Recovery Beyond Survival

A review of the quality of rehabilitation care provided to patients following an admission to an intensive care unit





RECOVERY BEYOND SURVIVAL

A review of the quality of rehabilitation care provided to patients following an admission to an intensive care unit

A report published by the National Confidential Enquiry into Patient Outcome and Death (2025)

The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) is an independent body to which a corporate commitment has been made by the medical and surgical royal colleges, associations and faculties related to its area of activity. <u>NCEPOD</u> is a company, limited by guarantee (3019382) and a registered charity (1075588).

The report has been compiled by:

David McWilliams MSc, PhD, MCSP - NCEPOD Clinical Co-ordinator

University Hospitals Coventry and Warwickshire NHS Trust NHS Foundation Trust and Centre for Care Excellence, Coventry University

Alexander Goodwin FRCA FFICM - NCEPOD Clinical Co-ordinator

Royal United Hospitals Bath NHS Foundation Trust

Hannah Shotton PhD - Senior Clinical Researcher, NCEPOD

D'Marieanne Koomson BSc (HONS) – Clinical Researcher NCEPOD

Marisa Mason PhD - Chief Executive, NCEPOD

The authors and trustees of NCEPOD would like to thank the NCEPOD staff for their work in collecting, importing, analysing and reviewing the data for this report: Peyman Aleboyeh, Donna Ellis, Heather Freeth, Rachael Gomez, Holly Hamilton, Nicholas Mahoney, Eva Nwosu, Karen Protopapa, Leah Shahzad, Neil Smith and Anisa Warsame.

This report should be cited as: The National Confidential Enquiry into Patient Outcome and Death. 'Recovery Beyond Survival. 2025. London

Cohort: All patients aged 18 and over who were admitted as an emergency to an ICU for four or more days between 1st October 2022 and 31st December 2022 and survived to hospital discharge.

The Medical and Surgical Clinical Outcome Review Programme is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). HQIP is led by a consortium of the Academy of Medical Royal Colleges and the Royal College of Nursing. Its aim is to promote quality improvement in patient outcomes. The Clinical Outcome Review Programmes, which encompass confidential enquiries, are designed to help assess the quality of healthcare, and stimulate improvement in safety and effectiveness by systematically enabling clinicians, managers, and policy makers to learn from adverse events and other relevant data. HQIP holds the contract to commission, manage and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising around 40 projects covering care provided to people with a wide range of medical, surgical and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual projects, other devolved administrations and crown dependencies www.hqip.org.uk/national-programmes.

ISBN: 978-1-7393029-7-9

CONTENTS

CONTENTS	3
SUPPORTING INFORMATION	3
INFOGRAPHIC SUMMARY	4
RECOMMENDATIONS	5
FOREWORD	12
WHAT PATIENTS SAY	13
INTRODUCTION	14
CHAPTER 1: METHODS AND DATA RETURNED - SUMMARY	15
CHAPTER 2: DEMOGRAPHICS - SUMMARY	16
CHAPTER 3: ASSESSMENT OF REHABILITATION NEED AND GOAL SETTING	17
Assessment of rehabilitation need in the ICU	17
Assessment of rehabilitation need on the ward	22
Assessment of rehabilitation need at discharge from hospital	24
CHAPTER 4: MULTIDISCIPLINARY DELIVERY OF REHABILITATION	25
Multidisciplinary delivery of rehabilitation in the intensive care unit	25
Multidisciplinary delivery of rehabilitation care on the ward	30
Multidisciplinary delivery of rehabilitation at discharge from hospital	34
CHAPTER 5: STEP-DOWN CARE AND COMMUNICATION	37
Communication on the ICU - MDT ward rounds	38
Communication and handover at step-down from the ICU	38
Communication and handover at hospital discharge	38
CHAPTER 6: PATIENT AND FAMILY INVOLVEMENT FROM THE ICU ADMISSION TO DISCHARGE	41
CHAPTER 7: QUALITY OF REHABILITATION CARE	44

SUPPORTING INFORMATION

- ✓ Chapter 1: Methods of data collection and data returned
- ✓ Chapter 2: Demographics of the study population
- ✓ The glossary
- ✓ The references
- ✓ The acknowledgments
- ✓ <u>Useful resources on this topic</u>
- ✓ QI tools for this study
- ✓ A line of sight between recommendations, key findings and national guidelines

INFOGRAPHIC SUMMARY

While many patients admitted to an intensive care unit (ICU) will make a good recovery, 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. The population included in this study represented a range of specialities and ward areas, highlighting the need for organisations to recognise the importance of rehabilitation not just within intensive care units but across all specialty areas, wards and in the community.

1,018 patients aged 18 and over who were admitted as an emergency to an ICU for four or more days between 1st October 2022 and 31st December 2022 and who survived to hospital discharge were included. A total of 365 sets of case notes and 671 clinician questionnaires were reviewed, along with 248 primary care clinician questionnaires, 166 organisational questionnaires and 67 community trust organisational questionnaires. In addition, 420 healthcare professional and 102 patient surveys were returned.

KEY MESSAGES







IN INTENSIVE CARE

ON THE WARD

AFTER DISCHARGE



Rehabilitation care was not well co-ordinated throughout the pathway; on admission to an ICU, at step-down to the ward and in the community. 70/166 (42.2%)
organisations had a
policy or standard
operating procedure for
the delivery of
rehabilitation, and only
24/70 undertook audits
against them.

The data showed an absence of good multidisciplinary team working and communication across the recovery pathway as the patient moved between healthcare settings.

Key workers to co-ordinate rehabilitation care were rarely available, yet when present they were associated with improved markers of care quality throughout the rehabilitation pathway.



Initial and subsequent assessments of rehabilitation need to set/update goals were not always undertaken.

104/365 (28.5%)
patients had a baseline
screen, and 327/574
(57.0%) patients had a
comprehensive
assessment on the ICU.

80/309 (25.9%) patients had a comprehensive assessment on the ward.

102/210 (48.6%)
patients who attended
a critical care
follow-up following
discharge were
comprehensively
reassessed.



Full multidisciplinary team (MDT) input was rarely available to meet all the rehabilitation needs of patients. Physiotherapists were most involved in rehabilitation (604/671; 90.0%); other specialties, such as psychologists (37/671; 5.5%) much less so.

111/318 (34.9%) patients had input from the ICU MDT; usually an intensive care nurse (70/111; 63.1%) or critical care outreach (44/111; 39.6%) with less focus on rehabilitation.

98/254 (18.2%) patients did not have all appropriate referrals made.



Ongoing rehabilitation needs/goals were often not shared between healthcare providers as the patient moved through the pathway.

125/671 (18.6%) patients had no evidence of any handover related to rehabilitation needs.

357/576 (62.0%) patients were provided with an ICU follow-up appointment.

GPs were aware that a patient they saw had spent time in the ICU in 170/248 (68.5%) cases.



Information for the patient or their family about the ICU admission and any lasting impact it may have was limited.

The patient and their family were updated in 165/302 (54.6%) instances.

131/435 (30.1%) patients were given a copy of the ICU discharge summary.

40/102 (39.2%) survey respondents reported they were given a leaflet or discharge booklet.

RECOMMENDATIONS

(BACK TO CONTENTS)

These recommendations have been formed by a consensus exercise involving all those listed in the acknowledgements. The recommendations have been independently edited by medical editors experienced in developing recommendations for healthcare audiences to act on.

The recommendations in this report support those made previously by other organisations, and for added value should be read alongside:

- NICE Guideline [CG83]: Rehabilitation after critical illness in adults, 2009
- NICE Quality Standard [QS158]: Rehabilitation after critical illness, 2017
- Intensive Care Society: Framework for assessing early rehabilitation needs following treatment in intensive care, Version 1. 2020
- GIRFT programme: National Specialty Report on Adult Critical Care, 2021
- Intensive Care Society and the Faculty of Intensive Care Medicine: Guidelines for the Provision of Intensive Care Services, 2022
- NHS England: Service specification for Adult Critical Care
- NHS England: Improving Rehabilitation
- Commissioning Guidance for Rehabilitation

The recommendations highlight areas that are suitable for regular local clinical audit and quality improvement initiatives. The results should be presented at quality or governance meetings, and action plans to improve care should be shared with executives in trust/health boards.

1	 Improve the co-ordination and delivery of rehabilitation following critical illness at both an organisational level and at a patient level. At an organisational level by assigning a trust/health board rehabilitation lead with oversight and responsibility for the provision of holistic rehabilitation. At a patient level by having a named rehabilitation care co-ordinator(s) role to oversee patients' rehabilitation needs within the ICU, on the ward and in the community.
FOR ACTION BY	Commissioners, integrated care boards, hospital trusts/health boards
ADDITIONAL STAKEHOLDERS	Intensive Care Society, Faculty of Intensive Care Medicine, British Dietetic Association, Royal College of Speech and Language Therapists, Royal College of Occupational Therapists, Chartered Society of Physiotherapists, British Geriatric Society.
RATIONALE FOR THE RECOMMENDATION	The data showed an absence of good multidisciplinary team working and communication across the recovery pathway as the patient moved between healthcare settings.
ASSOCIATED GUIDANCE	NICE Guideline [CG83] Rehabilitation after critical illness in adults, 2009 NICE Quality Standard [QS158] Rehabilitation after critical illness, 2017 Intensive Care Society: GPICS

IMPLEMENTATION SUGGESTIONS

AT A TRUST/HEALTH BOARD LEVEL

- Include a senior executive responsible for developing and overseeing implementation of a rehabilitation policy
- Include a senior manager responsible for the implementation of the rehabilitation policy
- Commission rehabilitation services and multidisciplinary team provision based on patient need rather than diagnosis, across multiple pathways of care
- Enable critical care survivors and their relatives/carers to be involved in the design of services
- Develop and introduce relevant training to non-specialists to increase knowledge of the impact of critical illness and rehabilitation requirements
- Regular audits would provide high level overview of rehabilitation services and evaluation of services/outcomes.

AT A PATIENT LEVEL

- Provide access to a rehabilitation care co-ordinator in hospital and in the community following hospital discharge
- 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 ringfenced 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	Develop and validate a national standardised rehabilitation screening tool to be used on admission to an intensive care unit. This would identify patients at risk of long-term physical, psychological, cognitive or social effects and trigger an earlier comprehensive assessment of their rehabilitation needs sooner than 'day four' currently defined by NICE Quality Standard 158.
FOR ACTION BY	Intensive Care Society, Faculty of Intensive Care Medicine, National Institute of Health Research (area of potential research), NHS England, Welsh Government, Health Department of Northern Ireland, Jersey.
ADDITIONAL STAKEHOLDERS	Commissioners, integrated care boards (England), Royal College of Speech and Language Therapists, Royal College of Occupational Therapists, Chartered Society of Physiotherapists British Dietetic Association, British Geriatric Society, Royal College of Psychiatrists, Association of Clinical Psychologists-UK, British Association of Critical Care Nurses, UK Critical Care Nursing Alliance.
RATIONALE FOR THE RECOMMENDATION	Baseline assessments were infrequently undertaken, and comorbidity and functional status were the most performed evaluations. However, baseline assessments should include both physical and non-physical factors.
	NICE Guideline [CG83] Rehabilitation after critical illness in adults, 2009
	NICE Quality Standard [QS158] Rehabilitation after critical illness, 2017
ASSOCIATED GUIDANCE	The post-ICU presentation screen (PICUPS) and rehabilitation prescription (RP) for intensive care survivors
	Commissioning Guidance for Rehabilitation
IMPLEMENTATION SUGGESTIONS	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	 Undertake and document a comprehensive, holistic assessment of the rehabilitation needs of patients admitted to an intensive care unit at risk of physical and/or non-physical morbidity. Assessments should be repeated and documented at key stages along the patient's pathway from admission to community services and GP follow-up.
5	NB: The assessment should be undertaken by day four following admission (in line with NICE Quality Standard 158) or sooner if the patient is identified as needing a more comprehensive assessment at the screening stage (see recommendation 2), noting that elements of the assessment not possible by day four (e.g. swallow if the patient is orally intubated) should be completed as soon as clinically possible.
FOR ACTION BY	Healthcare professionals involved with patients on the intensive care unit.
ADDITIONAL STAKEHOLDERS	Executives in trust/health boards, Royal College of Speech and Language Therapists, Royal College of Occupational Therapists, Chartered Society of Physiotherapists British Dietetic Association, British Geriatric Society, Royal College of Psychiatrists, Association of Clinical Psychologists-UK, British Association of Critical Care Nurses, UK Critical Care Nursing Alliance.
RATIONALE FOR THE RECOMMENDATION	Elements were often missing from comprehensive assessments. 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.
	NICE Guideline [CG83] Rehabilitation after critical illness in adults, 2009
ASSOCIATED	NICE Quality Standard [QS158] Rehabilitation after critical illness, 2017
GUIDANCE	Intensive Care Society: GPICS
IMPLEMENTATION SUGGESTIONS	 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. 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.
FOR ACTION BY	Commissioners, integrated care boards.
ADDITIONAL STAKEHOLDERS	Hospital trusts/health boards, Royal College of Speech and Language Therapists, Royal College of Occupational Therapists, Chartered Society of Physiotherapists British Dietetic Association, British Geriatric Society, Royal College of Psychiatrists, Association of Clinical Psychologists-UK, British Association of Critical Care Nurses, UK Critical Care Nursing Alliance.
RATIONALE FOR THE RECOMMENDATION	Multidisciplinary staffing levels often did not meet national guidance, resulting in a lack of dedicated time for patients within the intensive care unit.
ASSOCIATED GUIDANCE	NICE Guideline [CG83] Rehabilitation after critical illness in adults, 2009 NICE Quality Standard [QS158] Rehabilitation after critical illness, 2017 Intensive Care Society: GPICS GIRFT: Adult Critical Care The post-ICU presentation screen (PICUPS) and rehabilitation prescription (RP) for intensive care survivors
IMPLEMENTATION SUGGESTIONS	 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. Include assessment by geriatricians for physical and cognitive rehabilitation 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	Standardise the handover of rehabilitation needs and goals for patients as they transition from the intensive care unit to the ward and ward to community services.
FOR ACTION BY	Healthcare professionals involved with patients on the intensive care unit and hospital trusts/health boards.
ADDITIONAL STAKEHOLDERS	Intensive Care Society, Faculty of Intensive Care Medicine, Royal College of Speech and Language Therapists, Royal College of Occupational Therapists, Chartered Society of Physiotherapists British Dietetic Association, British Geriatric Society, Royal College of Psychiatrists, Association of Clinical Psychologists-UK, British Association of Critical Care Nurses, UK Critical Care Nursing Alliance.
RATIONALE FOR THE RECOMMENDATION	A good handover was associated with good continuity of care, including continued assessment and delivery of rehabilitation.
ASSOCIATED GUIDANCE	NICE Guideline [CG83] Rehabilitation after critical illness in adults, 2009 NICE Quality Standard [QS158] Rehabilitation after critical illness, 2017
IMPLEMENTATION SUGGESTIONS	 The standardised assessment proforma/care passport could be used to aid the handover process and include the current assessment of rehabilitation needs, individualised rehabilitation plan and current goals for treatment Members of the critical care multidisciplinary team (MDT) may support the handover processes from the intensive care unit (ICU) to the ward through joint rehabilitation sessions Critical care discharge summaries could be copied to GPs and include predicted rehabilitation needs Knowledge of an admission to an ICU could be used to trigger a telephone call from the GP to the patient Alerts/flags on primary care records could be used to identify patients who have had an admission to an ICU, making it easier for primary care to search for patients who might need support – there is a SNOMED CT code for this.

6	Provide patients and their family/carers with clear information about their admission to an intensive care unit, impact of critical illness and likely trajectory of recovery. Include the contact details of a named healthcare professional or rehabilitation care co-ordinator Involve patients/family/carers in multidisciplinary team discussions and rehabilitation planning.
FOR ACTION BY	Healthcare professionals involved with patients on the intensive care unit and hospital trusts/health boards, integrated care boards, and patient organisations.

ADDITIONAL STAKEHOLDERS	Intensive Care Society, Faculty of Intensive Care Medicine, ICUsteps.
RATIONALE FOR THE RECOMMENDATION	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.
ASSOCIATED GUIDANCE	NHS England: Involving patients in their care The Faculty of Intensive Care Medicine: Life After Intensive Care

IMPLEMENTATION SUGGESTIONS	 The standardised assessment proforma could take the form of a rehabilitation passport that travels with individual patients along their care pathway Regular family updates could 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
	 The use of renabilitation 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 could be provided digitally or part of the NHS app (or on paper if the patient is not digitally active)
	Provide contact details of a named healthcare professional (rehabilitation care co-ordinator) who has job-planned time to ensure they can respond to patients/families who get back in touch.

FOREWORD

(BACK TO CONTENTS)

Every year over 200,000 people spend time in intensive care units (ICU) in England and Wales and the majority are discharged home. However, surviving a critical care stay is not the end of the story; patients often need significant physical and psychological support to enable them to return to their previous quality of life. Although there is existing guidance on rehabilitation following critical illness, this report has identified areas for improvement and makes recommendations to support national and local quality improvement initiatives and provides practical suggestions for implementing change.

The recommendations in this report are aimed at all involved in resourcing and delivering care to those whose baseline function declines following a critical illness, including commissioners, integrated care boards and acute trusts/health boards, specialist societies, NHS England and devolved governments, healthcare staff in all relevant professional groups, and patient organisations. The recommendations support existing guidance and provide templates for quality improvement work.

As with previous reports, strong themes that emerge in this study are the need for co-ordinated multidisciplinary care and good communication between professional groups, patients and their families. The use of a standardised rehabilitation screening tool on admission would help identify patients' needs at an early stage and enable appropriate support to be arranged. Comprehensive assessments at regular intervals to address all aspects of physical and non-physical rehabilitation can greatly improve outcomes. Patients and their families should be involved in decision-making where appropriate and be given clear information at every stage of the patient's stay and on discharge. The transition points from the ICU to ward and ward to home are particularly important, with good handover being essential. Detailed, timely communication with the patient's GP is vital, as GPs are often the patient's main point of contact following discharge from hospital.

This report also identified examples of excellent practice, such as early assessment for rehabilitation, the setting of short-term rehabilitation goals, the use of patient diaries, providing a leaflet on discharge with information about the availability of ongoing support, and the provision of follow-up appointments with the critical care team. I hope that sharing these examples and the key recommendations will provide an easy-to-follow template to help improve care and outcomes for patients.

I would like to thank everyone involved in the development of this report, including NCEPOD staff, the study advisory group, case reviewers, clinical co-ordinators, local reporters, ambassadors and clinicians, the authors who have produced this clear and impactful document, and the trustees and steering group, who have been involved in every step of the process from topic selection to commenting on the final report.



Dr Suzy Lishman CBE, NCEPOD Chair

WHAT PATIENTS SAY

(BACK TO CONTENTS)

"I had no support except the psychologist, and I credit her with my survival and return to work. My physical needs were just the start, but I soon came to realise that my cognitive function and mental health needed support too.

There needs to be regular and frequent follow-up, psychological and cognitive (much overlooked) support and support in returning to work."

"I had great support while in ICU, mostly good support on the ward and good physiotherapy and psychological support after leaving hospital. It has been a long and very hard journey to attempt to get back to where I was before. I'm still not there and support with those long-term effects would be helpful.

You have to keep fighting to get better, but it is exhausting and at some point you have to accept that things are not going to improve much more. It would be good to have more realistic discussions with people who understand the post ICU issues as it becomes so frustrating to hear people say 'Are you all better now?' when it is so difficult to get through a day at times."

"When patients step-down from ICU to a ward, this is where continuity often stops. I was transferred to a ward after ten days in the ICU, where I then spent a further two and a half months. By the end of my stay, the ICU stay had been forgotten by staff, it wasn't spoken about at all, so it's no wonder I got forgotten by the ICU team.

Once you've been through ICU, that connection should continue right through to discharge and beyond, certainly to GPs."

"Myself and my family were kept up to date with what was going on in hospital.

I found my diary was very helpful and going to the ICUsteps has helped me a lot. I still go to the meetings they are great to talk to others about their stay in hospital."

INTRODUCTION

(BACK TO CONTENTS)

Critical care provides specialised hospital treatment and constant monitoring for people who are seriously ill. Patients often have a 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. 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). 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. Early rehabilitation strategies, implemented throughout the rehabilitation pathway, 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 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.

Notes on terminology

■ The term 'step-down' is used to describe moving from an ICU to a lower level of critical care, a ward or community services.

CHAPTER 1: METHODS AND DATA RETURNED - SUMMARY

THE FULL DATASET CAN BE ACCESSED HERE

(BACK TO CONTENTS)

Study aims and objectives

The objectives of the study were to explore the clinical and organisational structures in place for the provision of rehabilitation care for patients who had been admitted to an intensive care unit (ICU).

Study population and case ascertainment

Inclusion criteria

All patients aged 18 and over who were admitted as an emergency to an ICU for four or more days between 1st October 2022 and 31st December 2022 and who survived to hospital discharge.

Exclusion criteria

Neurology/trauma patients who received care as part of a defined care pathway.

Data collection

- A clinician questionnaire was sent to the named intensive care consultant for each patient
- A primary care questionnaire was disseminated to the named general practitioner for each patient in the sample. This short questionnaire collected data on the organisational structures in place in the GP practice, to promote quality care for patients post-discharge from an ICU
- An organisational questionnaire was sent to each acute hospital and community hospital where patients could be admitted for rehabilitation care following an admission to an ICU to collect data around the organisational structures, staffing provision and policies to deliver rehabilitation to patients in an ICU and following step-down to the ward and community care
- Copies of the case notes were requested from primary care, secondary care and community providers for peer review and a multidisciplinary group of case reviewers peer reviewed the case notes and associated clinician questionnaires
- An online anonymous clinician survey collected information on the training, experience and opinions of clinicians from each stage of the rehabilitation pathway
- An online anonymous patient survey, aimed at patients who had been in an ICU to collect data on their individual experiences of rehabilitation care throughout the rehabilitation pathway.

Data returned

- > 1,018 patients included with 365 sets of case notes and 671 clinician questionnaires
- 248 primary care clinician questionnaires
- 166 organisational questionnaires and 67 community trust organisational questionnaires
- ➤ 420 healthcare professional surveys and 102 patient surveys.

Data analysis rules

- Small numbers have been suppressed if they risk identifying an individual
- Any percentage under 1% has been presented in the report as <1%</p>
- Percentages were not calculated if the denominator was less than 100 so as not to inflate the findings, unless to compare groups within the same analysis
- There is variation in the denominator for different data sources and for each individual question as it is based on the number of answers given.

CHAPTER 2: DEMOGRAPHICS - SUMMARY

THE FULL DATASET CAN BE ACCESSED HERE

(BACK TO CONTENTS)

- The mean age of the study population was 58 years, ranging from 18-95 years (Figure 2.1), indicating that a large proportion of patients with critical illness may have many socially and economically productive years ahead if they make an uncomplicated, fully rehabilitated recovery.
- Ethnicity of the study population was in line with recent census data. [6] Although the ethnicity of 65/671 (9.7%) patients was unknown, this was a similar finding to the recent Intensive Care National Audit and Research Centre (ICNARC) dataset (Table 2.1). [7]
- A total of 385/664 (58.0%) patients spent more than one week on an intensive care unit ICU (Table 2.2).
- There were 505/671 (75.3%) patients admitted to the ICU due to a medical condition and 166/671 (24.7%) for a surgical condition.
- Only 56/671 (8.3%) patients had no pre-existing comorbidities, while 170/671 (25.3%) had a single comorbidity and 421/671 (62.7%) had two or more comorbidities (Table 2.3).
- Whilst noting that that some patients will have received multiple organ support, respiratory support was the most common organ support (543/671; 80.9%), the majority of which was invasive mechanical ventilation (intubation) (451/543; 83.1%) (Table 2.4 and Table 2.5). It is well evidenced that patients receiving respiratory support are more likely to functionally deteriorate so early rehabilitation planning is essential. [8.9]
- Assessing the grade of functional status by the Rockwood clinical frailty score only 224/602 (37.2%) patients left hospital with the same level of function as on admission. Of the 378/602 (62.8%) patients who had a different level of function, 59/378 (15.6%) improved and 319/378 (84.4%) deteriorated (Figure 2.2). Within the group who deteriorated, 245/319 (76.8%) had received invasive ventilation.

CHAPTER 3: ASSESSMENT OF REHABILITATION NEED AND GOAL SETTING

(BACK TO CONTENTS)

CLINICAL MESSAGE: The quality of initial screening assessments and identification of 'high-risk' patients likely to need complex rehabilitation was inconsistent. Comprehensive assessments were infrequently carried out and, along with the baseline assessments tended to focus solely on physical rehabilitation. However, both should include all aspects of physical and non-physical rehabilitation. This was reflected by the healthcare professionals involved in the completion of assessments, which consisted predominantly of physiotherapists without much input from other specialties.

The physical and psychological effects of critical illness and treatment in an intensive care unit (ICU) can be profound. To identify those most at risk of developing a long-term health condition (morbidity) during or after their admission to an ICU, a short clinical assessment should be carried out as early as clinically possible. Where a risk is identified, a comprehensive, holistic assessment of rehabilitation need should be performed within four days of admission and then repeated as the patient progresses through their pathway of care. [3,4]

Assessment of rehabilitation need in the ICU

Initial screen/baseline assessment

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%) (unknown for 86). However, case reviewers found that only 104/365 (28.5%) patients had evidence of an initial screen recorded in their case notes. In their opinion the failure to screen impacted the care of 102/186 (54.8%) patients (unknown for 75), due to no goals being set, no multidisciplinary team (MDT) involvement, delay and the opportunity to address complex social and psychological needs being missed.

In those patients whose initial screen was documented, 63/104 (60.6%) were on a proforma, 37/104 (35.6%) consisted of a written entry in the case notes and 5/104 (4.8%) were on a label in the notes.

Baseline assessments of comorbidity and functional status were the most performed evaluations (comorbidity: (550/671; 82.0%); functional status (514/671; 76.6%) (Table 3.1). However, baseline assessments should include both physical and non-physical factors. For 474/671 (70.6%) patients no psychological assessment was carried out. This was despite 89/530 (16.8%) patients having had contact with mental health services prior to the admission (unknown for 141), 52/565 (9.2%) patients having a history of recreational drug use (unknown for 106) and 107/575 (18.6%) a history of excessive alcohol intake (unknown for 96).

Table 3.1 Baseline assessments undertaken on admission to the ICU

Assessment	Number of patients	%
Comorbidities	550	82.0
Functional status	514	76.6
Social history	489	72.9
Psychological/mental health history	197	29.4
None	69	10.3
Unknown	3	<1

Clinical questionnaire data: answers may be multiple; n=671

While the reviewers considered the baseline assessment of comorbidities to be adequate in 317/351 (90.3%) patients, they considered 80/309 (25.8%) assessments of functional status to be inadequate as they lacked detail about cognitive function and social background (Figure 3.1).

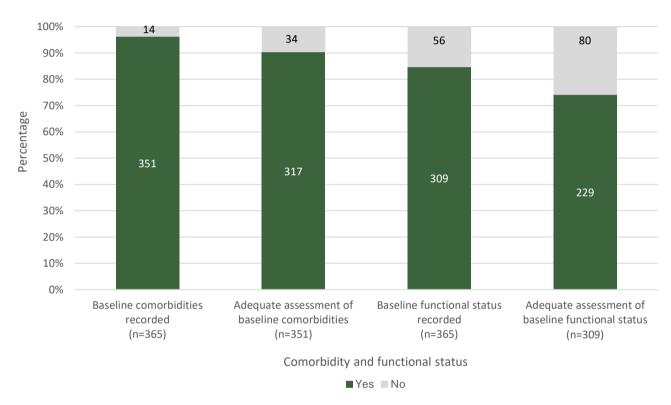


Figure 3.1 Adequacy of baseline assessments undertaken on admission to the ICU Reviewer assessment form data

Comprehensive assessment

It was reported in 130/166 (78.3%) organisational questionnaires that patients routinely underwent comprehensive assessments of rehabilitation need. 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 (unknown for 97). Where these were completed, clinicians said that most were carried out as early as clinically possible in 290/327 (88.7%) patients.

Figure 3.2 illustrates the difference in the opinions of clinicians at the hospital and reviewers as to whether a comprehensive assessment had been undertaken. Reviewers believed that due to clinical reasons the lack of comprehensive assessment was appropriate for 29/267 (10.9%) patients.

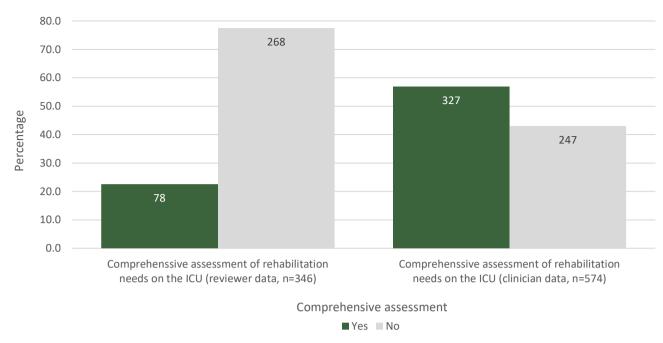


Figure 3.2 Clinician and reviewer views on whether a comprehensive assessment had been undertaken *Clinician questionnaire (n=574) and reviewer assessment form (n=346) data*

Figure 3.3 shows the components of the comprehensive assessments carried out, demonstrating that they were far from comprehensive and predominantly focused on physical function and mobility.

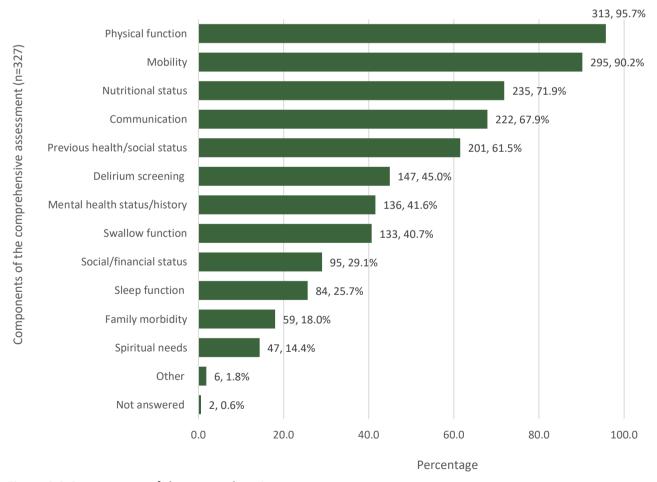
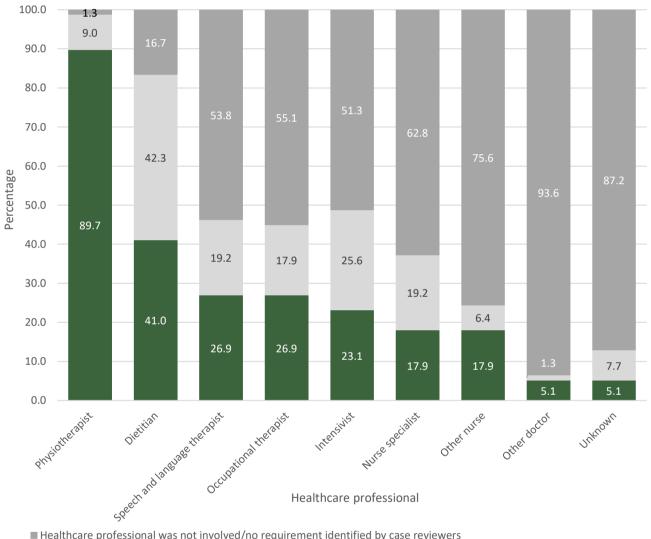


Figure 3.3 Components of the comprehensive assessment Clinical questionnaire data

Reviewers found that a comprehensive assessment was completed for 78/346 (22.6%) patients and considered that there were elements missing from 48/78 of the assessments. Non-physical aspects of rehabilitation, nutrition and a lack of multidisciplinary team (MDT) involvement were the most frequently cited missing elements.

Figure 3.4 shows the healthcare professionals involved in the comprehensive assessments and where, in the opinion of reviewers, patients would have benefited from their involvement. Assessments most frequently involved physiotherapists, although reviewer identified a lack of required input across all staff groups (physiotherapist: 7/78 (9.0%), dietitian: 33/78 (42.3%); speech and language therapist: 15/78 (19.2%), occupational therapist: 14/78 (17.9%), practitioner psychologist: 27/78 (34.6%).



- Healthcare professional was not involved/no requirement identified by case reviewers
- Healthcare professional was not involved but patient would have benefited from their involvement
- Healthcare professional was involved in comprehensive assessment of rehabilitation need in ICU

Figure 3.4 Healthcare professionals involved in the comprehensive assessment and those who should have been (n=78)

Reviewer assessment form data

Once an assessment has taken place, short-term rehabilitation goals and an individual rehabilitation plan should be devised. The reviewers reported that short-term rehabilitation goals had been set for just 138/365 (37.8%) patients and when set these were mostly at the right time (132/138; 95.7%).

Once established, rehabilitation goals should be reviewed regularly. The reviewers believed the frequency of updates was appropriate in only 80/138 (58.0%) cases reviewed.

In addition, an individualised rehabilitation plan in the ICU was documented for only 94/365 (25.8%) patients, and the reviewers considered that the absence of an individualised plan negatively impacted the quality of care of 117/178 (65.7%) patients (unknown for 93).

CASE STUDY - AN EXAMPLE OF GOOD CARE

A 62-year-old patient admitted to an ICU with sepsis was assessed for physical morbidities and current functional status. A 'problem list' together with goals, a rehabilitation plan and rehabilitation risks were documented in a specific proforma. The proforma included outcome measures and a care bundle signposting to other healthcare professionals. There was timely input from a speech and language therapist and an occupational therapist despite it being during the Christmas period. *Reviewers considered that this demonstrated the value of proforma in rehabilitation care.*

CASE STUDY - AN EXAMPLE OF IMPROVEMENT NEEDED

On day three of a patient's stay in intensive care, a dietitian-based plan for insertion of a nasogastric (NG) tube was made. A decision was made later the same day at a consultant ward round not to insert the NG tube and for reassessment the following morning. The next day the NG tube was inserted by a doctor. The speech and language therapist reviewed the patient on day five and considered the patient to be safe for an oral diet, but on the same day, dietetics said the patient should continue with NG feeding. On the ward NG feeding was stopped and oral food intake resumed but the NG tube remained in place until the issue was identified by the critical care outreach team. The reviewers believed this was an example of 'siloed' working and had a formal MDT approach been in place, allowing common goals to be agreed, this unnecessary confusion could have been avoided.

Assessment prior to discharge from ICU

For all patients, even those considered to be at low risk, a short clinical assessment should be undertaken before their discharge from the ICU to determine their ongoing risk of developing physical and non-physical long-term conditions (morbidities).

Patients who have started an individualised, structured rehabilitation programme in the ICU should have a comprehensive clinical reassessment to identify their current and ongoing rehabilitation needs, reviewing aspects of physical, sensory and communication morbidity that might have changed during their ICU stay. Patients should be regularly reassessed regarding their rehabilitation needs and have their goals adjusted as needed.

The clinicians stated that reassessment had taken place in 224/671 (33.4%) patients. Reviewers found evidence of reassessment prior to discharge from the ICU in only 63/365 (17.3%) patients and only 41/63 of those assessed had any alteration or update to their rehabilitation goals.

Screening/outcome tools

Screening/outcome tools in rehabilitation provide a structured method that helps to assess a patient's condition and inform the setting of goals. The same tool can be used to assess progress and alter goals as required. Clinicians stated that screening tools were used in 122/241 (50.6%) (unknown

for 86) comprehensive assessments undertaken and reviewers found that there was evidence of the use of an outcome tool in 86/365 (23.6%) cases reviewed (Table 3.2).

Table 3.2 Outcome tools utilised

Outcome tools used	Number of patients
Chelsea Critical Care Physical Assessment Tool (CPAx)	66
Improving the flow of Patients between Acute, Community and Social Care (IPACS)	20
Local Patient-Reported Outcome Measures (PROMs)	15
Manchester Mobility Score (MMS)	10
ICU Mobility Scale (ICUMS)	5
Barthel Index (BI)	4
Post-ICU Presentation Screen (PICUPS)	4

Reviewer assessment form data: answers may be multiple; n=86

Figure 3.5 shows the quality of rehabilitation care rating for patients in the ICU against the use of outcome measures. These data suggest that the use of outcome measures was associated with better rehabilitation care.



Figure 3.5 The use of outcome measures and quality of care in the ICU Reviewer assessment form data

Assessment of rehabilitation need on the ward

Following discharge from the ICU a further comprehensive assessment was carried out in only 80/309 (25.9%) patients (unknown for 56). 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.

A functional reassessment and redefinition of goals should be undertaken before discharging patients from hospital who are receiving an individualised rehabilitation programme during ward-based care. [3] This was carried out for 235/487 (48.3%) patients (unknown for 184).

Elements of the comprehensive assessment mainly covered mobility (219/235; 93.2%) and physical function (197/235; 83.8%), but in only 63/235 (26.8%) assessments was any aspect of non-physical

function reviewed (Figure 3.6). It re-emphasises the issue that practice was very focused on physical conditions.

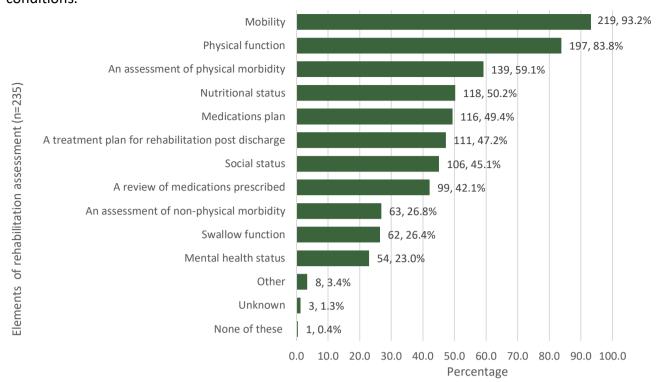


Figure 3.6 Elements of the rehabilitation assessment at discharge from hospital Clinician questionnaire data: answers may be multiple; n=235

Figure 3.7 shows the healthcare professionals who were involved in the rehabilitation assessments at different stages of the rehabilitation pathway (ICU, step-down at the ward and discharge). Physiotherapists predominantly undertook the process (189/235; 80.4%) while mental health practitioners were the least likely (0/235) to be involved in reassessment prior to discharge.

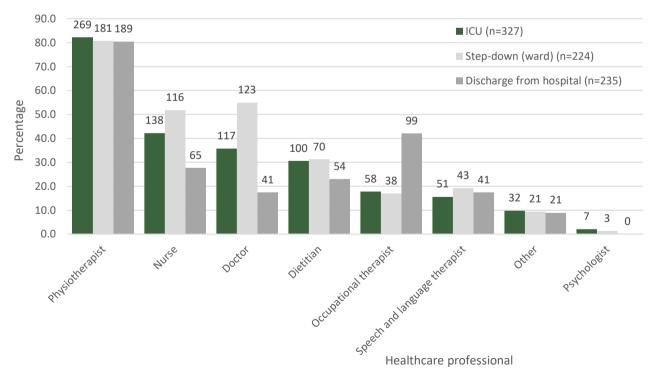


Figure 3.7 Healthcare professionals involved in assessments of rehabilitation need in different locations Clinician questionnaire data

Assessment of rehabilitation need at discharge from hospital

A follow-up appointment with the critical care team was made for 278/506 (54.9%) patients (unknown for 165). There were 210 patients who attended a follow-up assessment following discharge of which 102/210 (48.6%) were comprehensively reassessed (Table 3.3) and 51/156 (32.7%) patients had their rehabilitation plan updated (unknown or not applicable for 122), indicating changing needs.

Table 3.3 Rehabilitation assessment at the follow-up appointment

Assessment	Number of patients	%
An assessment of ongoing physical health needs	97	95.1
An assessment of functional status	85	83.3
An assessment of psychological needs – new and ongoing	79	77.5
An assessment of social care needs	67	65.7
A review of previously identified rehabilitation needs	51	50.0
Other	4	3.9

Clinician questionnaire data: answers may be multiple; n=102

CASE STUDY - AN EXAMPLE OF GOOD CARE

A 58-year-old patient was admitted to an ICU following an emergency laparotomy. They had good rehabilitation assessments. The comprehensive assessment included mobility, sleep, diet, swallow, medical symptoms and social situation. There was evidence of referrals to the surgical ward. At a critical care follow-up clinic psychological issues were identified, and a referral was made for counselling and a patient support group. The patient was discharged with a critical care patient diary, which they reported to be invaluable in coming to terms with what had happened in the ICU. They had physiotherapy in the community and returned to part-time work three-months after discharge. The reviewers considered that, although not perfect, the care this patient received demonstrated the benefits of early assessment and interdisciplinary and patient communication.

CHAPTER 4: MULTIDISCIPLINARY DELIVERY OF REHABILITATION

(BACK TO CONTENTS)

CLINICAL MESSAGE: Multidisciplinary staffing levels often did not meet national guidance, resulting in staff being shared with other areas and a lack of dedicated time for patients within the intensive care unit and the other areas in which they are needed. This led to delays or inconsistency in the assessment and delivery of rehabilitation, with a tendency to focus on the physical/mobility aspects of care, with areas such as cognition and psychological need often not addressed.

Survivors of critical illness have complex rehabilitation needs, in both the short- and long-term, impacting on return to pre illness quality of life and function. The provision of early, structured and holistic rehabilitation is therefore of paramount importance to support recovery and long-term outcomes. [10] Multidisciplinary team (MDT) involvement is essential to ensure that patients receive personalised rehabilitation that meets all their needs.

Multidisciplinary delivery of rehabilitation in the intensive care unit

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.

Even when present, staffing levels across the MDT did not reach the national recommended levels, [5] with particularly low levels across all non-medical/nursing roles (Figure 4.1).

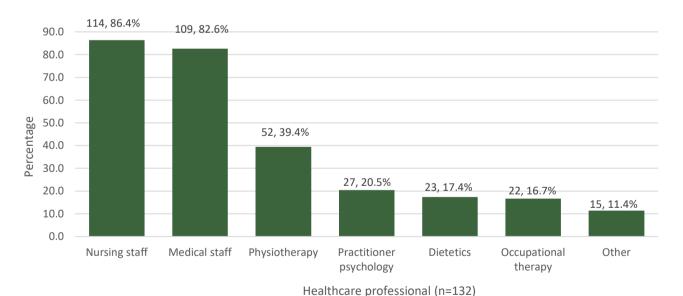


Figure 4.1 Organisations with healthcare professionals meeting GPICS standards Organisational questionnaire data

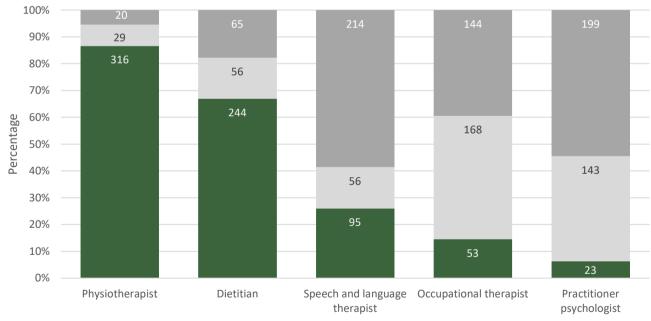
Clinicians found that involvement of members of the MDT varied. The presence of a physiotherapist was the most common (604/671; 90.0%), while other professions such as speech and language therapists (211/671; 31.4%), occupational therapists (116/671; 17.3%) and psychologists (37/671; 5.5%) were less frequently involved in the care of patients within the ICU (Table 4.1).

Table 4.1 Healthcare professionals involved in delivering rehabilitation care during the ICU stay

Healthcare professionals	Number of patients	%
Physiotherapist	604	90.0
Nurse	558	83.2
Doctor	519	77.3
Dietitian	463	69.0
Speech and language therapist	211	31.4
Occupational therapist	116	17.3
Practitioner psychologist	37	5.5
Rehabilitation practitioner	24	3.6
Other	16	2.4
Unable to answer	12	1.8
Pharmacist	7	1.0

Clinician questionnaire data: answers may be multiple; n=671

While not every patient who is admitted to an ICU will require input from all members of the MDT, reviewers found that patients did not receive services that they required. Again, physiotherapist involvement was the most common (316/365; 86.6%), although it was not possible to discern whether this was provided for rehabilitation or respiratory care only. Dietetic involvement in the patients who required it was also relatively common (244/300; 81.3%), while only 53/221 (24.0%) patients who were deemed to need it received input from an occupational therapist or a psychologist (23/166; 13.9%) (Figure 4.2).



Healthcare professional (n=365)

- Healthcare professional was not involved/ requirement was not identified by case reviewers
- Healthcare professional was not involved, but patient would have benefited from their involvement
- Healthcare professional was involved in the delivery of rehabilitation

Figure 4.2 Healthcare professionals who treated patients on the ICU and those patients who would have benefited from other specialty input

Reviewer assessment form data

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%) (unknown for 122) and consistency (90/562; 16.0%) of rehabilitation delivered (unknown for 109). This was the case for all members of the MDT, with the biggest delays in timing seen for speech and language and occupational therapists (Figure 4.3). This may have been the result of a lack of understanding or recognition of need, leading to delays in referrals to some staff groups.

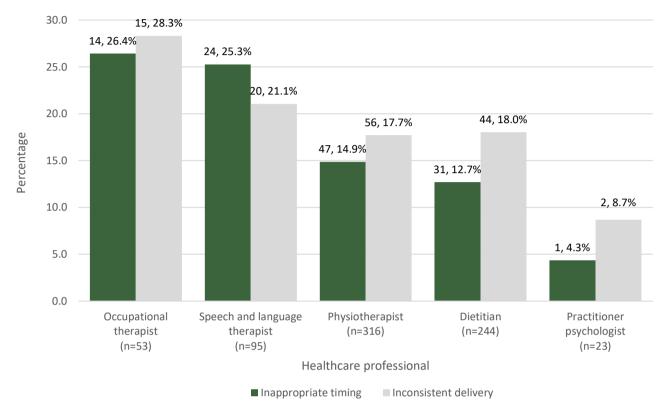


Figure 4.3 Timing and consistency of delivery of rehabilitation in the ICU by different healthcare professionals

Reviewer assessment form data

Weekend cover

Guidelines for the provision of intensive care services recommend seven-day physiotherapy services for both acute respiratory and physical rehabilitation assessment and interventions. They also recommend that other therapy services are provided as needed at weekends. 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%) (Table 4.2).

Table 4.2 Weekend rehabilitation care delivered

Weekend rehabilitation care	Number of patients	%
Yes – full multidisciplinary team	6	1.8
Yes – but not full multidisciplinary team care over the weekend	186	54.9
No – rehabilitation care was provided over the weekend	127	37.5
NA – patient did not stay over the weekend	20	5.9
Subtotal	339	
Unknown	26	
Total	365	

Reviewer assessment form data

Rehabilitation needs

While it is acknowledged that multiprofessional working often means different professions may be providing specific elements of the comprehensive assessment, gaps were seen across multiple areas.

Physical function, strength and mobility

From a physical perspective, 465/534 (87.1%) patients had evidence of an assessment of strength or mobility (unknown for 69 and not required for 68), with 315/424 (74.3%) having an individualised physical rehabilitation plan (unknown for 41 and not required for 77).

However, when goals were set these were most associated with physical rehabilitation 266/327 (81.3%) and mobility 233/327 (71.3%). Despite this, reviewers reported room for improvement in the delivery of mobility-focused rehabilitation in 116/331 (35.0%) patients and strength-based rehabilitation in 120/321 (37.4%) patients.

Communication and swallowing

Evidence shows that swallowing and communication issues are common but often unidentified in ICU patients. [11,12] Failure to detect and manage these issues, coupled with little or delayed speech and language therapy involvement, can lead to adverse medical outcomes including increased morbidity and mortality, as well as negatively impacting psychological and functional recovery. [13]

The guideline for the provision of intensive care services states that people with critical care needs who have difficulty with communication and/or swallowing require timely access to a speech and language therapy service. There were 147 patients who had a communication need according to the clinician questionnaire. There was evidence that an attempt was made to establish a form of communication for 109/147 (74.1%) patients who needed it. This was more common in those who were invasively ventilated (99/109, 90.8%).

Where clinicians identified the need for a swallow review, this was completed on 262/308 (85.1%) occasions. Once again this was more likely to occur at some point during the ICU admission if patients had been invasively ventilated (235/262, 89.7%). With a reported prevalence of dysphagia of up to 93% for patients following tracheostomy, [14] national guidelines recommend all patients with a tracheostomy are reviewed by a speech and language therapist. [5,15] Despite this, reviewers found only 25/77 (32.5%) patients with a tracheostomy had evidence of an assessment of their swallow and only 8/25 (32.0%) of these involved a speech therapist.

Nutrition

Evidence suggests that up to half of all patients admitted to an ICU are malnourished, meaning a baseline assessment of nutritional status is essential. Despite this, only 354/528 (67.0%) patients reviewed had an assessment completed of their pre-admission nutritional status (unknown for 143), of which 98/354 (27.7%) had evidence of malnutrition.

Clinicians found evidence of an individualised nutritional plan in 469/594 (79.0%) patients, but only 370/428 (86.4%) patients appeared to achieve their nutritional targets. The involvement of a dietitian did improve these values, increasing the proportion of patients with an individualised nutritional plan (419/443; 94.6%) and those reported to have met their nutritional targets (316/339; 93.2%) (Table 4.3).

Table 4.3 Involvement of a dietitian on individualised nutritional plan and nutritional targets

Dietitian involved	Individualised nutritional pla (when a dietitian was involve		Nutritional targets were (when a dietitian was invo	
	Number of patients	%	Number of patients	%
Yes	419	94.6	316	93.2
No	24	5.4	23	6.8
Subtotal	443		339	
Unknown	20		80	
Total	463		419	

Clinician questionnaire data

CASE STUDY – AN EXAMPLE OF IMPROVEMENT NEEDED

A 56-year-old patient had a myocardial infarction leading to an emergency coronary artery bypass graft and admission to an ICU for six days. Physiotherapy involvement commenced on day one, focusing on chest clearance and mobility. Despite documentation on the patient's poor oral intake and looking 'malnourished' there was no dietetic involvement during the hospital stay and poor healing was noted at a two-month cardiac follow-up appointment.

The reviewers believed that this was an example of services focused on physical rehabilitation and mobility only, with a lack of wider multidisciplinary team involvement in care.

Mental health

There were 125/671 (18.6%) patients reviewed who had a documented pre-existing mental health condition. Despite this, clinicians reported that only 197/671 (29.4%) patients had a documented assessment that included consideration of their pre-admission mental health state. The presence of a known mental health history did not impact on the likelihood of a mental health assessment taking place (60/197; 30.5%). This may reflect a lack of knowledge by clinicians delivering care in the assessment of mental health needs. Consequently, room for improvement was identified in the care of 130/288 (45.1%) patients with regards to mental health rehabilitation.

CASE STUDY – AN EXAMPLE OF GOOD CARE

A 35-year-old patient was admitted following a drug overdose and deliberate self-harm. The patient required renal support and ventilation while in the ICU and experienced significant psychological distress on waking. Delirium and a previous diagnosis of post-traumatic stress disorder made care of the patient and the process of taking them off invasive ventilation challenging. The patient was given access to the full multidisciplinary team in the ICU and discussed regularly as part of multidisciplinary team rounds to co-ordinate care. They were discharged to the ward where treatment continued with liaison psychiatry colleagues and later followed up in the community for ongoing support.

Reviewers considered that this case demonstrated the positive outcomes from providing early and structured multidisciplinary care.

Delirium and cognition

Around a third of all patients admitted to ICUs develop delirium, although rates can increase to almost 80% for patients receiving invasive ventilation. [17] When present, delirium is associated with increased lengths of stay in both the ICU and hospital, increased mortality and poor long-term outcomes, including residual cognitive impairment and a reduced quality of life.

Daily screening for delirium is essential to ensure timely recognition and management. It was reported from 109/166 (65.7%) organisations that there was a policy for the identification and management of delirium, although reviewers reported only 116/303 (38.3%) patients were screened daily for delirium (unknown for 62). Of those who were not screened, reviewers believed that this negatively impacted the outcome for 74/187 (39.6%) patients. A total of 37/286 (12.9%) patients were identified as having room for improvement in their care with regards to cognitive rehabilitation (unknown for 79), although the room for improvement decreased with the involvement of an occupational therapist (13/53) (Figure 4.4).

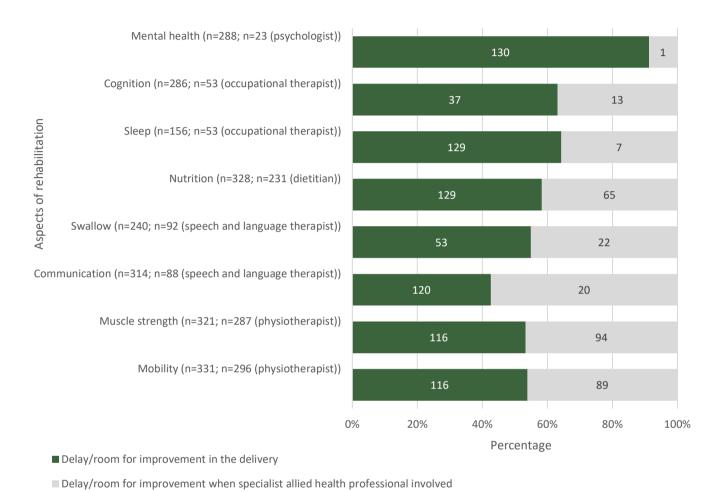


Figure 4.4 Room for improvement in different aspects of rehabilitation in the ICU and involvement of specialist allied healthcare professionals

Reviewer assessment form data

Multidisciplinary delivery of rehabilitation care on the ward

Due to the multi-specialty nature of ICU admissions, patients may be discharged to a variety of different ward locations. Ongoing care ultimately falls to the primary specialty related to their original admission and the available resources within that setting. The most common discharge destinations were to a general or specialist medical ward (379/671; 56.5%) and general or specialist surgical ward (193/671; 28.8%) (Table 4.4).

Table 4.4 Type of ward the patient was admitted to following the ICU stay

Ward type	Number of patients	%
General medical ward (level 1/0)	233	34.7
General surgical ward (level 1/0)	146	21.8
Specialist medical ward	146	21.8
Specialist surgical ward	47	7.0
Discharged home	33	4.9
Transferred to another hospital	23	3.4
Level 2 ward	18	2.7
Specialist neurological ward	16	2.4
Other	7	1.0
Specialist trauma ward	2	<1
Total	671	

Clinician questionnaire data

To aid the step-down from an ICU to a ward, ongoing support and rehabilitation provision may be provided by the ICU MDT on the ward. This ensures continuity for patients on step-down to a ward environment, where competing priorities can often limit the ongoing rehabilitation provided by ward-based staff. [18]

The reviewers found that 111/365 (30.4%) patients received ongoing input from the ICU MDT, most commonly a review by an intensive care nurse (70/111; 63.1%) or the critical care outreach team (44/111; 39.6%). Reviewers noted that critical care outreach team reviews did not necessarily incorporate a review of rehabilitation needs and were mainly medically orientated.

A total of 34/111 (30.6%) patients were seen on the ward at least once by the ICU physiotherapist (Figure 4.5). The reviewers believed that 80/154 (51.9%) (unknown for 100) patients who did not receive a review would have benefited from ongoing ICU MDT involvement.

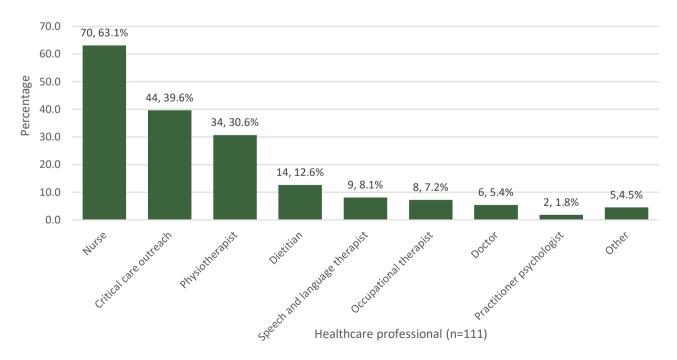


Figure 4.5 Healthcare professional review by ICU MDT post-step-down from the ICU Reviewer assessment form data

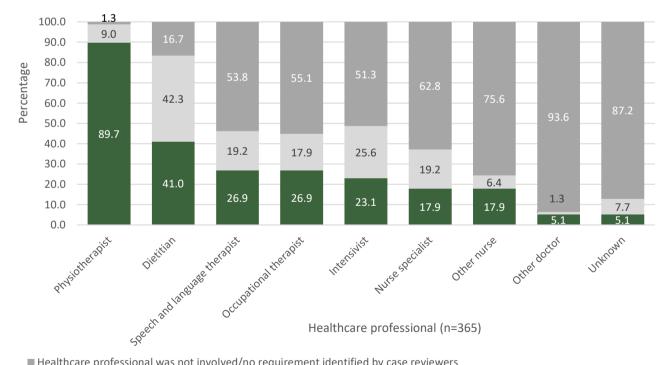
Most organisations reported broad access to the MDT for patients stepping down from ICU to the ward. However, clinicians identified that full MDT rehabilitation was only provided for the minority of patients on the ward following ICU discharge. The most common provision was physiotherapy (483/671; 72.0%) (Table 4.5) and reviewers believed physiotherapy was provided for most patients who needed it (257/280; 91.8%).

Table 4.5 Healthcare professionals delivering rehabilitation care to the patient following an ICU stay

Healthcare professional	Number of patients	%
Physiotherapist	483	72.0
Dietitian	317	47.2
Registered nurse	267	39.8
Occupational therapist	213	31.7
Doctor	206	30.7
Speech and language therapist	149	22.2
Unknown	88	13.1
Specialist rehabilitation nurse	43	6.4
Practitioner psychologist	37	5.5
Other	26	3.9
Rehabilitation practitioner	26	3.9

Clinician questionnaire data: answers may be multiple; n=671

Patients mostly received dietitian (201/252; 79.8%) and speech and language therapist (97/119; 81.5%) input when required. The largest proportion of unmet need related to psychologists, where only 21/159 (13.2%) patients who may have benefited were seen (Figure 4.6).



- Healthcare professional was not involved/no requirement identified by case reviewers
- Healthcare professional was not involved but patient would have benefited from their involvement
- Healthcare professional was involved in comprehensive assessment of rehabilitation need in ICU

Figure 4.6 Healthcare professionals who treated patients on the ward and those who would have benefited from other specialty input

Reviewer assessment form data

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%) (Figure 4.7).

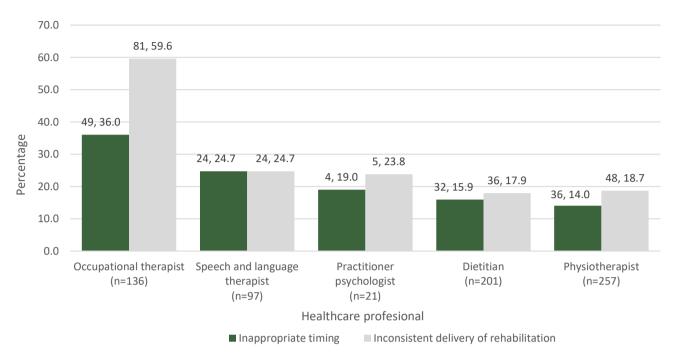


Figure 4.7 Timing and consistency of input from the healthcare professionals delivering rehabilitation Reviewer assessment form data

Daily input for rehabilitation was rare for all staff groups (physiotherapist: 238/483 (49.2%); speech and language therapist: 13/149 (8.7%); dietitian: 39/317 (11.2%); occupational therapist: 27/213 (12.7%)), and only some patients received any rehabilitation care at the weekend (physiotherapist: 82/483 (17.0%) speech and language therapist: 3/149 (2.0%) dietitian: 10/317 (3.2%) occupational therapist: 9/213 (4.2%). Due to limitations in provision, delays in initiation and inconsistency in delivery, reviewers identified several areas which required room for improvement with regard to rehabilitation on the ward (Figure 4.8).

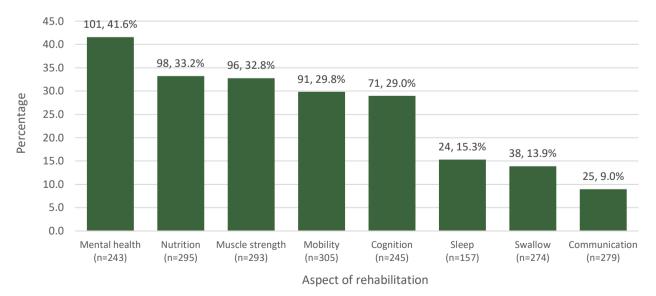


Figure 4.8 Room for improvement in different aspects of rehabilitation on the ward Reviewer assessment form data

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. Quotes from respondents include:

"A better MDT approach to rehabilitation, it is everyone's responsibility not just OT or physio. Training may be required to ensure other members of staff are clear about what this includes as it is not just physical rehabilitation that needs to be worked on."

"A proper clear pathway to be followed for patients. As long as patients 'belong' to different medical specialties once they step-down who then have different priorities (rehab usually not being one of them) patients are always going to have inequitable care and poor outcomes..."

"There needs to be a national unity of therapists working across all acute and community services to sign up to a pathway that ensures all critical care survivors have appropriate assessment, goal-setting and onward planning/referrals to ensure they receive rehabilitation, whether it happens as an inpatient, in neuro or other bed-based rehab, or at home in the community."

Multidisciplinary delivery of rehabilitation at discharge from hospital

Critical illness leaves patients at significant risk of long-term physical, cognitive and psychological problems. Discharge from the ICU is only the start of a long recovery process which may take months to years, with considerable impact on the patient's morbidity and longevity, as well as impact on their family. 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. [1]

Most patients were discharged directly home from hospital (520/671, 77.5%), with 33/671 (4.9%) being directly discharged home from the ICU (Table 4.6).

Table 4.6 Discharge destination from the hospital

Discharge destination	Number of patients	%
Home	520	77.5
Another hospital (secondary care)	57	8.5
Community hospital (for inpatient rehabilitation)	49	7.3
Hospice	21	3.1
Care home	16	2.4
Other	5	<1
Unknown	3	<1
Total	671	

Clinician questionnaire data

Reviewers believed that discharge locations were appropriate for most (318/365; 87.1%) patients. Data from the clinicians highlighted the complicated rehabilitation pathway experienced by survivors of critical illness following hospital discharge, with 33/394 (8.4%) patients dying within 12 months (unknown for 277). There were 222/608 (36.5%) patients readmitted to hospital within the first 12 months after ICU discharge (unknown for 63). A total of 114/222 (51.4%) patients were readmitted two or more

times. There were 60/222 (27.0%) admissions related to the ICU admission and the reviewers believed that 13 of these admissions could have been prevented.

Patients were frequently referred to a variety of services for ongoing medical evaluation, supportive care and rehabilitation, with only 157/671 (23.4%) having no documented referrals in place. Most referrals were related to ongoing medical care, through either medical specialist secondary care follow-up (176/671; 26.2%), surgical specialist secondary care follow-up (84/671; 12.5%) or their GP (75/671; 11.2%) (Figure 4.10). Despite the significant ongoing physical and non-physical morbidity, only 114/160 (71.3%) organisations reported any form of post-ICU follow-up of patients, and clinicians found that only 357/576 (62.0%) patients were provided with an ICU follow-up appointment (95 unknown).

Reviewers stated that 107/250 (42.8%) patients did not receive all the appropriate referrals. They specifically cited a sparsity of referrals to dedicated specialist community rehabilitation services, alongside an absence of ICU follow-up referrals or referral to specific MDT groups such as physiotherapy, dietetics or psychology where a clear need existed.

The lack of available NHS-funded rehabilitation was also identified in the patient surveys, which showed that 16/88 (18.2%) patients had accessed private healthcare to support ongoing rehabilitation after hospital discharge.

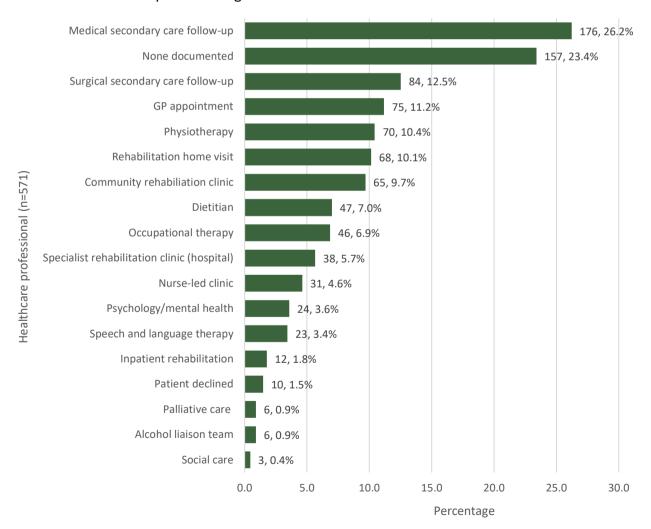


Figure 4.10 Referrals made post-discharge from hospital Clinician questionnaire data: answers may be multiple; n=571

CASE STUDY - AN EXAMPLE OF IMPROVEMENT NEEDED

A 56-year-old patient developed sepsis following surgery and spent 16 days in an ICU. There was no formal baseline assessment and delays in the initiation of therapy. While the medical team raised concerns regarding a potential refeeding risk, the patient was not reviewed by a dietitian until day 11 of the ICU admission. Goals were set following the initial assessment, but these were never reviewed and there was no evidence of a handover to the ward. A comprehensive review was completed by the ICU follow-up nurse on the ward, which identified complex rehabilitation needs. However, no follow-up was arranged, and the patient was given a leaflet and told to contact their GP for support.

The reviewers highlighted a lack of timely referral to specialists, in this case the dietitian, and the importance of goal setting and reviews throughout the stay. They also noted the lack of access to available services such as outpatient rehabilitation medicine to provide support after discharge.

CASE STUDY - AN EXAMPLE OF GOOD CARE

A 76-year-old patient with Parkinson's disease was admitted to the ICU with septic shock following a long period lying on the floor after a fall at home. A comprehensive assessment was completed early in the ICU stay and triggered the involvement of a full complement of therapy input. Rehabilitation needs were discussed and goals set at a weekly MDT meeting. A comprehensive, documented handover of care was provided, and MDT rehabilitation was continued on the ward. Despite the patient's underlying frailty and history of Parkinson's disease, they made a good recovery, returning to their baseline function and being discharged home.

The reviewers considered this to be an example of good care with a comprehensive assessment and documentation of goals contributing to a favourable outcome for the patient.

CASE STUDY – AN EXAMPLE OF IMPROVEMENT NEEDED

A frail 74-year-old patient with a history of chronic obstructive pulmonary disease was admitted to the ICU following an emergency laparotomy. Initial assessments on admission identified that the patient was living independently at home, although had a limited exercise tolerance being able to walk 50 metres and used a stair lift. While the patient was extubated quickly, they required ongoing organ support in the form of renal replacement therapy and vasopressors. The patient was reviewed by a physiotherapist, but this was solely focused on sputum clearance and no rehabilitation was provided in the ICU by the physiotherapist or any other member of the multidisciplinary team.

The reviewers considered that delays in initiating rehabilitation resulted in significant deconditioning and potentially preventable morbidity, leading to a long stay in hospital and a requirement for ongoing rehabilitation in a community hospital.

CHAPTER 5: STEP-DOWN CARE AND COMMUNICATION

(BACK TO CONTENTS)

CLINICAL MESSAGE: There was variation in the handover of rehabilitation care and often either key information was missing, or handovers were not carried out at all. However, a good handover was associated with good continuity of care, including continued assessment and delivery of rehabilitation, as well as overall quality of care.

Patients surviving critical illness are often left with significant physical, psychological and cognitive impairments, collectively termed 'post-intensive care syndrome'. Effective rehabilitation requires access to multiple members of the multidisciplinary team (MDT) across various stages of the recovery pathway both within hospital and after hospital discharge. As patients step-down from the intensive care unit (ICU) to the ward they often return to the medical specialty overseeing their primary reason for admission. However, their care needs have often changed because of their stay in an ICU and may no longer be solely related to the reason for their original admission. In addition, responsible teams and team members will often change, so effective communication is essential to optimise outcomes.

Only 70/166 (42.2%) organisations reported having a policy or standard operating procedure (SOP) for the delivery of rehabilitation. Where these did exist, they were almost always based on the available NICE guidance (59/70; 84.3%). Only 24/70 organisations reported audits against these policies or SOPs, and only 8/24 had audited their rehabilitation services in the previous 12 months. The same 70/166 (42.2%) organisations had an ICU rehabilitation lead but only 28/70 with designated sessions within their job plan for this leadership activity.

Key workers

A recommendation in NICE CG83 is the need for named key workers to co-ordinate rehabilitation for survivors of critical illness and ensure continuity of care. This is an approach used effectively in other specialty areas such as major trauma or cancer care, where care co-ordinators act as advocates for patients, ensuring delivery of the right care at the right time. Most organisations reported the presence of named healthcare professionals to co-ordinate the rehabilitation pathway (112/114; 98.2%) (Table 5.1). However, the clinicians identified only 107/420 (25.5%) patients as having a named healthcare professional/key worker for co-ordinating rehabilitation (unknown for 251).

Table 5.1 Named healthcare professional/key worker assigned to co-ordinate rehabilitation

Named key worker	Number of hospitals	%
Yes – all patients who have had an ICU stay	17	14.9
Yes – certain patients who have had an ICU stay	95	83.3
No	2	1.8
Subtotal	114	
Unknown	52	
Total	166	

Organisational questionnaire data

Where key workers were present, reviewers found that they had a positive effect on care. Patients with a named key worker were found to be more likely to have undergone a comprehensive

assessment (70/101; 69.3% vs 151/290; 52.1%) and to have an individualised rehabilitation plan (77/101; 76.2% vs 143/283; 50.5%) in comparison to when no key worker was present.

Communication on the ICU - MDT ward rounds

National Institute for Health and Care Excellence quality standards recommend that all patients admitted to an intensive care unit and at risk of physical and non-physical morbidity are discussed at MDT ward wounds. [4] These rounds provide an ideal opportunity to complete or update comprehensive clinical assessments, co-ordinate care and set goals for ongoing treatment. Clinicians reported that rehabilitation was discussed as part of an MDT ward round in 272/546 (49.8%) patients (unknown for 125), although reviewers only found documented evidence of MDT rounds in 70/365 (19.2%) cases reviewed. This discrepancy was largely due to a lack of involvement from the full MDT.

Where MDT rounds did occur, these were mostly considered to be taking place frequently enough to meet the recommendation of being at least weekly (41/70).

Patients discussed at an MDT meeting were more likely to have undergone a comprehensive assessment (28/70; 40.0% vs 44/295; 14.9%) and have rehabilitation goals set (41/70; 58.6% vs 94/295; 31.9%) than those who were not.

Communication and handover at step-down from the ICU

At step-down from the ICU to the ward, care and rehabilitation is usually taken over by the receiving ward teams. To facilitate this process, a thorough handover of the patient's rehabilitation needs and current goals for treatment is essential. Clinicians found that 304/671 (45.3%) patients had a documented, structured handover, 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. Where handovers were completed, reviewers believed that information was missing for 241/317 (76.0%) patients (unknown in 48), specifically a lack of information regarding the comprehensive assessment, rehabilitation goals and the current rehabilitation plan.

CASE STUDY - AN EXAMPLE OF GOOD CARE

A 64-year-old patient had a three-week stay in the ICU following a perforated duodenal ulcer complicated by a bile leak. An excellent handover of both physical and non-physical rehabilitation needs was provided on step-down to the ward, ensuring seamless continuation of rehabilitation. Ongoing rehabilitation needs were assessed in a follow-up appointment after hospital discharge. There was clear evidence of family involvement in decisions regarding the patient's care. The patient highlighted at their ICU follow-up appointment that the critical care diary had been invaluable in helping them come to terms with their admission.

Reviewers considered this to be an example of good care, addressing the patient's physical and mental needs and including an exemplary handover.

Communication and handover at hospital discharge

The presence of a named healthcare professional/key worker to co-ordinate rehabilitation after hospital discharge remained uncommon, with clinicians reporting such a role for only 151/491 (30.8%) patients (unknown for 180). 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 (not answered for 68).

Absence of a named healthcare professional to contact for support means that patients will often contact their GP as the only means of access for support. Clinicians reported that 207/241 (85.9%) patients had attended for a GP appointment in the first year after hospital discharge, and the reason for these attendances was related to the ICU admission for 91/207 (44.0%) patients. In total, 93/198 (47.0%) GPs reported completing an assessment of rehabilitation needs, with 60/204 (29.4%) patients requiring onward referrals for rehabilitation and recovery (Table 5.2).

Table 5.2 Assessment of rehabilitation needs and onward rehabilitation referrals

Assessment	Assessment of rehabilitation needs at any of the appointments		Onward referrals made to support of the covery	
	Number of patients	%	Number of patients	%
Yes	93	47.0	60	29.4
No	105	53.0	144	70.6
Subtotal	198		204	
Unknown	50		44	
Total	248		248	

Primary care clinician questionnaire data

Reviewers stated that there was room for improvement in the handover of rehabilitation care in 186/292 (63.7%) cases reviewed (unknown for 73). Patients can be left feeling isolated following hospital discharge. 'Transitions of care' was a key theme highlighted in the patient's survey, with one stating:

"When patients step-down from the ICU to a ward, this is where continuity often stops... I got forgotten by the ICU team. Once you've been through an ICU, that connection should continue right through to discharge and beyond, certainly to GPs as well."

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. There was evidence of GP letters at hospital discharge for 484/671 (72.1%) patients. Even when completed, reviewers reported room for improvement in discharge documentation in 245/323 (75.9%) cases reviewed (unknown for 42). Important information, including details about the ICU stay and organ support received was often missing, as well as any ongoing rehabilitation needs or plans.

A total of 69/205 (33.7%) (unknown for 43) primary care clinicians reported a standardised approach to identify whether patients had been admitted to hospital and required ICU care. When GP practices were aware of an ICU admission, 78/248 (31.5%) stated it triggered the practice to contact the patient and 14/248 (5.6%) would add a flag to the patient's electronic record (Table 5.3).

Table 5.3 Methods used to contact patients who had been admitted to an ICU

GP notification	Number of patients	%
A copy of the discharge summary would be received and filed in the patient's notes	234	94.4
Details of the ongoing community-based rehabilitation would be recorded on the patient's electronic record	83	33.5
It would trigger the practice contacting the patient	78	31.5
Other	47	19.0
A flag would be placed on the patient's electronic record	14	5.6
Unknown	4	1.6

Primary care clinician questionnaire data: answers may be multiple; n=248

Some GPs highlighted a need for more education around likely post-ICU rehabilitation needs and how they could support recovery. They also highlighted a lack of awareness of what rehabilitation pathways were available, with one stating:

"There is no information available in primary care as to what help is available for rehabilitation. The wait list for any community services in our area is so long that any input is irrelevant by the time it is received."

CASE STUDY – AN EXAMPLE OF IMPROVEMENT NEEDED

A 64-year-old delivery worker spent seven days in the ICU due to sepsis related to an infected abscess. The patient was ventilated for three days and received timely physiotherapy and speech and language therapy in the ICU. There was no evidence of a handover of rehabilitation needs or goals on step-down to the ward. A review and comprehensive assessment by the critical care outreach team showed some cognitive issues and incontinence. The patient was also noted to be struggling with oral intake. Despite this, the patient only received physiotherapy input on the ward, and this was primarily focused on mobility practice and discharge. No ICU follow-up was provided after hospital discharge, with GP appointment notes showing that the patient had still not returned to work six-months later due to poor exercise tolerance and fatigue.

The reviewers believed that this showed how a lack of handover and uncoordinated follow-up rehabilitation care could lead to unsatisfactory outcomes.

CASE STUDY - AN EXAMPLE OF GOOD CARE

A 38-year-old patient attended the emergency department following a fall and alcohol withdrawal symptoms. The patient was admitted to the ICU due to a decreased Glasgow Coma Score and required invasive mechanical ventilation. A comprehensive assessment was completed involving all members of the MDT with clear ongoing involvement from a physiotherapist, occupational therapist, speech and language therapist and dietitian. The patient's progress was also reviewed weekly at a dedicated MDT rehabilitation meeting. The patient was later discharged to a specialist rehabilitation unit for ongoing care, with a clear summary of their rehabilitation needs and current goals.

Reviewers considered this to be an example of good care, involving a co-ordinated MDT focused on rehabilitation and follow-up care.

CHAPTER 6: PATIENT AND FAMILY INVOLVEMENT FROM THE ICU ADMISSION TO DISCHARGE

(BACK TO CONTENTS)

CLINICAL MESSAGE: While excellent examples exist supported by charities such as <u>ICUsteps</u>, clinicians reported that this was rare, with often no standardised approach to the provision of information to patients before discharge from hospital.

An admission to an intensive care unit (ICU) can be a frightening time for patients and their family. Uncertainty around the likely outcome of treatment, along with the high stress environment of an ICU often leads to anxiety, depression and post-traumatic stress disorder in both patients and relatives. Good communication is an essential component of care to attempt to mitigate this is, and involving family in care in the ICU is associated with improved outcomes and reduced cost. [19] National guidance emphasises the importance of providing patients and their loved ones with information about their rehabilitation and likely trajectory for recovery. [3-5]

The person before the patient

Understanding the individual patient is crucial for providing personalised, patient-centred care. 'All about me' documents provide important information about the patient and can be particularly important when the person is unable to convey information about themselves. These documents capture useful information about the person, their family and loved ones, along with hobbies and interests to allow greater personalisation of care. While 46/88 organisations reported the use of 'All about me' documents, clinicians found that these were only present for 113/446 (25.3%) (unknown for patients. They included information about key relationships (108/113; 95.6%), interests and hobbies (90/113; 79.6%) and patient preferences (84/113; 74.3%). 'All about me' or patient diaries should form part of the patient record, even as an addendum. If patients/families are involved in multidisciplinary team discussions, their views should be captured in the notes.

Patient and family engagement

Despite the need for good communication with patients and their family, clinicians reported only moderate evidence of engagement in rehabilitation discussions throughout the recovery pathway. This was even less common with regard to family involvement and interaction (Figure 6.1). As a result, patients surveyed highlighted the need for realistic goals and being told what to expect as a key area that requires improvement.

"The information leaflets I was given gave the impression that the residual health issues would be short-term and soon resolve. For me, this has not been the case and nearly fifteen years later, I continue to live with the physical, psychological and cognitive issues because of my critical illness event."

"Family need to be included in the process, so they understand when the patient is unable to communicate clearly and understand."

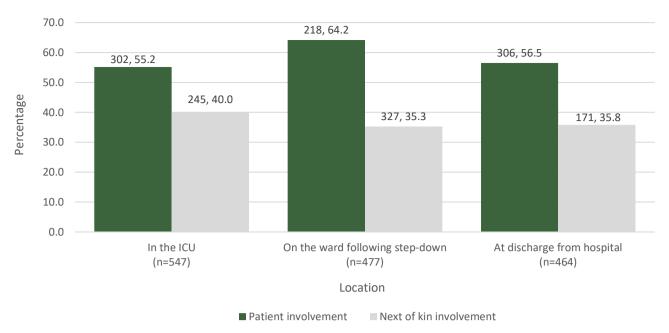


Figure 6.1 Patient and family involvement in rehabilitation discussions Clinician questionnaire data

Reviewers found documentation that the patient and their family were adequately updated in only 165/302 (54.6%) cases (unknown for 63) and considered that there was room for improvement in this area for 114/293 (38.9%) patients (unknown for 65).

Patient diaries are an effective method of capturing the ICU experience for the patient and family, with the goal of improving psychological outcomes. Diaries can help patients to make sense of what has happened to them, in a manner that they can reflect upon and engage with when they feel ready. Despite this, clinicians completing questionnaires reported diaries were used with 199/483 (41.2%) patients (unknown for 188). In addition, 131/435 (30.1%) patients were given a copy of the ICU discharge summary (unknown for 236), although these were often written for healthcare professionals rather than providing a lay summary of events.

A total of 343/671 (51.1%) patients were provided with a copy of their hospital discharge summary. The information included in the summary is shown in table 6.1.

Table 6.1 Information given to the patient prior to discharge from hospital

Information given	Number of patients	%
What to do if they become acutely unwell	184	27.4
Managing their activities of daily living	159	23.7
General guidance, especially for the family and/or carer, on what to expect and how to support the person at home	159	23.7
Who to contact if the recovery is not going well	151	22.5
Their physical recovery based on goals set	132	19.7
Information about local statutory and non-statutory support	78	11.6
General information leaflet	15	2.2

Clinician questionnaire data: answers may be multiple; n=343

Of the patients who responded to the survey only 40/102 (39.2%) reported they were given a leaflet or discharge booklet, and limited information was provided regarding ongoing support options in

the community (Table 6.2). Furthermore, information was rarely shared with family members (69/671; 10.3%). This was a key aspect highlighted through the patient surveys:

"The whole discharge process, family need to be included so they know and understand. Even when the patient is able to communicate clearly and understand."

Table 6.2 Information and advice given to patients following an admission to an ICU

Sources of information	Number of responses	%
Provided with a leaflet	40	39.2
Signposted to ICUsteps	38	37.3
Referred to peer support groups	17	16.7
Local resource provided by your hospital	14	13.7
Online support groups	13	12.7
Signposted to other online resource	11	10.8
Other	9	8.8
Unsure	4	3.9
Advised to undertake an internet search	2	2.0
Not answered	32	31.4

Patient survey data: answers may be multiple; n=102

In total, 37/91 patients who answered the question stated that they were satisfied or very satisfied with the overall information and advice they were given (Figure 6.2).

"I felt that once I was discharged, I was left on my own to get better with no other offer of assistance."

"I think when you are in ICU it is such a shock to you and your family it is too much to process. You need regular reassurance even if there are no answers. My GP was unsure what to do with me and wanted me to contact the hospital for advice, the hospital felt the GP should deal with me. I ended up feeling a nuisance, so trying to cope alone now without asking for advice/help/researching things myself."

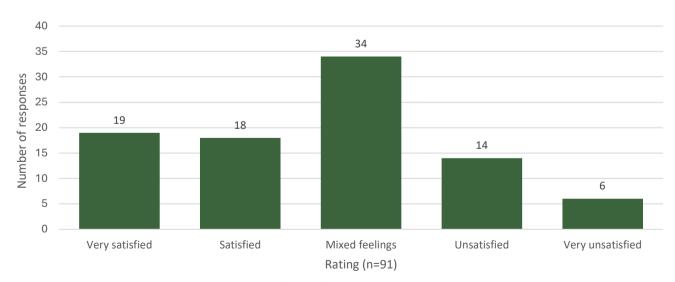


Figure 6.2 Overall rehabilitation services satisfaction following your critical illness Patient survey

CHAPTER 7: QUALITY OF REHABILITATION CARE

(BACK TO CONTENTS)

CLINICAL MESSAGE: Involving relevant members of the intensive care multidisciplinary team and undertaking early assessments of rehabilitation led to an improved quality of rehabilitation care.

Reviewers rated the quality of rehabilitation care in the intensive care unit (ICU), on the ward and following discharge from hospital. Care was rated as adequate or good most of the time in the ICU (124/247; 50.2%) and on the ward (200/298; 67.1%), but less frequently following discharge 75/201 (37.3%) (Figure 7.1).

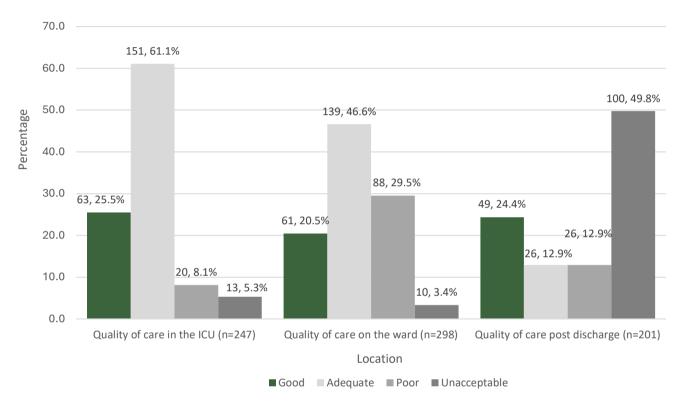


Figure 7.1 Quality of rehabilitation care in different locations Reviewer assessment form data

Length of stay in an ICU had no apparent effect on the reviewers grading of quality of care (Table 7.1).

Table 7.1 Quality of care following discharge by average ICU length of stay (days)

Quality of care following discharge	Average length of stay in ICU (days)
Good practice	11
Room for improvement (clinical factors)	10
Room for improvement (organisational factors)	10
Room for improvement (clinical and organisational factors)	12
Less than satisfactory	15

Combined clinician questionnaire and reviewer assessment form data

Rehabilitation following an admission to an ICU requires multidisciplinary team (MDT) input with many elements that need to come together to deliver the highest standards of care.

There were examples throughout this study of excellent care in the rehabilitation pathway. The key parts were prompt assessment, goal setting, MDT oversight and delivery, communication, and review.

The presence of a comprehensive assessment improved the quality of care provided, both in the ICU (61/78; 78.2% vs 148/268; 55.2%) and throughout the rehabilitation pathway (23/78; 29.5% vs 24/268; 9.0%) (Figure 7.2).

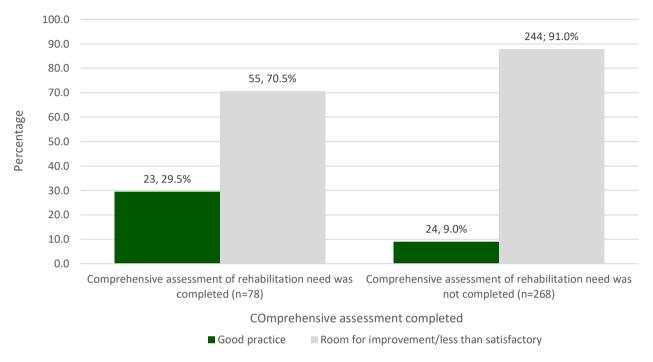


Figure 7.2 Comprehensive assessment and overall quality of care rating *Reviewer assessment form data*

The setting of goals as part of the comprehensive assessment also increased the likelihood of care being rated as good by reviewers (Figure 7.3).

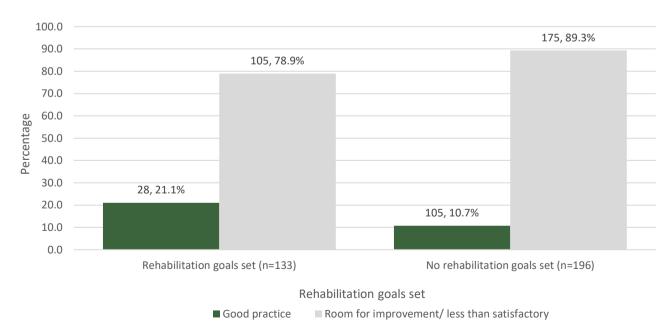


Figure 7.3 Goal setting and overall quality of care rating Reviewer assessment form data

As patients transition between the ICU and ward areas, continuity of rehabilitation is essential to optimise outcomes. The presence of a formal rehabilitation handover was associated with an increased likelihood of receiving good care on the ward 52/172 (30.2%) vs 8/90 (8.9%) (Figure 7.4).

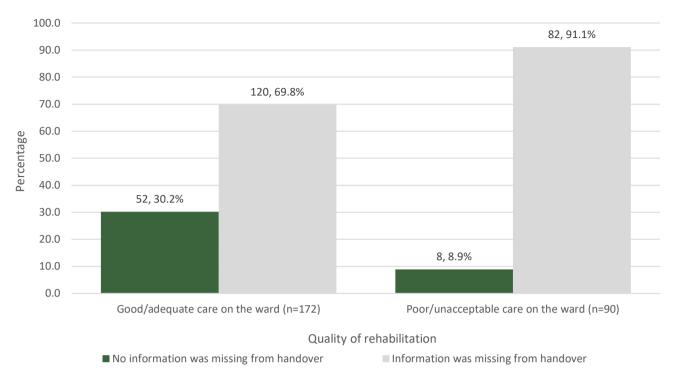


Figure 7.4 ICU handover by quality of rehabilitation on ward Reviewer assessment form data

In addition to assessing various aspects of care, reviewers were also asked to assign an overall quality of care grade. Overall, the reviewers rated the care as good in 46/342 (13.5%) patients. There was room for improvement in 266/342 (77.8%) and care was less than satisfactory in 30/342 (8.8%) (Figure 7.5).

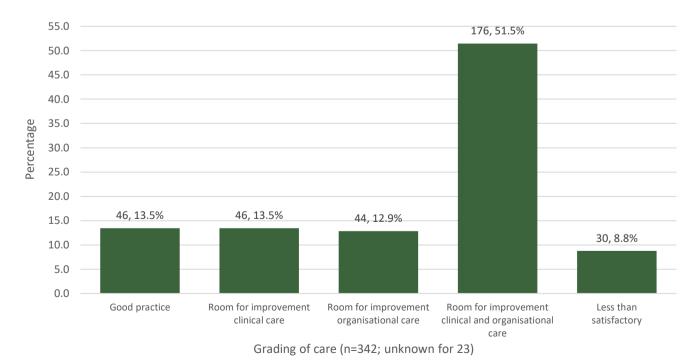


Figure 7.5 Overall quality of rehabilitation care Reviewer assessment form data

Clinicians completing questionnaires highlighted where improvements could have been made for patients while in the ICU or following their stay in an ICU (Table 7.2).

Table 7.2 Room for improvement in rehabilitation care

Area for improvement	Number of patients	%
Rehabilitation assessments in the ICU	274	40.8
Rehabilitation delivery post-discharge from hospital	233	34.7
Rehabilitation on the ward following step-down from the ICU	226	33.7
Communication with patients and families	203	30.3
MDT delivery of rehabilitation treatment in the ICU	184	27.4
MDT support throughout the pathway	170	25.3
Documentation of rehabilitation	24	3.6
Other	14	2.1
Follow-up	5	<1

Clinician questionnaire data: answers may be multiple; n=671

The areas identified as room for improvement in rehabilitation care were the lack of rehabilitation assessments in ICU, as well as the overall delivery of rehabilitation in ICU, on the ward following step-down, and after hospital discharge.