respiratory support or basic respiratory support together with support of two or more organ systems.

Over 200,000 people in the UK spend time receiving critical care each year with the majority surviving to be discharged home.[1] While many patients will make a good recovery, there is a perception that following a short period of convalescence, people will return to their previous life, in terms of both quantity and quality. However, the impact of a stay in an ICU can be profound with long-lasting effects and people may require ongoing rehabilitation to support their recovery.

While survival rates are a benchmark of the quality of an ICU, the term 'survivorship' has been used to describe the long-term physical, psychological, cognitive and social effects following a patient's stay in an ICU, often encompassed within post-intensive care syndrome (PICS).[2] Rehabilitation aims to maximise recovery and improve outcomes through early identification and implementation of a multidisciplinary approach in people who have received critical care.

For many, discharge from an ICU is the start of an uncertain pathway to recovery, characterised by problems that impact normal living and social relationships. Recovery from critical illness is an individual pathway that needs a tailored therapeutic plan to optimise recovery, with input from all the relevant healthcare specialties and disciplines to cover the full array of patients' needs.

Early rehabilitation strategies, implemented throughout the rehabilitation pathway, from the ICU through to stepdown to the ward and post-hospital discharge reduce morbidity and improve outcome. NICE guideline CG83 sets out a framework for rehabilitation during and following a stay in an ICU.[3-5]

This NCEPOD study sets out to evaluate the rehabilitation provided to critically ill adults within ICUs, as well as throughout the recovery pathway to encompass both ward-based and community services.

The study was developed with wide multidisciplinary input, reviewing the care of patients who had been admitted to critical care (level 3) for a stay of more than 3 days and survived to discharge from hospital.

This study aimed to identify priority areas for improvement in the rehabilitation pathway of patients who are admitted to critical care.

PATIENT POPULATION

Inclusion criteria

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.

Exclusion criteria

Neurology/ trauma patients were excluded as there are more often specific rehabilitation pathways in place.

Clinical and Organisational Issues

The co-ordination of the delivery of rehabilitation

- Only 70/166 (42.2%) organisations reported having a policy or standard operating procedure (SOP) for the delivery of rehabilitation and a Lead clinician for rehabilitation.
- Most organisations reported the presence of named healthcare professionals to co-ordinate the rehabilitation pathway (112/114; 98.2%). However, the clinicians identified only 107/420 (25.5%) patients as having a named healthcare professional/key worker for co-ordinating rehabilitation
- Clinicians found that 304/671 (45.3%) patients had a documented, structured handover at discharge from ICU, 83/671 (12.4%) had a documented verbal handover and 125/671 (18.6%) patients had no evidence of any handover related to rehabilitation needs. There was room for improvement in the handover of rehabilitation care in 186/292 (63.7%) cases reviewed.
- Only 117/365 (32.1%) patients had documented contact details of a named healthcare professional to support them following hospital discharge, while the patient survey reported that 21/34 patients were told that the GP would be their first point of contact
- Despite the high proportion of patients accessing primary care for support, GPs were only aware that a patient they saw had spent time in the ICU in 170/248 (68.5%) cases

The multidisciplinary team delivering rehabilitation

- Most organisations reported the presence of physiotherapists (152/166; 91.6%), speech and language therapists (145/166; 87.3%), and dietitians (148/166; 89.2%) as a part of the intensive care unit (ICU) MDT. The provision of occupational therapists (98/166; 59.0%), psychologists (71/166; 42.8%) and therapy support workers dedicated to rehabilitation (36/166; 21.7%) was less common. Staffing levels across the MDT did not reach the national recommended levels, with particularly low levels across all non-medical/nursing roles
- The absence of sufficient staff often meant that where input was provided, room for improvement was identified with regard to both the timing (128/549; 23.3%) and consistency (90/562; 16.0%) of rehabilitation delivered. This was the case for all members of the MDT, with the biggest delays in timing seen for speech and language and occupational therapist
- Reviewers found that while 192/339 (56.6%) patients received rehabilitation at the weekend, this very rarely included the full MDT (6/339; 1.8%)
- The largest proportion of unmet need related to psychologists, where only 21/159 (13.2%) patients who may have benefited were seen

- Reviewers also identified room for improvement in rehabilitation on the ward, with delays in the timing and consistency of rehabilitation identified across all MDT groups. The largest delays in initiation were seen for occupational therapy (49/136; 36.0%), practitioner psychology (4/21; 19.0%) and speech and language therapy (24/97; 24.7%)
- This theme of delays in initiating rehabilitation was also highlighted in the healthcare professional survey, where 130/420 (31.0%) respondents believed that they did not have adequate time to assess rehabilitation needs and 171/420 (40.7%) stated that they did not have sufficient access to the MDT to deliver rehabilitation following an admission to an ICU.

Initial screening of rehabilitation needs on admission to ICU

- A total of 115/166 (69.3%) participating organisations confirmed that initial screening for rehabilitation needs was routinely undertaken, and clinicians completing questionnaires confirmed that this was the case (356/585; 60.9%). However, case reviewers found that only 104/365 (28.5%) patients had evidence of an initial screen recorded in their case notes.
- In the opinion of case reviewers, the failure to screen impacted the care of 102/186 (54.8%) patients, due to no goals being set, no multidisciplinary team (MDT) involvement, delay and the opportunity to address complex social and psychological needs being missed.

Comprehensive assessment and reassessment of rehabilitation needs throughout the pathway

- It was reported in 130/166 (78.3%) hospitals, that patients routinely underwent comprehensive assessments of rehabilitation need in ICU. However, only 30/130 (23.1%) had a policy detailing which healthcare professionals were competent to carry out the assessment. Furthermore, clinicians caring for the patients reported that the comprehensive assessment was only carried out in 327/574 (57.0%) patients, and assessments, where they were completed, did not involve all the required staff groups.
- Individualised rehabilitation plans in the ICU was documented for only 94/365 (25.8%) patients, which reviewers considered negatively impacted the quality of care of 117/178 (65.7%) patients.
- Following discharge from the ICU a further comprehensive reassessment was carried out in only 80/309 (25.9%) patients. Of the 80 assessments carried out there were often key elements missing, these included no occupational therapist, speech and language therapist, psychologist or dietitian assessment and no MDT or inter-team communication.
- At discharge from hospital a functional reassessment was only carried out for 235/487 (48.3%) patients and a follow-up appointment with the critical care team was made for 278/506 (54.9%) patients, and 102/210 (48.6%) were comprehensively reassessed at follow-up

Information for patients and family/carers

- While 46/88 organisations reported the use of 'All about me' documents, clinicians found that these were only present for 113/446 (25.3%) patients.
- Reviewers found documentation that the patient and their family were adequately updated in only 165/302 (54.6%) cases and considered that there was room for improvement in this area for 114/293 (38.9%) patients Discharge and follow-up

KEY FEATURES OF A SERVICE

1. Multidisciplinary team delivery of rehabilitation should be coordinated throughout the rehabilitation pathway

The report showed an absence of good multidisciplinary team working and communication across the recovery pathway as the patient moved between healthcare settings, from within ICU to the ward setting, and post discharge from hospital. Many hospitals did not have dedicated leadership roles for rehabilitation at board or senior management level or an audited policy or standard operating procedure (SOP). Many did not have named rehabilitation coordinators overseeing the patient's rehabilitation needs throughout the pathway. Rehabilitation was often not mentioned in the handovers of care as the patient progressed through the rehabilitation pathway.

- At an organisational level there should be an audited rehabilitation policy/ SOP based on NICE CG83, and each trust/health board should have a dedicated rehabilitation lead with oversight and responsibility for the provision of holistic rehabilitation and the development of a rehabilitation policy, supported by a senior manager responsible for implementation of the rehabilitation policy. The rehabilitation policy should be developed with input from critical care survivors and their relatives/ carers, be audited regularly and training provided, particularly to non-specialist staff to increase knowledge of the impact of critical illness and rehabilitation requirements.
- At a patient level there should be named rehabilitation care co-ordinator(s) role to oversee patients' rehabilitation needs within the ICU, on the ward and in the community. The rehabilitation care co-ordinator role could be like that of a major trauma co-ordinator, any healthcare professional with the appropriate skills and competency and a designated role with its own job description and ring-fenced time. There may be more than one in larger units.

The rehabilitation care co-ordinator role could:

- Triage patients at risk while having a general oversight
- Co-ordinate the assessments and make sure they are being done
- Ensure that handovers are taking place and being received
- Ensure that patients are getting access to the multidisciplinary team members that they need at all stages of the pathway
- Support communication/information to patients, their carers and families, such as rehabilitation plans and goals
- Ensure that all referrals are in place as patients step-down to the community
- Be a named point of contact for patients following hospital discharge
- Liaise with primary care. Many patients only see their GP in the first year after an ICU admission. As an example, major trauma centres provide telephone follow-up by co-ordinators at two- and six-weeks following discharge. These calls can identify patients who are struggling and then generate early face-to-face review or referral to an appropriate service

2. Ensure that patients at high risk of rehabilitation need are flagged on admission to ICU through the introduction of a standard rehabilitation need screening tool

In the report, baseline assessments were infrequently undertaken, and a lack of initial screening was shown to impact on the quality of subsequent rehabilitation care received. The tool could be developed by incorporating some of those already available (e.g. clinical frailty scales) and might include:

- Severity of illness
- Underlying comorbidities and frailty
- Pre-existing sensory deficits
- Baseline status
 - Physical factors: respiratory function, muscle weakness, activities of daily living
 - Nutrition
 - Cognition: memory, attention and performance
 - Psychological factors: post-traumatic stress disorder and affective disorders
- The tool should include the patient's voice, be validated and should be useable by any healthcare professional working in critical care services

3. A comprehensive, holistic assessment of the rehabilitation needs of patients admitted to an intensive care unit who are at risk of physical and/or non-physical morbidity should be undertaken and documented then repeated at key points of the recovery pathway.

Despite being part of NICE CG83, in the report, assessments were often not completed in ICU or redone throughout the pathway. When they were completed, elements were often missing. Non-physical aspects of rehabilitation, nutrition and a lack of multidisciplinary team (MDT) involvement were the most frequently cited missing elements. However, the completion of comprehensive assessments was associated with better quality of care throughout the rehabilitation care pathway. Performing comprehensive assessments of rehabilitation need throughout the pathway should form part of the rehabilitation policy/SOP in each hospital.

A standardised assessment proforma/tool of rehabilitation needs would aid this process to ensure that all required specialties are included

- This could be held electronically as part of the patient's care record and repeated as required, but to include ICU discharge and hospital discharge as key milestones for reassessment
- The latest version of the assessment proforma could also be part of the discharge summary to general practitioners
- Where available, outcome measures could be used to capture progress as part of the proforma.

4. Ensure that multidisciplinary teams are in place to deliver the required level of rehabilitation in intensive care units and across the recovery pathway.

These should include:

- **All relevant healthcare professionals needed to provide co-ordinated, consistent care in the ICU, ward and community**
- **Regular communication between specialties and discussion of patients' needs at a dedicated multidisciplinary team meeting or rehabilitation rounds when appropriate**
- **Staff to deliver the required rehabilitation.**

Multidisciplinary staffing levels in the ICU often did not meet national guidance (GPICS), resulting in a lack of dedicated time for patients within the intensive care unit, and delays and lack of consistency in the delivery of rehabilitation. Rehabilitation delivery on the ward was even more lacking in the full

compliment of required MDT members. Throughout the pathway, there was less provision of those delivering non-physical rehabilitation needs.

Rehabilitation provision should be commissioned based on patient need rather than diagnosis and cover the ICU, ward and community rehabilitation, using local clinical networks to share resources where possible

Along with the medical and nursing teams, these specialties could be part of the multidisciplinary team (MDT): physiotherapists, dietitians, speech and language therapists, occupational therapists, psychiatrists and mental health professionals, psychologists, and pharmacists

- Ring-fence MDT planning time
- Provide MDT care seven days per week both on the ICU and wards
- Formal MDT meetings or ward rounds within intensive care units (ICUs) could be held at least weekly and attended by all required members of the MDT. A structured tool, such as the standardised assessment proforma/passport (see recommendation 3) could be used
- Formal post-ICU ward rounds may not be practical due to the geographical spread of patients following step-down to the ward. Processes could be put in place to ensure that the MDT jointly discuss and document rehabilitation needs/discharge planning for all patients and track progress.

5. Patients and their family/carers should be provided with clear information about their admission to an intensive care unit, the impact of critical illness and likely trajectory of recovery

This should include the contact details of a named healthcare professional or rehabilitation care coordinator. Patients and their family/ carer should be involved in multidisciplinary team discussions about rehabilitation and rehabilitation planning.

In the report, the patient survey highlighted that this was the most important issue for patients but was not often carried out. Patients were often not updated by the hospital or GP, and there was a lack of follow-up.

- The standardised assessment proforma could take the form of a rehabilitation passport that travels with individual patients along their care pathway
- Regular family updates should be provided regarding rehabilitation progress, including the involvement of the patient and their family in rehabilitation rounds as appropriate
- The 'All About Me' booklets help to provide insight and understanding of the person who is being looked after
- The use of rehabilitation boards in the patient's bedspace can help to share information about current goals and treatment plans
- Patient diaries can be an effective method of capturing the critical care experience
- A discharge summary (with technical terms explained) and/or providing relevant patient information booklets. Explaining the events of their critical illness, what to expect in recovery and their individualised rehabilitation plan are all vital parts of this communication to patients and their families. This should be provided digitally or part of the NHS app, (or paper if the patient is not digitally active)

SUPPORTING NATIONAL GUIDANCE AND REPORTS

- 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>
- NCEPOD - Tracheostomy Care: On the right Trach? (2014). <https://www.ncepod.org.uk/2014tc.html>
- NCEPOD - In Hospital Care of Out-of-Hospital Cardiac Arrests: Time Matters (2022).
<https://www.ncepod.org.uk/2021ohca.html>
- NHS Outcomes Framework 2016-17.
<https://www.gov.uk/government/publications/nhs-outcomes-framework-2016-to-2017>
 - 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.