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A UK Survey of Rehabilitation Following Critical Illness: The Failure to Implement NICE Clinical Guidance 83 (CG83)

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Critical illness, rehabilitation, guidelines, implementation, survey

ABSTRACT

Objective

To determine the implementation of National Institute for Health and Clinical Excellence guidance (NICE CG83) for post hospital discharge critical illness follow-up and rehabilitation programmes.

Design

Closed-question postal survey.

Setting

Adult intensive care units (ICU), across the UK, identified from national databases of organisations. Specialist-only and private ICUs were not included.

Participants

Senior respiratory critical care physiotherapy clinicians.

Results

A representative sample of 182 surveys were returned from 240 distributed (75.8% (95%CI 70.4-81.2)). Only 48 organisations (27.3% (95%CI 20.7 to 33.9)) offered a follow-up service 2-3 months following hospital discharge, the majority (n=39, 84.8%) in clinic format. Twelve organisations reported post hospital discharge rehabilitation programmes (6.8% (95%CI 3.1 to 10.5)), albeit only ten of these operated on a regular basis. Lack of funding was reported as both the most frequent (n=149/164, 90.0%) and main barrier (n=99/156, 63.5%) to providing services. Insufficient resources (n=71/164, 43.3%) and lack of priority by the clinical management team (n=66/164, 40.2%) were also highly cited barriers to service delivery.

Conclusion

NICE CG83 has been successful in profiling the importance of rehabilitation for survivors of critical illness. However, four years following publication of CG83 there has been limited development of this clinical service across the UK. Strategies to support delivery of such quality improvement programmes are urgently required to enhance patient care.

Word Count

216

Article summary

Strengths and limitations of this study

- This is the largest, and most comprehensive survey conducted across the UK of post hospital discharge follow-up and rehabilitation for survivors of critical illness
- Data from this survey indicate a low reported prevalence of available services, with barriers to service implementation reported by clinicians examined in detail
- This survey was profession-specific, directed only to physiotherapy clinicians rather than multiple members of the interdisciplinary team
- Specialist-only and private organisations were excluded, which may have provided additional, potentially beneficial data

INTRODUCTION

Intensive care unit (ICU) admission with critical illness can have catastrophic and often long-term consequences for survivors. Physical and psychological impairments including reduced exercise capacity and health-related quality of life can persist for many years following hospital discharge [1-4]. These features are now referred to as the 'post intensive care syndrome' [5]. In recent years the importance of survivorship, or quality of survival, has been increasingly recognised [6], and the role of rehabilitation interventions to facilitate the recovery pathway of patients have become a major focus for the clinician [7].

In the UK, the National Institute of Health and Clinical Excellence (NICE) in 2009 published clinical guideline 83 (CG83) focussed on 'Rehabilitation After Critical Illness'. This profiled the importance of this area of clinical practice aiming to improve the standards of care and previously unmet clinical needs of this patient group. NICE CG83 advocated a continuum of multidisciplinary rehabilitation along the recovery pathway from within the ICU to the ward and following hospital discharge [8]. Despite the intentions, widespread clinical implementation of these guidelines has been challenged by the limited evidence underpinning the recommendations, as well as sparse detail provided to characterise the optimum type, intensity, frequency and duration of exercise therapy and rehabilitation interventions [9]. Furthermore, critical care survivors experience inadequate and disjointed multidisciplinary care following hospital discharge with inconsistent service provision, which can be strongly influenced by local resources and geographical location [10].

Failure to implement national guidelines or respond to published evidence is not uncommon. Disparity between the prevalence of conditions such as chronic

cardiorespiratory disease, diabetes mellitus and sleep-related disorders, and availability of recommended services for their management, is evident across the UK [11-13]. Previous surveys relating to provision of critical care rehabilitation have focussed on ICU follow-up [14] or physiotherapy practice within the ICU [15-17]. Two recent surveys reported on NICE CG83, but these were limited in content and detail [18 19]. The aim of the current study was to comprehensively determine, across the UK, implementation of NICE CG83 during the post hospital discharge period with detailed characterisation of available follow-up and rehabilitation services, and including establishing barriers to service provision.

METHODS

Details for all adult ICUs across the UK (England, Scotland, Wales and Northern Ireland) were obtained via two central registries; the Intensive Care National Audit and Research Centre (ICNARC) and the Scottish Intensive Care Society Audit Group (SICSAG). A total of 240 organisations were identified. Specialist-only and private ICUs were excluded were from survey.

The authors designed a predominantly closed-question survey (available from the corresponding author) to evaluate clinical practice regarding follow-up and rehabilitation services for survivors of critical illness post hospital discharge. Demographic details were requested regarding number, type and bed-capacity of critical care areas at each organisation. In addition, detail of service provision including follow-up, content, delivery and evaluation of rehabilitation programmes was requested, and barriers to offering services were sought if none were currently in operation. The majority of questions allowed respondents to select from multiple options with space available for free-text comments

throughout. These options were not ranked, nor were respondents asked to mark their response in terms of perceived importance or grading, with the exception of asking respondents to detail the main limiting barrier to service availability. The survey was piloted using three senior clinicians and clinical-academics (ICU clinical experience ranging 7-14 years) at two tertiary referral university teaching hospitals in London, UK. Constructive critique of survey design, content, structure, user-acceptability and time for completion was requested, following which further refinement was undertaken.

In March 2013, the survey and a covering letter of invitation to participate were distributed by post to the senior physiotherapist for critical care at each of the organisations with an included ICU. Stamped, self-addressed envelopes (SAEs) were enclosed for return of completed surveys. Surveys were coded to identify responses. Throughout the period of survey distribution a variety of strategies were employed to assist with survey promotion and enhance rates of completion and return. Six weeks following initial survey distribution, a reminder letter was sent by post to non-responders with a second copy of the survey and further SAEs. A further six weeks later, telephone calls were made to remaining non-responders. Direct contact was attempted with the senior critical care physiotherapist to determine willingness to participate, who were offered the choice of telephone or email completion of the survey. Respondents were also contacted via email or telephone if there were missing data.

Data Handling

In line with guidance produced by the UK National Research Ethics Service (available at http://www.nres.nhs.uk/) the project was deemed an evaluation of service provision, and

therefore ethical approval was not required. Completion and return of the survey was considered indicative of willingness to participate in the survey and implied consent. All data were stored in standard spreadsheets, transcribed from hard copies of returned surveys. Due to the nature of the study and data collected, descriptive statistics were used to analyse quantitative responses including number, percentage and 95% confidence intervals where appropriate, and additional qualitative review of free-text comments made. A response rate of 65% rate was considered *a priori* to provide a representative sample.

RESULTS

Responding institutions

One hundred and eighty-two of the 240 distributed surveys were returned, indicating a 75.8% (95%CI 70.4 to 81.2) response rate (*Figure 1*). One survey was returned blank with the respondent indicating that they lacked sufficient time for completion. Demographic data for the hospitals surveyed are reported in *Table 1*. The majority were district general (DG) hospitals with ICUs and high dependency units (HDUs) managing mixed general medical and surgical patient casemixes. A large number of responses reported 'combination' units accepting both Level 3 and 2 patients (*Table 2*).

Five respondents indicated that available rehabilitation programmes at their organisations were the direct result of active research studies (*Figure E1, Data Supplement*). These responses were excluded as the aim of the survey was to characterise current clinical practice rather than research activity. These five respondents completed the section asking for barriers to offering a clinical service had the research study not been implemented.

Table 1. Demographics of organisations

Characteristic	n (%)
Response rate according to UK country	
England	145 (75.1)
Scotland	20 (87.0)
Wales	12 (80.0)
Northern Ireland	5 (55.6)
Type of hospital	
University teaching	66 (36.5)
District general	115 (63.5)
Total number of Critical Care Units*	
Level 3 (ICU)	112
Level 2 (HDU)	170
Combination Level 3 and 2 units	98
Total number of Critical Care Beds*	
Level 3 (ICU)	1007
Level 2 (HDU)	1090
Combination Level 3 and 2 units	1354
Frequency of reported types of patients admitted to Critical Care Unit*#	
General	230
Surgical	52
Medical	38
Cardiac/Cardiology/Cardiothoracic	35
Neurological	22
Respiratory	17
Trauma	14
Renal	5
Burns	4
Liver	4
ENT	3
Other~	10

n=181 responses. *n=2 non-responses. #Data presented indicates frequency of reported occurrence of type. Multiple responses could be given. ~Other e.g. haematology, infectious disease, maxillo-facial, vascular.

Abbreviations: ICU = intensive care unit. HDU = high dependency unit. ENT = ear, nose, throat.

Table 2. Classifications of level of clinical care provided to patients

Level	Classification
0	Patients whose needs can be met through normal ward care in an acute hospital.
1	Patients at risk of their condition deteriorating, or those recently located from higher levels of care, whose needs can be met on an acute ward with additional advice and support from the critical care team.
2	Patients requiring more detailed observation or intervention including support for a single failing organ system or post-operative care and those 'stepping down' from higher levels of care.
3	Patients requiring advanced respiratory support alone or basic respiratory support together with support of at least two organ systems. This level includes all complex patients requiring support for multi-organ failure.

From Comprehensive Critical Care, DH, 2000 [20]

Post hospital discharge follow-up clinical services

Forty-eight organisations (27.3%, 95%CI (20.7 to 33.9)) indicated availability of follow-up of post critical illness patients at 2-3months following hospital discharge (*Figure E1, Data Supplement*). Thirty-two (66.7%) of these were from DG hospitals and 16 (33.3%) from university teaching (UT) hospitals. Forty-five organisations offering follow-up were located in England, two in Scotland, one in Northern Ireland and none in Wales. Two respondents did not provide details of follow-up provision. Of the remaining responses (n=46), ICU follow-up clinics were the most frequently reported form of follow-up (n=39, 84.8%) (*Table 3*). Eleven respondents indicated more than one form of follow-up was in place.

Table 3. Follow-up services for critical care survivors post hospital discharge

Form of follow-up	**n (%)**
ICU follow-up clinic	39 (84.8)
Rehabilitation class	10 (21.7)
Other	6 (13.0)
Did not specify	2 (4.3)
Postal survey	1 (2.2)
Telephone call	1 (2.2)
Medical outpatient appointment	0 (0)
Multidisciplinary team member	**n (%)**
Physiotherapist	43 (89.6)
Critical Care nurse	42 (87.5)
Critical Care doctor	31 (64.6)
Psychologist	10 (20.8)
Dietician	2 (4.2)
Occupational therapist	2 (4.2)
Content of follow-up	**n (%)**
HRQL	40 (83.3)
Psychological status	39 (81.3)
Medical status	34 (70.8)
Nursing-related issues	29 (60.4)
Exercise capacity	28 (58.3)
Diet/nutrition	24 (50.0)
Other	9 (18.8)

For follow-up, n=frequency of reported occurrence out of 46 responses. Multiple forms of follow-up could be indicated. Other included informal coffee morning, patient support group, physiotherapy outreach, ad hoc appointments with ICU nursing staff. For multidisciplinary team members, n=frequency of reported occurrence out of 48 responses. Multiple team members could be listed. For follow-up content, n=frequency of reported occurrence out of 48 responses. Multiple content could be listed. Other included 'problem-based' or 'patient-dependent' discussion

Abbreviation: ICU = intensive care unit. HRQL = health-related quality of life.

Forty-three (89.6%) respondents reported that physiotherapists were part of the multidisciplinary team (MDT) involved in follow-up of post critical illness patients. However, just under one-third of these, n= 13 (30.2%), indicated that this was on an *ad hoc* referral basis only. Other MDT members involved in follow-up are detailed in *Table 3*. In five cases access to critical care doctors, occupational therapists, psychologists or dieticians was also reported to be on a referral basis only. Critical care nurses were the most consistently featured MDT members and occupational therapists and dieticians were rarely involved in follow-up. The scale of MDT involvement ranged from one member (10.4%) to five members (2.0%), with three being the most common (43.8%). No other healthcare professionals, other than those listed, were documented to be part of the MDT.

Nearly half of those with follow-up services included a functional reassessment for comparison with assessment conducted at the time of hospital discharge (n = 20, 42.6%). *Table 3* details other aspects of follow-up assessments; health-related quality of life (n = 40, 83.3%) and psychological status (n= 39, 81.3%) were the most frequently reported items. Exercise capacity and nursing-related issues were included in approximately half of cases.

Availability of post hospital discharge rehabilitation programmes

Twelve organisations reported a rehabilitation programme was available following hospital discharge for post critical illness patients (6.8%, 95% CI (3.1 to 10.5)) (*Figure E1, Data Supplement).* Two indicated that their programme was only available on an *ad hoc* basis only. Of the remaining ten programmes implemented on a regular basis, 4 (40%) were conducted at UT hospitals and 6 (60%) at DG hospitals), and all based at organisations in

England. All had also reported offering a follow-up service, with eight of these in the form of an ICU follow-up clinic.

Senior ICU physiotherapists led all available rehabilitation programmes, with the exception of one led by a rehabilitation physiotherapist. The majority (n=9) were hospital-based, outpatient programmes, specific for post critical illness patients. Exercise was a component of all programmes including cardiovascular, muscle strength, balance and functional activities. Exercise prescription was usually based on clinician judgement, and on occasion using results of physical assessment of walking capacity of function. Clinical and physiological parameters were used to monitor exercise intensity during sessions. Less than half of all programmes (n=4) included education sessions. Measures used to evaluate effectiveness of these rehabilitation programmes varied greatly with exercise capacity and health-related quality of life most commonly reported.

Further detail on the leadership, format and structure, content and monitoring and evaluation of available post hospital discharge rehabilitation programmes can be found in the Data Supplement (E2).

Barriers to delivery of post hospital discharge rehabilitation programmes

Respondents were requested to report the barriers to delivery of post hospital discharge rehabilitation programmes from a non-hierarchical list including clinical, pragmatic, managerial and administrative options. From the reasons selected, respondents were also requested to confirm the main reason. From a potential 171 responses, there were seven non-responses to both parts of this question (n=164), and a further 8 non-responses to

specifying the main barrier (n=156). 91% (n = 149) of respondents reported lack of funding as one barrier to offering a post hospital discharge rehabilitation programme, and 75% reported lack of staff (Table 4). Only 2.4% of respondents reported that a lack of evidence and less than 1% of respondents reported time constraints as barriers to implementing a post hospital discharge rehabilitation programme. 6% (10/164) of respondents listed only one barrier, 20% (33/164) listed two barriers and 73% (120/164) listed greater than two barriers.

Table 4. Barriers to post hospital discharge rehabilitation programmes for survivors of critical illness

Barrier	Frequency reported overall, n (%)	Frequency reported as main barrier, n (%)
Lack of funding	149 (90.9)	99 (63.5)
Lack of sufficient staff	128 (78.0)	17 (10.9)
Resources prioritised to other patient groups/clinical areas	71 (43.3)	4 (2.7)
Not considered required service at managerial level	66 (40.2)	22 (14.1)
Lack of available space	50 (30.5)	2 (1.3)
Insufficient patient numbers to justify	35 (21.3)	11 (7.1)
Extra-contractual (out-of-area) patient caseload	15 (9.1)	0 (0.0)
Lack of trained staff	13 (7.9)	0 (0.0)
No evidence	4 (2.4)	0 (0.0)
Not sure what to include in a programme	2 (1.2)	0 (0.0)
Other (time constraints)	1 (0.6)	1 (0.6)

For frequency of reported barriers overall, n=164 responses. For frequency of reporting as main barrier, n=156 responses. (n=182 responses, excluding one blank response, ten non-applicable responses relating to rehabilitation programmes in regular operation, seven non-responses to both parts of this question, and a further eight non-responses to specifying the main barrier).

Alternative rehabilitation programmes

57.3% (98/171) of respondents reported that in the absence of a specific post hospital discharge rehabilitation programme for survivors of critical illness at their organisation, patients were referred into alternative rehabilitation streams, including pulmonary rehabilitation (PR) (62/98, 63.3%) and cardiac rehabilitation (38/98, 38.8%) (e.g. those patients post cardiac surgery and post myocardial infarction) and various community-based services (59/98; 60.2%). Free-text comments from respondents regarding barriers to offering rehabilitation programmes and the use of alternative rehabilitation streams for ICU survivors following hospital discharge can be found in the Data Supplement (E3).

DISCUSSION

These data from the first comprehensive UK survey highlight the limited implementation of NICE CG83 and the poor delivery across the UK of post hospital rehabilitation services for survivors of critical illness. Indeed, of one-hundred and eighty-two surveys returned, less than one-third of all institutions surveyed provided any form of follow-up for these patients. Of major clinical concern is that only 5% of respondents reported the provision of a regular rehabilitation programme for critical illness survivors, a major focus of CG83. A lack of funding was the most frequently reported and main barrier to service availability. Furthermore, lack of managerial support for this type of service and prioritisation of resource allocation to other clinical areas were reported as barriers by over 40% of the respondents. These data indicate that inadequate clinical infrastructure exists for hospitals and community teams to successfully adhere to NICE CG83. The limited impact of NICE guidance on clinical practice is not unique to critical care rehabilitation and is, rather

disappointingly, a theme observed in other areas of healthcare that have been subject to the development of NICE guidelines.

Implementation NICE CG83 across the UK

The lack of implementation of NICE CG83 evident from these data could have reflected poor motivation on the part of clinicians to actively engage in the delivery of recommendations. However, the key barriers to service delivery were reported as lack of funding, limited resources and infrastructure with reduced priority at managerial level. In the modern National Health Service (NHS), such obstacles to the application of NICE CG83 are at either a clinical commissioning or clinical operational level, or both, rather than at the level of the clinicians. Interestingly, the paucity of data to support the effectiveness of post ICU rehabilitation was not perceived as a barrier by the vast majority of clinicians, and highlights the complexities in the management and clinical delivery of a critical care rehabilitation service. A conflict between clinicians, managers and commissioners has developed as the lack of high level clinical evidence supporting NICE CG83 provides a major challenge to the funding of a critical care survivor rehabilitation service by both managers and commissioners.

Alternatives to post hospital discharge rehabilitation programmes

Rehabilitation for survivors of critical illness is a complex intervention [21], that requires further translational work and clinical trials to provide the evidence [22-24]. Until these data are available, the unmet clinical need will remain evident and unaddressed. Referral into established rehabilitation programmes, such as cardiac and pulmonary rehabilitation, offers one potential resolution with over 50% of respondents reported the use of other

rehabilitation programmes for the critical care survivors, and this may further be influenced by the designated speciality of the ward destination of patients following ICU discharge. Indeed the up-to-date guidelines for pulmonary rehabilitation [25], advocate individualised patient management and these interventions could be easily adapted for patients recovering from critical, albeit that additional referrals places an increased burden these services. However, whilst valuable resources, these programmes are disease-specific and may not fully address the range of impairments demonstrated by survivors of critical illness as part of 'post intensive care syndrome' [5].

The clinical usefulness of post ICU clinics

Post-ICU clinics provided the majority of available follow-up services in the current survey. Profiled in the late 1990s and early 2000s following updating of the NHS agenda for critical care [20 26], these clinics have been reported by patients to play a valuable contribution to their physical, emotional and psychological recovery [27]. However, trial data have failed to demonstrate clinical effectiveness or cost benefit [28]. An alternative approach to the conduct and purpose of post ICU clinics would be to robustly monitor over time the trajectory of recovery of ICU survivors with onward referral into specific speciality care where identified as required. Wide variability in responses regarding post hospital discharge rehabilitation programmes for ICU survivors severely limits any consensus on the optimum approach for these services. The marked heterogeneity of the patient population makes it increasingly likely that a bespoke, individualised approach, akin to the approach of personalised medicine, may be more appropriate.

Barriers to implementation of national guidelines

The implementation of, and adherence to, a clinical guideline can be inconsistent [29 30]. The limited detail in terms of the rehabilitation programme in the guideline *per se* as well as local conditions such as staff infrastructure, organisation and resource were the main source of restriction to implementation of NICE CG83 in the current survey [31]. This is the first survey to investigate reasons behind failure to implement such a national guideline and offer significant insight into the requirements necessary for successful clinical application of recommendations designed to enhance patient care. Whilst the goals of NICE CG83 were important and raised the profile of this area of clinical practice the influence will be short-lived without further investment in support systems at operational and staffing level. Disappointingly, this scenario appears to be mirrored in other common clinical conditions. Although evidence supports the use of early pulmonary rehabilitation (PR) following acute exacerbation of chronic obstructive pulmonary disease (AECOPD) to enhance exercise capacity, health status and reduce hospital readmissions [25 32-34], recent data suggest that only one-third of eligible patients are referred to early PR programmes and less than 10% of all hospital discharges for AECOPD complete early post-hospitalisation PR [12]. This implementation failure is also observed following the NICE guidance on the management of obstructive sleep apnoea [35] with a recent national mapping exercise highlighting a significant mismatch between predictive healthcare requirements, based on prevalence of known associated risk factors, and delivery of related services [13]. Furthermore, the 2012 NHS Atlas of Variation in Healthcare for People with Diabetes [11] revealed substantial numbers of patients were not in receipt of the basic clinical standards of care. The barriers to the implementation of these guidelines are specific to each clinical area, but there are generic barriers, such as lack of adequate funding and resource, that need to be considered carefully. However, it must be highlighted that robust clinical trial and other data are

required to support a guideline if it is to be commissioned within the NHS and delivering a guideline prematurely will lead to implementation failure, despite major enthusiasm by clinicians.

Critique of the method

A major strength of this survey is the employment of a variety of strategies to optimise completion, resulting in a 76% response rate. Nonetheless, survey non-response is a challenge to the robustness of the current findings, introducing bias through the potential for non-responders to differ significantly from responders [36 37]. Despite this, one must consider this as a most satisfactory return indicating external validity [37 38]. The high response rate may represent the clinical concern of the respondents in terms of poor implementation of NICE CG83, in particular, as the core standards for care of the critically ill patient have been recently published highlighting rehabilitation as an important core clinical care standard [39].

Postal questionnaires can be preferable for conducting surveys of large populations over a wide geographical range, offering a cost-efficient as well as time-efficient format with often improved response rates in comparison to alternative routes such as telephone interview or email [40]. Furthermore, an email or internet-based platform would have been restricted in the current study due to lack of available electronic contact details for clinicians, and where postal distribution offered a more standardised approach for monitoring and identifying respondents. Nonetheless, we acknowledge that in the current technology climate, many respondents may have preferred this option for survey participation. We utilised both email and telephone contact at later stages of survey distribution as a more feasible and less cost-

prohibitive means to target previous non-responders with good effect. Despite encountering some difficulty with locating designated senior clinicians [41], this resulted in a relatively high conversion rate of 36% of non-responders. The current survey took advantage of a range of design and formatting strategies to enhance completion, additionally including a personalised cover letter and stamped addressed envelopes [37 38 42]. Survey review was undertaken during piloting with three senior clinical-academics, and we aimed to minimise additional burden to potential respondents by not utilising a larger sample at this stage. Furthermore, we adopted an approach to survey distribution in keeping with that suggested to minimise non-response [43]. However, the current survey lacked sufficient demographic or other data regarding non-responders to attempt comparison between the two groups [36 37], although 95% confidence intervals are narrow supporting the respondents as representative sample of the whole respondent population.

We identified ICUs for inclusion based on data provided by two national registries (ICNARC and SICSAG). Whilst specialist-only and private institutions were excluded, assuming that rehabilitation services offered to these patient cohorts may be influenced by disease-specific or institutional status-related factors, we acknowledge that future survey data acquired from these organisations may add further benefit to characterising service provision. We adopted a more rigorous approach to data acquisition than previous similar surveys that were country-specific [18] or excluded key regions [19], albeit these authors examined NICE CG83 implementation across the patient pathway and results observed at the post hospital discharge stage mirrored those of the current study.

The current study focussed on post hospital discharge management as it is at this stage that patients may be more likely to experience insufficient input for reasons such as lack of available services, repatriation back to other geographical regions or follow-up under non-ICU teams [44]. In contrast to previous surveys, we examined barriers to service availability in detail to gain further insight regarding this. Furthermore, rehabilitation for ICU survivors following hospital discharge has been the focus of recent research interest with randomised controlled trial data now available [45]. The current survey could be critiqued for being discipline-specific. However, it was considered that senior critical care physiotherapy clinicians would be well-informed as key members of the multi-disciplinary team involved in management of ICU survivors, to comment on follow-up and rehabilitation service provision at their institutions.

CONCLUSION

These data from this first comprehensive UK survey of post hospital discharge rehabilitation programmes for critical illness survivors have demonstrated a low reported prevalence and, more importantly, this survey has showed a failure to implement NICE CG83. Lack of clinical prioritisation and funding was reported by the clinicians as the major cause for the failure to implement the guideline, but the paucity of evidence that supported the guideline must be regarded as a major contributor to the limited engagement between clinicians, managers and commissioners to deliver NICE CG83. Without clinical and cost effectiveness evidence for such a programme, it would be a significant challenge to commission such a service in an NHS that is driven to commission both clinical and specialist services with an established evidence base. The focus of the clinicians must be to ensure that clinical guidelines have a

robust and strong evidence base to maximise their implementation and this will result in an enhancement in patient care that will be both clinical and cost effective.

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CONTRIBUTORS

BC, LD and NH contributed to the conception and design of the study. BC and AD analysed the data. BC and NH interpreted the data. BC drafted the manuscript and all authors critically revised for significant intellectual content and insight. All authors had full access to all of the data and can take responsibility for the integrity and accuracy of data analysis. Furthermore all authors gave final approval of the manuscript version for publication. BC and NH are responsible for the overall content as guarantors.

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COMPETING INTERESTS

All authors have completed the Unified Competing Interest Form at www.icmje.org.coi_disclosure.pdf (available from the corresponding author) and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years; no spouse, partner or children have any financial relationships that may be relevant to the submitted work; and no other non-financial interests that may be relevant to the submitted work.

ETHICAL APPROVAL

Ethical approval was not required for this study.

DATA SHARING

No additional data available.

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What is already known on this topic

Survivors of critical illness demonstrate impairment of physical function, psychological well-being , cognitive function and health-related quality of life that are recognised clinical features of the post intensive care syndrome.

In the UK, rehabilitation following critical illness as a continuum that spans the whole patient pathway of recovery has been recommended in national guidance.

What this study adds

Limited implementation of NICE CG83 is evident across the UK in terms of clinical follow-up and rehabilitation programmes.

Establishing robust evidence to support national guidelines will maximise implementation to ensure clinical and cost-effective patient care is delivered.

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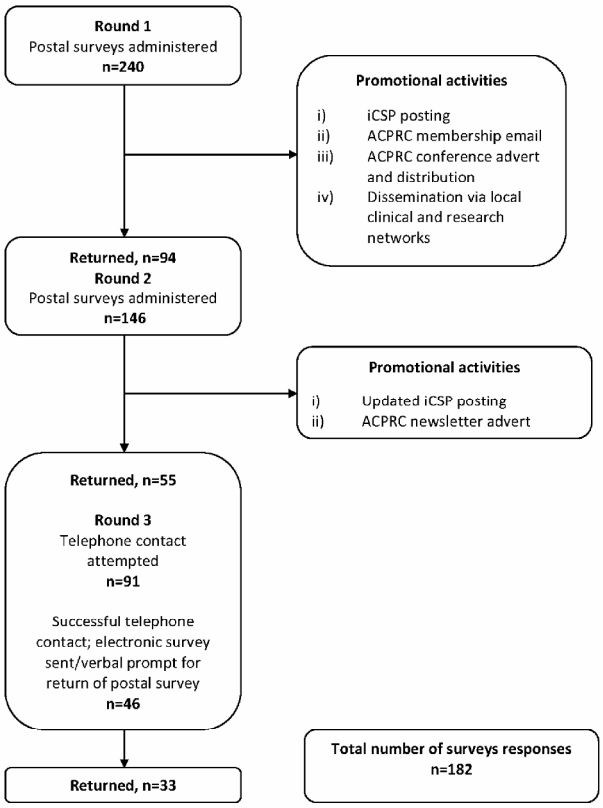
FIGURE LEGENDS

Figure 1. Flow-chart of survey distribution stages, response rates and promotional activities

Abbreviations: iCSP = interactive Chartered Society of Physiotherapy. ACPRC = Association of Chartered Physiotherapists in Respiratory Care.



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208x278mm (300 x 300 DPI)

Rehabilitation Following Critical Illness: The Failure to Implement NICE Clinical Guidance 83 (CG83) in the UK

DATA SUPPLEMENT

E1. Post hospital discharge follow-up services and rehabilitation programmes

Figure E1 reports available follow-up services and rehabilitation programmes for survivors of critical illness post hospital discharge.

E2. Detail on characteristics of available post hospital discharge rehabilitation programmes for survivors or critical illness

Leadership of, and enrolment into, post hospital discharge rehabilitation programmes

In the majority of cases (n=9) this was a senior ICU physiotherapist (median (IQR) duration ICU experience 7.0 (4.0-13.0) years). A rehabilitation physiotherapist led one programme. One programme reported additional involvement of an occupational therapist and a fitness instructor with three including critical care nurses. There were no other MDT members reported. Limited data were provided regarding enrolment criteria of patients into available rehabilitation programmes (*Table E1*).

Table E1. Enrolment criteria for post hospital discharge rehabilitation programmes

Eligibility criteria	n (%)	Detail of assessment measure
Duration mechanical ventilation	7 (70.0)	>5 days; >4 days; >3 days; 48hours
Duration ICU Admission	3 (30.0)	>5 days; >4 days
Duration hospital admission	2 (20.0)	"lengthened"
Physical function at ICU discharge	2 (20.0)	"reduced from pre-admission"
Muscle strength at ICU discharge	2 (20.0)	No detail provided
Exercise capacity at ICU discharge	2 (20.0)	No detail provided
HRQL at ICU discharge	0	-
Physical function at hospital discharge	4 (40.0)	No detail provided
Muscle strength at hospital discharge	3 (30.0)	No detail provided
Exercise capacity at hospital discharge	3 (30.0)	No detail provided
HRQL at hospital discharge	1 (10.0)	No detail provided
All patients eligible	1 (10.0)	"any ITU stay"
Other	2 (20.0)	"those with profound weakness or functional limitation regardless of LOS"; "screen for low or high risk throughout ICU/hospital stay. If high risk, exercise plan, goals and rehab class if suitable. All plus 2 day ICU are automatically sent SF8 and depending on score, either 1:1 follow up or group follow-up"

n=10 responses. Multiple criteria could be reported per response.

Abbreviations: ICU/ITU = intensive care/therapy unit. HRQL = health-related quality of life. LOS = length of stay. SF8 = Short Form-8 (health-related quality of life survey).

Format and structure of post hospital discharge rehabilitation programmes

Of the ten rehabilitation programmes, nine were hospital-based and one was home-based. Patients exercised under supervision in four programmes, and with a combination of supervised and independent exercise in the remaining six. Only one programme used an accompanying rehabilitation manual, however three others reported providing printed, individualised home exercises for patients. All programmes were designed specifically for post critical illness patients. None were combined with existing disease-specific services such as pulmonary or cardiac rehabilitation. Programmes started immediately (n=4), at one week (n=1), within two weeks (n=3), within one month (n=1) and at 2-3 months (n=1) post hospital discharge. The number of sessions in each programme varied from 6 to 12, excluding assessment sessions. Data were absent for two programmes. Three programmes had the capacity and flexibility to allow patients to continue until individual goals or target physical function level had been achieved. Typically sessions ran weekly (n=7) or twice-weekly (n=3). All programmes included sessions of one hour duration. Eight programmes were 'rolling' programmes and patients could start and finish the programme at any point in time. One was stand-alone such that cohorts of post critical illness patients all started and completed programmes together. No enrolment, initiation timing, frequency or duration data were reported for one programme.

Content and monitoring of post hospital discharge rehabilitation programmes

All rehabilitation programmes included an exercise component, involving a combination of cardiovascular, muscle strength, whole body balance and functional activity (*Table E2*). Nine programmes incorporated at least two different forms of exercise prescription during the programme usually based on clinician judgement, sometime informed by results of walking

tests and physical function assessment. All programmes included at least two forms of patient monitoring during exercise sessions, based on a range of physiological and clinical factors. Seven programmes used target rates of perceived exertion with four programmes using oxygen saturation levels and 3 programmes monitoring heart rate. In contrast, patient-related parameters were adopted in 8 programmes which monitored exercise performance based on verbal feedback of the patient, 6 based on clinician judgement of the patient and 2 based on visual analogue scales undertaken by the patient.

Surprisingly, less than half of all programmes included an education component (n=4). A range of topics were covered including exercise, stress management and relaxation, nutrition, return to work, energy conservation, medications, recovery following critical illness, smoking cessation, managing breathlessness and breathing control, delivered predominantly by physiotherapists but with additional input from occupational therapist and nursing colleagues.

Group size

Group size and staff-to-patient ratio was also highly variable between the 10 post rehabilitation programmes. One programme incorporated a 1:1 staff-to-patient ratio whilst another adopted a flexible approach that depended on the complexity of the patient and individual rehabilitation needs. Across the remaining programmes group sizes ranged from 5 to 14 patients with one qualified staff member for every 3 patients. Seven of the ten programmes adopted patient-specific exercise plans, whilst the remaining three reported that patients exercised in a pre-determined circuit.

Table E2. Exercise component and evaluation of post hospital discharge rehabilitation programmes

Category of exercise	Specific exercise	n (%)
Cardiovascular	Static bike	10 (100.0)
	Step-ups	9 (90.0)
	Treadmill	7 (70.0)
	Cross-trainer	2 (20.0)
Strength	Lower limb	10 (100.0)
	Upper limb	10 (100.0)
	Theraband/resistance	9 (90.0)
	Free weights	7 (70.0)
Balance	Dynamic	9 (90.0)
	Static	5 (50.0)
Functional	Sit-to-stand	8 (80.0)
	Walking	6 (60.0)
	Timed Up And Go	2 (20.0)
Outcome	**Detail of outcome measure**	**n (%)**
HRQL	SF-36, HADS, EQ5D, FIM, SF-8	10 (100.0)
Exercise capacity	6MWT; ISWT	9 (90.0)
Other	Achievement of patient-specific goals; BMI; Impacts of Events Score	3 (30.0)
Functional	TUAG; patient-specific goals	2 (20.0)
Strength	2 minute step-ups	1 (10.0)
Mental/cognitive	-	0

For exercise component and outcome measures, n=frequency of reported occurrence out of 10 responses. Multiple options could be listed per response.

Abbreviations: HRQL = health-related quality of life. 6MWT = Six Minute Walk Test. ISWT = Incremental Shuttle Walk Test. SF-36 = Short Form 36. HADS = Hospital Anxiety and Depression Scale. EQ5D = EuroQol 5 Dimensions. FIM = Functional Independence Measure. SF-8 = Short Form 8. TUAG = Timed Up And Go. BMI = body mass index.

Evaluation of post hospital discharge rehabilitation programmes

Four of the programmes reported reassessment of baseline measures as a form of evaluation of the programme. However, subjective clinician judgement was the most commonly utilised form of evaluation followed by the objective changes in walking tests and physical function. Physiological parameters, such as target perceived rate of exertion and heart rate, and results of balance assessments were used infrequently in the evaluation of the response to the rehabilitation programme. Exercise capacity and health-related quality of life outcome measures were the most commonly utilised. Interestingly, none of the programmes incorporated the use of the repetition maximum principle to prescribe strengthening exercises.

E3. Individual comments made by respondents regarding barriers to offering post hospital rehabilitation discharge services and use of alternative rehabilitation streams.

The following free-text comments were made by respondents regarding barrier to offering specific post hospital discharge rehabilitation programmes and further elucidate the themes of funding restriction, resource allocation/availability (Including staffing) and strategic management priorities as key limiting factors. (Note: words in italics added by the author for full interpretation):

> "...we at times struggle to fight for staff for in pt rehab (*in-patient rehabilitation*) let alone fight for a budget for op (*out-patient*) care

> "...we run a voluntary f-u (*follow-up*) clinic but have had to withdraw the rehab (*rehabilitation*) and psych (*psychology*) elements due to no (sic) support from therapy managers

"...despite extensive work the business case was declined

"...a rehab (*rehabilitation*) programme was run for 12m using charitable funds money. Ongoing funding was not secured as it was not deemed a Trust priority

"...historically no service available, no need established by current ICU services

"...and not considered required at managerial level; Some years ago charitable funding was available to open follow-up clinic to include rehab (*rehabilitation)* service but Trust board refused the 2 year funding as they could not commit to continuing to fund the service once the charitable monies expired. So the reason we didn't introduce the service at that time was a mix of funding and managerial issues. Currently I would think staffing would be another issue.

"...previously ran post ICU rehab (*rehabilitation*) class but had to stop because reduced staffing (prioritising in-pt) and difficult to get numbers (no transport provided)

"...The main barriers to this aspect are time constraints, lack of staff and funding alongside limited knowledge of potential co-morbidities following ICU stay. Critical Care follow up clinics do not take place in an adequate time frame in this trust and as such many people do not attend, therefore we are missing potential problems. Additionally the clinic is not an MDT run clinic, limiting clinical identification of potential problems.

"...absence of vertical integration of health and social care

"...not so much not considered as required - sure the team believe it's required just not enough resources

"6.5WTE PT (*6.5 whole-time equivalent physiotherapists*) in team covering 7 different ward specialities, 3x critical care areas, resp o/p (*respiratory out-patients*), resp pts (*respiratory patients*) in A&E/admissions

Other comments described the interaction between acute and primary care services, which in some cases offer a route for ongoing rehabilitation input, and clinical and logistical factors for consideration in determining need for specific critical care services:

"...inpt (in-patient) and outpt (out-patient) services are provided by two separate organisations, therefore although the inpt (*in-patient*) team would like to provide a service the community team will not lend support

"...pt (*patient*) needs met by other community services available

"...not sure if we would have individual class therefore combined with PR (*pulmonary rehabilitation*); we would like to set one-up

"...numbers are very small and tends to be post-op (*post-operative*); back to baseline 5/7 (*at five days*). not seen need to provide service separate to our IRS (*in-patient rehabilitation or integrated respiratory service*)

"...We have a follow up clinic run by our CCORT (*critical care outreach team*), but no physical rehab (*rehabilitation*) post D/C (*discharge*) home (unless needing regular community physio (*physiotherapy*) input)

"...very structured in hospital critical care rehab (*rehabilitation*) service to maximise pt (*patient*) status at hospital d/c (*discharge*), has significantly reduced LOS (*length of stay*), readmissions to critical care, QOL (*quality of life*) scores and ongoing co-morbidity/health problems. Insufficient numbers for group rehab (*rehabilitation*) specific to CCD (*critical care disease*) post d/c (*discharge*)

"...patients who need long-term rehab (*rehabilitation*) are followed up by community staff

"...we use PR (*pulmonary rehabilitation*) programme for many post ITU patients

"...cardiac patients go to CR (*cardiac rehabilitation*)

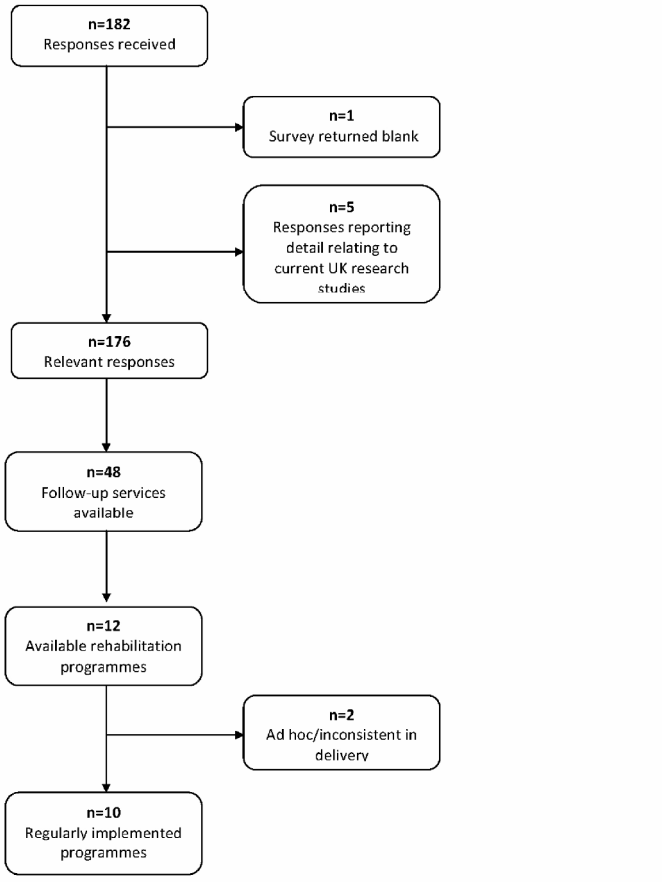

Figure E1. Flow-chart outlining available follow-up services and rehabilitation programmes for survivors of critical illness post hospital discharge

1

Figure E1. Flow-chart outlining available follow-up services and rehabilitation programmes for survivors of critical illness post hospital discharge
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BMJ Open

A UK Survey of Rehabilitation Following Critical Illness: Implementation of NICE Clinical Guidance 83 (CG83) Following Hospital Discharge

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A UK Survey of Rehabilitation Following Critical Illness: Implementation of NICE Clinical Guidance 83 (CG83) Following Hospital Discharge

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Key words

Critical illness, rehabilitation, guidelines, implementation, survey

ABSTRACT

Objective

To determine the implementation of National Institute for Health and Care Excellence guidance (NICE CG83) for post hospital discharge critical illness follow-up and rehabilitation programmes.

Design

Closed-question postal survey.

Setting

Adult intensive care units (ICU), across the UK, identified from national databases of organisations. Specialist-only and private ICUs were not included.

Participants

Senior respiratory critical care physiotherapy clinicians.

Results

A representative sample of 182 surveys were returned from 240 distributed (75.8% (95%CI 70.4-81.2)). Only 48 organisations (27.3% (95%CI 20.7 to 33.9)) offered a follow-up service 2-3 months following hospital discharge, the majority (n=39, 84.8%) in clinic format. Twelve organisations reported post hospital discharge rehabilitation programmes (6.8% (95%CI 3.1 to 10.5)), albeit only ten of these operated on a regular basis. Lack of funding was reported as both the most frequent (n=149/164, 90.0%) and main barrier (n=99/156, 63.5%) to providing services. Insufficient resources (n=71/164, 43.3%) and lack of priority by the clinical management team (n=66/164, 40.2%) were also highly cited barriers to service delivery.

Conclusion

NICE CG83 has been successful in profiling the importance of rehabilitation for survivors of critical illness. However, four years following publication of CG83 there has been limited development of this clinical service across the UK. Strategies to support delivery of such quality improvement programmes are urgently required to enhance patient care.

Word Count

216

Article summary

Strengths and limitations of this study

- This is the largest, and most comprehensive survey conducted across the UK of post hospital discharge follow-up and rehabilitation for survivors of critical illness
- Data from this survey indicate a low reported prevalence of available services, with barriers to service implementation reported by clinicians examined in detail
- This survey was profession-specific, directed only to physiotherapy clinicians rather than multiple members of the interdisciplinary team
- Specialist-only and private organisations were excluded, which may have provided additional, potentially beneficial data

INTRODUCTION

Intensive care unit (ICU) admission with critical illness can have catastrophic and often long-term consequences for survivors. Physical and psychological impairments including reduced exercise capacity and health-related quality of life can persist for many years following hospital discharge [1-4]. These features are now referred to as the 'post intensive care syndrome' [5]. In recent years the importance of survivorship, or quality of survival, has been increasingly recognised [6], and the role of rehabilitation interventions to facilitate the recovery pathway of patients have become a major focus for the clinician [7].

In the UK, the National Institute of Health and Care Excellence (NICE) in 2009 published clinical guideline 83 (CG83) focussed on 'Rehabilitation After Critical Illness' (available at http://publications.nice.org.uk/rehabilitation-after-critical-illness-cg83). This profiled the importance of this area of clinical practice aiming to improve the standards of care and previously unmet clinical needs of this patient group. NICE CG83 advocated a continuum of multidisciplinary rehabilitation along the recovery pathway from within the ICU to the ward and following hospital discharge, albeit these recommendations were largely based on expert consensus due to the lack of published evidence [8]. Specifically, at the point of hospital discharge, it is recommended that patients are referred to appropriate rehabilitation services if ongoing needs are identified. At 2-3 months following hospital discharge, a review and functional reassessment of the patient should be undertaken to determine the extent of recovery and additional rehabilitation input in the event of a slower than anticipated recovery or identification of new physical and/or psychological morbidity [8].

Despite the intentions, widespread clinical implementation of these guidelines has been challenged by the limited evidence underpinning the recommendations, as well as sparse detail provided to characterise the optimum type, intensity, frequency and duration of exercise therapy and rehabilitation interventions [9]. Furthermore, critical care survivors experience inadequate and disjointed multidisciplinary care following hospital discharge with inconsistent service provision, which can be strongly influenced by local resources and geographical location [10].

Failure to implement national guidelines or respond to published evidence is not uncommon. Disparity between the prevalence of conditions such as chronic cardiorespiratory disease, diabetes mellitus and sleep-related disorders, and availability of recommended services for their management, is evident across the UK [11-13]. Previous surveys relating to provision of critical care rehabilitation have focussed on ICU follow-up [14] or physiotherapy practice within the ICU [15-17]. Two recent surveys reported on NICE CG83, but these were limited in content and detail [18 19]. The aim of the current study was to comprehensively determine, across the UK, implementation of NICE CG83 during the post hospital discharge period with detailed characterisation of available follow-up and rehabilitation services, and including establishing barriers to service provision.

METHODS

Details for all adult ICUs across the UK (England, Scotland, Wales and Northern Ireland) were obtained via two central registries; the Intensive Care National Audit and Research Centre (ICNARC) and the Scottish Intensive Care Society Audit Group (SICSAG). A total of 240

organisations were identified (85 university teaching (UT) hospitals and 155 district general (DG) hospitals). Specialist-only and private ICUs were excluded were from survey.

The authors designed a predominantly closed-question survey (Web file 1) to evaluate clinical practice regarding follow-up and rehabilitation services for survivors of critical illness post hospital discharge. Demographic details were requested regarding number, type and bed-capacity of critical care areas at each organisation. In addition, detail of service provision including follow-up, content, delivery and evaluation of rehabilitation programmes was requested, and barriers to offering services were sought if none were currently in operation. The majority of questions allowed respondents to select from multiple options with space available for free-text comments throughout. These options were not ranked, nor were respondents asked to mark their response in terms of perceived importance or grading, with the exception of asking respondents to detail the main limiting barrier to service availability. The survey was piloted using three senior physiotherapy clinicians and clinical-academics (ICU clinical experience ranging 7-14 years) at two tertiary referral university teaching hospitals in London, UK. Constructive critique of survey design, content, structure, user-acceptability and time for completion was requested, following which further refinement was undertaken.

In March 2013, the survey and a covering letter of invitation to participate were distributed by post to the senior physiotherapist for critical care at each of the organisations with an included ICU. Stamped, self-addressed envelopes (SAEs) were enclosed for return of completed surveys. Surveys were coded to identify responses. Throughout the period of survey distribution a variety of strategies were employed to assist with survey promotion

and enhance rates of completion and return. Six weeks following initial survey distribution, a reminder letter was sent by post to non-responders with a second copy of the survey and further SAEs. A further six weeks later, telephone calls were made to remaining non-responders. Direct contact was attempted with the senior critical care physiotherapist to determine willingness to participate, who were offered the choice of telephone or email completion of the survey. Respondents were also contacted via email or telephone if there were missing data.

Data Handling

In line with guidance produced by the UK National Research Ethics Service (available at http://www.nres.nhs.uk/) the project was deemed an evaluation of service provision, and therefore ethical approval was not required. Completion and return of the survey was considered indicative of willingness to participate in the survey and implied consent. All data were stored in standard spreadsheets, transcribed from hard copies of returned surveys. Due to the nature of the study and data collected, descriptive statistics were used to analyse quantitative responses including number, percentage and 95% confidence intervals where appropriate, and additional qualitative review of free-text comments made. A response rate of 65% rate was considered *a priori* to provide a representative sample.

RESULTS

Responding institutions

One hundred and eighty-two of the 240 distributed surveys were returned, indicating an overall response rate of 75.8% (95%CI 70.4 to 81.2) (*Figure 1*). Specifically, nearly three-quarters of all surveys distributed to both university teaching (UT) and district general (DG)

hospitals were returned (66/85, 75% and 115/155, 74.2% respectively) indicating that the groups of respondents were a representative sample of the original cohort of organisations. One survey was returned blank with the respondent indicating that they lacked sufficient time for completion. Demographic data for the hospitals surveyed are reported in *Table 1.* The majority were district general (DG) hospitals with ICUs and high dependency units (HDUs) managing mixed general medical and surgical patient casemixes. A large number of responses reported 'combination' units accepting both Level 3 and 2 patients (*Table 2*).

Five respondents reported that available rehabilitation programmes at their organisations were the direct result of active research studies (*Figure E1, Web only file 2*). These responses were excluded as the aim of the survey was to characterise current clinical practice rather than research activity. These five respondents completed the section asking for barriers to offering a clinical service had the research study not been implemented.

Table 1. Demographics of respondent organisations

Characteristic	n (%)
Response rate according to UK country	
England	145 (75.1)
Scotland	20 (87.0)
Wales	12 (80.0)
Northern Ireland	5 (55.6)
Type of hospital	
University teaching	66 (36.5)
District general	115 (63.5)
Total number of Critical Care Units*	
Level 3 (ICU)	112
Level 2 (HDU)	170
Combination Level 3 and 2 units	98
Total number of Critical Care Beds*	
Level 3 (ICU)	1007
Level 2 (HDU)	1090
Combination Level 3 and 2 units	1354
Frequency of reported types of patients admitted to Critical Care Unit*#	
General	230
Surgical	52
Medical	38
Cardiac/Cardiology/Cardiothoracic	35
Neurological	22
Respiratory	17
Trauma	14
Renal	5
Burns	4
Liver	4
ENT	3
Other~	10

n=181 responses (except for response rate according to country, n=192 resonses). Critical care units and bed numbers refers to the total number within respondent organisations overall e.g. one organisation may have multiple critical care areas. *n=2 non-responses. #Data presented indicates frequency of reported occurrence of type. Multiple responses could be given. ~Other e.g. haematology, infectious disease, maxillo-facial, vascular.

Abbreviations: ICU = intensive care unit. HDU = high dependency unit. ENT = ear, nose, throat.

Table 2. Classifications of level of clinical care provided to patients

Level	Classification
0	Patients whose needs can be met through normal ward care in an acute hospital.
1	Patients at risk of their condition deteriorating, or those recently located from higher levels of care, whose needs can be met on an acute ward with additional advice and support from the critical care team.
2	Patients requiring more detailed observation or intervention including support for a single failing organ system or post-operative care and those 'stepping down' from higher levels of care.
3	Patients requiring advanced respiratory support alone or basic respiratory support together with support of at least two organ systems. This level includes all complex patients requiring support for multi-organ failure.

From Comprehensive Critical Care, DH, 2000 [20]

Post hospital discharge follow-up clinical services

Forty-eight organisations (27.3%, 95%CI (20.7 to 33.9)) reported availability of follow-up of post critical illness patients at 2-3months following hospital discharge (*Figure E1, Web only file 2 and 3*). Thirty-two (66.7%) of these were from DG hospitals and 16 (33.3%) from university teaching (UT) hospitals. Forty-five organisations offering follow-up were located in England, two in Scotland, one in Northern Ireland and none in Wales. Two respondents did not provide details of follow-up provision. Of the remaining responses (n=46), ICU follow-up clinics were the most frequently reported form of follow-up (n=39, 84.8%) (*Table 3*). Eleven respondents reported more than one form of follow-up was in place.

Table 3. Follow-up services for critical care survivors post hospital discharge

Form of follow-up	**n (%)**
ICU follow-up clinic	39 (84.8)
Rehabilitation class	10 (21.7)
Other	6 (13.0)
Did not specify	2 (4.3)
Postal survey	1 (2.2)
Telephone call	1 (2.2)
Medical outpatient appointment	0 (0)
Multidisciplinary team member	**n (%)**
Physiotherapist	43 (89.6)
Critical Care nurse	42 (87.5)
Critical Care doctor	31 (64.6)
Psychologist	10 (20.8)
Dietician	2 (4.2)
Occupational therapist	2 (4.2)
Content of follow-up	**n (%)**
HRQL	40 (83.3)
Psychological status	39 (81.3)
Medical status	34 (70.8)
Nursing-related issues	29 (60.4)
Exercise capacity	28 (58.3)
Diet/nutrition	24 (50.0)
Other	9 (18.8)

For follow-up, n=frequency of reported occurrence out of 46 responses. Multiple forms of follow-up could be indicated. Other included informal coffee morning, patient support group, physiotherapy outreach, ad hoc appointments with ICU nursing staff. For multidisciplinary team members, n=frequency of reported occurrence out of 48 responses. Multiple team members could be listed. For follow-up content, n=frequency of reported occurrence out of 48 responses. Multiple content could be listed. Other included 'problem-based' or 'patient-dependent' discussion

Abbreviation: ICU = intensive care unit. HRQL = health-related quality of life.

Forty-three (89.6%) respondents reported that physiotherapists were part of the multidisciplinary team (MDT) involved in follow-up of post critical illness patients. However, just under one-third of these, n= 13 (30.2%), reported that this was on an *ad hoc* referral basis only. Other MDT members involved in follow-up are detailed in *Table 3*. In five cases access to critical care doctors, occupational therapists, psychologists or dieticians was also reported to be on a referral basis only. Critical care nurses were the most consistently featured MDT members and occupational therapists and dieticians were rarely involved in follow-up. The scale of MDT involvement ranged from one member (10.4%) to five members (2.0%), with three being the most common (43.8%). No other healthcare professionals, other than those listed, were documented to be part of the MDT.

Nearly half of those with follow-up services included a functional reassessment for comparison with assessment conducted at the time of hospital discharge (n = 20, 42.6%). *Table 3* details other aspects of follow-up assessments; health-related quality of life (n = 40, 83.3%) and psychological status (n= 39, 81.3%) were the most frequently reported items. Exercise capacity and nursing-related issues were included in approximately half of cases.

Availability of post hospital discharge rehabilitation programmes

Twelve organisations reported a rehabilitation programme was available following hospital discharge for post critical illness patients (6.8%, 95% CI (3.1 to 10.5)) (*Figure E1, Web only file 2).* Two reported that their programme was only available on an *ad hoc* basis only. Of the remaining ten programmes implemented on a regular basis, 4 (40%) were conducted at UT hospitals and 6 (60%) at DG hospitals), and all based at organisations in England. All had

also reported offering a follow-up service, with eight of these in the form of an ICU follow-up clinic.

Senior ICU physiotherapists led all available rehabilitation programmes, with the exception of one led by a rehabilitation physiotherapist. The majority (n=9) were hospital-based, outpatient programmes, specific for post critical illness patients. Exercise was a component of all programmes including cardiovascular, muscle strength, balance and functional activities. Exercise prescription was usually based on clinician judgement, and on occasion using results of physical assessment of walking capacity of function. Clinical and physiological parameters were used to monitor exercise intensity during sessions. Less than half of all programmes (n=4) included education sessions. Measures used to evaluate effectiveness of these rehabilitation programmes varied greatly with exercise capacity and health-related quality of life most commonly reported.

Further detail on the leadership, format and structure, content and monitoring and evaluation of available post hospital discharge rehabilitation programmes can be found in Web only file 2.

Barriers to delivery of post hospital discharge rehabilitation programmes

Respondents were requested to report the barriers to delivery of post hospital discharge rehabilitation programmes from a non-hierarchical list including clinical, pragmatic, managerial and administrative options. From the reasons selected, respondents were also requested to confirm the main reason. From a potential 171 responses, there were seven non-responses to both parts of this question (n=164), and a further 8 non-responses to

specifying the main barrier (n=156). 91% (n = 149) of respondents reported lack of funding as one barrier to offering a post hospital discharge rehabilitation programme, and 75% reported lack of staff (Table 4). Only 2.4% of respondents reported that a lack of evidence and less than 1% of respondents reported time constraints as barriers to implementing a post hospital discharge rehabilitation programme. 6% (10/164) of respondents reported only one barrier, 20% (33/164) reported two barriers and 73% (120/164) reported greater than two barriers.

Table 4. Barriers to post hospital discharge rehabilitation programmes for survivors of critical illness

Barrier	Frequency reported overall, n (%)	Frequency reported as main barrier, n (%)
Lack of funding	149 (90.9)	99 (63.5)
Lack of sufficient staff	128 (78.0)	17 (10.9)
Resources prioritised to other patient groups/clinical areas	71 (43.3)	4 (2.7)
Not considered required service at managerial level	66 (40.2)	22 (14.1)
Lack of available space	50 (30.5)	2 (1.3)
Insufficient patient numbers to justify	35 (21.3)	11 (7.1)
Extra-contractual (out-of-area) patient caseload	15 (9.1)	0 (0.0)
Lack of trained staff	13 (7.9)	0 (0.0)
No evidence	4 (2.4)	0 (0.0)
Not sure what to include in a programme	2 (1.2)	0 (0.0)
Other (time constraints)	1 (0.6)	1 (0.6)

For frequency of reported barriers overall, n=164 responses. For frequency of reporting as main barrier, n=156 responses. (n=182 responses, excluding one blank response, ten non-applicable responses relating to rehabilitation programmes in regular operation, seven non-responses to both parts of this question, and a further eight non-responses to specifying the main barrier).

Alternative rehabilitation programmes

57.3% (98/171) of respondents reported that in the absence of a specific post hospital discharge rehabilitation programme for survivors of critical illness at their organisation, patients were referred into alternative rehabilitation streams, including pulmonary rehabilitation (PR) (62/98, 63.3%) and cardiac rehabilitation (38/98, 38.8%) (e.g. those patients post cardiac surgery and post myocardial infarction) and various community-based services (59/98; 60.2%). Free-text comments from respondents regarding barriers to offering rehabilitation programmes and the use of alternative rehabilitation streams for ICU survivors following hospital discharge can be found in the Data Supplement (E3).

DISCUSSION

These data from the first comprehensive UK survey highlight the limited implementation of NICE CG83 and the poor delivery across the UK of post hospital rehabilitation services for survivors of critical illness. Indeed, of one-hundred and eighty-two surveys returned, less than one-third of all institutions surveyed provided any form of follow-up for these patients. Of major clinical concern is that only 5% of respondents reported the provision of a regular rehabilitation programme for critical illness survivors, a major focus of CG83. A lack of funding was the most frequently reported and main barrier to service availability. Furthermore, lack of managerial support for this type of service and prioritisation of resource allocation to other clinical areas were reported as barriers by over 40% of the respondents. These data indicate that inadequate clinical infrastructure exists for hospitals and community teams to successfully adhere to NICE CG83. The limited impact of NICE guidance on clinical practice is not unique to critical care rehabilitation and is, rather

disappointingly, a theme observed in other areas of healthcare that have been subject to the development of NICE guidelines.

Implementation of NICE CG83 across the UK

The lack of implementation of NICE CG83 evident from these data could have reflected poor motivation on the part of clinicians to actively engage in the delivery of recommendations. However, the key barriers to service delivery were reported as lack of funding, limited resources and infrastructure with reduced priority at managerial level. In the modern National Health Service (NHS), such obstacles to the application of NICE CG83 are at either a clinical commissioning or clinical operational level, or both, rather than at the level of the clinicians. Interestingly, the paucity of data to support the effectiveness of post ICU rehabilitation was not perceived as a barrier by the vast majority of clinicians, and highlights the complexities in the management and clinical delivery of a critical care rehabilitation service. A conflict between clinicians, managers and commissioners has developed as the lack of high level clinical evidence supporting NICE CG83 provides a major challenge to the funding of a critical care survivor rehabilitation service by both managers and commissioners. Of note, the survey identified five respondents who reported availability of post hospital discharge rehabilitation services as part of existing research studies ([21-23], examining the effect of various exercise-based interventions delivered in outpatient settings to post critical illness patients following hospital discharge. At present, only abstract data are available from one of these studies, that demonstrate a significant improvement in exercise capacity and balance as a result of the intervention [24]. Further data from this, and other similar studies, will assist in establishing the evidence-base post critical illness rehabilitation.

Alternatives to post hospital discharge rehabilitation programmes

Rehabilitation for survivors of critical illness is a complex intervention [25], that requires further translational work and clinical trials to provide the evidence [26-28]. Until these data are available, the unmet clinical need will remain evident and unaddressed. Referral into established rehabilitation programmes, such as cardiac and pulmonary rehabilitation, offers one potential resolution with over 50% of respondents reported the use of other rehabilitation programmes for the critical care survivors, and this may further be influenced by the designated speciality of the ward destination of patients following ICU discharge. Indeed the up-to-date guidelines for pulmonary rehabilitation [29], advocate individualised patient management and these interventions could be easily adapted for patients recovering from critical, albeit that additional referrals places an increased burden these services. However, whilst valuable resources, these programmes are disease-specific and may not fully address the range of impairments demonstrated by survivors of critical illness as part of 'post intensive care syndrome' [5].

The clinical usefulness of post ICU clinics

Post-ICU clinics provided the majority of available follow-up services in the current survey. Profiled in the late 1990s and early 2000s following updating of the NHS agenda for critical care [20 30], these clinics have been reported by patients to play a valuable contribution to their physical, emotional and psychological recovery [31]. However, trial data have failed to demonstrate clinical effectiveness or cost benefit [32]. An alternative approach to the conduct and purpose of post ICU clinics would be to robustly monitor over time the trajectory of recovery of ICU survivors with onward referral into specific speciality care where identified as required. Wide variability in responses regarding post hospital discharge

rehabilitation programmes for ICU survivors severely limits any consensus on the optimum approach for these services. The marked heterogeneity of the patient population makes it increasingly likely that a bespoke, individualised approach, akin to the approach of personalised medicine, may be more appropriate.

Barriers to implementation of national guidelines

The implementation of, and adherence to, a clinical guideline can be inconsistent [33 34]. The limited detail in terms of the rehabilitation programme in the guideline *per se* as well as local conditions such as staff infrastructure, organisation and resource were the main source of restriction to implementation of NICE CG83 in the current survey [35]. This is the first survey to investigate reasons behind failure to implement such a national guideline and offer significant insight into the requirements necessary for successful clinical application of recommendations designed to enhance patient care. Whilst the goals of NICE CG83 were important and raised the profile of this area of clinical practice the influence will be short-lived without further investment in support systems at operational and staffing level. Disappointingly, this scenario appears to be mirrored in other common clinical conditions. Although evidence supports the use of early pulmonary rehabilitation (PR) following acute exacerbation of chronic obstructive pulmonary disease (AECOPD) to enhance exercise capacity, health status and reduce hospital readmissions [29 36-38], recent data suggest that only one-third of eligible patients are referred to early PR programmes and less than 10% of all hospital discharges for AECOPD complete early post-hospitalisation PR [12]. This implementation failure is also observed following the NICE guidance on the management of obstructive sleep apnoea [39] with a recent national mapping exercise highlighting a significant mismatch between predictive healthcare requirements, based on prevalence of

known associated risk factors, and delivery of related services [13]. Furthermore, the 2012 NHS Atlas of Variation in Healthcare for People with Diabetes [11] revealed substantial numbers of patients were not in receipt of the basic clinical standards of care. The barriers to the implementation of these guidelines are specific to each clinical area, but there are generic barriers, such as lack of adequate funding and resource, that need to be considered carefully. However, it must be highlighted that robust clinical trial and other data are required to support a guideline if it is to be commissioned within the NHS and delivering a guideline prematurely will lead to implementation failure, despite major enthusiasm by clinicians.

Critique of the method

A major strength of this survey is the employment of a variety of strategies to optimise completion, resulting in a 76% response rate. Nonetheless, survey non-response is a challenge to the robustness of the current findings, introducing bias through the potential for non-responders to differ significantly from responders [40 41]. Despite this, one must consider this as a most satisfactory return indicating external validity [41 42]. Furthermore, the sample of respondents was representative of the original cohort. The high response rate may represent the clinical concern of the respondents in terms of poor implementation of NICE CG83, in particular, as the core standards for care of the critically ill patient have been recently published highlighting rehabilitation as an important core clinical care standard [43].

Postal questionnaires can be preferable for conducting surveys of large populations over a wide geographical range, offering a cost-efficient as well as time-efficient format with often

improved response rates in comparison to alternative routes such as telephone interview or email [44]. Furthermore, an email or internet-based platform would have been restricted in the current study due to lack of available electronic contact details for named critical care physiotherapy clinicians, and where postal distribution offered a more standardised approach for monitoring and identifying respondents. Nonetheless, we acknowledge that in the current technology climate, many respondents may have preferred this option for survey participation. We utilised both email and telephone contact at later stages of survey distribution as a more feasible and less cost-prohibitive means to target previous non-responders with good effect. Despite encountering some difficulty with locating designated senior clinicians [45], this resulted in a relatively high conversion rate of 36% of non-responders. However, we recognise that it was not possible to control who was responsible for actual completion of the postal surveys returned, and that this may have been by more junior staff depending on local staffing arrangements, perceived importance and time constraints of senior clinicians. However, we also specified in the accompanying cover letter that respondents be in a position to comment on the content of the survey, and therefore this may have been appropriate for different personnel.

The current survey took advantage of a range of design and formatting strategies to enhance completion, additionally including a personalised cover letter and stamped addressed envelopes [41 42 46]. Survey review was undertaken during piloting with three senior physiotherapy clinical-academics, and we aimed to minimise additional burden to potential respondents by not utilising a larger sample at this stage. Furthermore, we adopted an approach to survey distribution in keeping with that suggested to minimise non-response [47]. However, the current survey lacked sufficient demographic or other data

regarding non-responders to attempt comparison between the two groups [40 41], although 95% confidence intervals are narrow supporting the respondents as representative sample of the whole respondent population.

We identified ICUs for inclusion based on data provided by two national registries (ICNARC and SICSAG). Whilst specialist-only and private institutions were excluded, assuming that rehabilitation services offered to these patient cohorts may be influenced by disease-specific or institutional status-related factors, we acknowledge that future survey data acquired from these organisations may add further benefit to characterising service provision. We adopted a more rigorous approach to data acquisition than previous similar surveys that were country-specific [18] or excluded key regions [19], albeit these authors examined NICE CG83 implementation across the patient pathway and results observed at the post hospital discharge stage mirrored those of the current study.

The current study focussed on post hospital discharge management as it is at this stage that patients may be more likely to experience insufficient input for reasons such as lack of available services, repatriation back to other geographical regions or follow-up under non-ICU teams [48]. In contrast to previous surveys, we examined barriers to service availability in detail to gain further insight regarding this. Furthermore, rehabilitation for ICU survivors following hospital discharge has been the focus of recent research interest with randomised controlled trial data now available [49]. The current survey could be critiqued for being discipline-specific. However, it was considered that senior critical care physiotherapy clinicians would be well-informed as key members of the multi-disciplinary team involved in

management of ICU survivors, to comment on follow-up and rehabilitation service provision at their institutions.

CONCLUSION

These data from this first comprehensive UK survey of post hospital discharge rehabilitation programmes for critical illness survivors have demonstrated a low reported prevalence and, more importantly, this survey has showed a failure to implement NICE CG83. Lack of clinical prioritisation and funding was reported by the clinicians as the major cause for the failure to implement the guideline, but the paucity of evidence that supported the guideline must be regarded as a major contributor to the limited engagement between clinicians, managers and commissioners to deliver NICE CG83. Without clinical and cost effectiveness evidence for such a programme, it would be a significant challenge to commission such a service in an NHS that is driven to commission both clinical and specialist services with an established evidence base. The focus of the clinicians must be to ensure that clinical guidelines have a robust and strong evidence base to maximise their implementation and this will result in an enhancement in patient care that will be both clinical and cost effective.

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CONTRIBUTORS

BC, LD and NH contributed to the conception and design of the study. BC and AD analysed the data. BC and NH interpreted the data. BC drafted the manuscript and all authors critically revised for significant intellectual content and insight. All authors had full access to all of the data and can take responsibility for the integrity and accuracy of data analysis. Furthermore all authors gave final approval of the manuscript version for publication. BC and NH are responsible for the overall content as guarantors.

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COMPETING INTERESTS

All authors have completed the Unified Competing Interest Form at www.icmje.org.coi_disclosure.pdf (available from the corresponding author) and declare:

no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years; no spouse, partner or children have any financial relationships that may be relevant to the submitted work; and no other non-financial interests that may be relevant to the submitted work.

ETHICAL APPROVAL

Ethical approval was not required for this study.

DATA SHARING

No additional data available.

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What is already known on this topic

Survivors of critical illness demonstrate impairment of physical function, psychological well-being, cognitive function and health-related quality of life that are recognised clinical features of the post intensive care syndrome.

In the UK, rehabilitation following critical illness as a continuum that spans the whole patient pathway of recovery has been recommended in national guidance.

What this study adds

Limited implementation of NICE CG83 is evident across the UK in terms of clinical follow-up and rehabilitation programmes.

Establishing robust evidence to support national guidelines will maximise implementation to ensure clinical and cost-effective patient care is delivered.

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FIGURE LEGENDS

Figure 1. Flow-chart of survey distribution stages, response rates and promotional activities

Abbreviations: iCSP = interactive Chartered Society of Physiotherapy. ACPRC = Association of Chartered Physiotherapists in Respiratory Care.

A UK Survey of Rehabilitation Following Critical Illness: Implementation of NICE Clinical Guidance 83 (CG83) Following Hospital Discharge

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Critical illness, rehabilitation, guidelines, implementation, survey

ABSTRACT

Objective

To determine the implementation of National Institute for Health and Care Excellence guidance (NICE CG83) for post hospital discharge critical illness follow-up and rehabilitation programmes.

Design

Closed-question postal survey.

Setting

Adult intensive care units (ICU), across the UK, identified from national databases of organisations. Specialist-only and private ICUs were not included.

Participants

Senior respiratory critical care physiotherapy clinicians.

Results

A representative sample of 182 surveys were returned from 240 distributed (75.8% (95%CI 70.4-81.2)). Only 48 organisations (27.3% (95%CI 20.7 to 33.9)) offered a follow-up service 2-3 months following hospital discharge, the majority (n=39, 84.8%) in clinic format. Twelve organisations reported post hospital discharge rehabilitation programmes (6.8% (95%CI 3.1 to 10.5)), albeit only ten of these operated on a regular basis. Lack of funding was reported as both the most frequent (n=149/164, 90.0%) and main barrier (n=99/156, 63.5%) to providing services. Insufficient resources (n=71/164, 43.3%) and lack of priority by the clinical management team (n=66/164, 40.2%) were also highly cited barriers to service delivery.

Conclusion

NICE CG83 has been successful in profiling the importance of rehabilitation for survivors of critical illness. However, four years following publication of CG83 there has been limited development of this clinical service across the UK. Strategies to support delivery of such quality improvement programmes are urgently required to enhance patient care.

Word Count

216

Article summary

Strengths and limitations of this study

- This is the largest, and most comprehensive survey conducted across the UK of post hospital discharge follow-up and rehabilitation for survivors of critical illness
- Data from this survey indicate a low reported prevalence of available services, with barriers to service implementation reported by clinicians examined in detail
- This survey was profession-specific, directed only to physiotherapy clinicians rather than multiple members of the interdisciplinary team
- Specialist-only and private organisations were excluded, which may have provided additional, potentially beneficial data

INTRODUCTION

Intensive care unit (ICU) admission with critical illness can have catastrophic and often long-term consequences for survivors. Physical and psychological impairments including reduced exercise capacity and health-related quality of life can persist for many years following hospital discharge [1-4]. These features are now referred to as the 'post intensive care syndrome' [5]. In recent years the importance of survivorship, or quality of survival, has been increasingly recognised [6], and the role of rehabilitation interventions to facilitate the recovery pathway of patients have become a major focus for the clinician [7].

In the UK, the National Institute of Health and Care Excellence (NICE) in 2009 published clinical guideline 83 (CG83) focussed on 'Rehabilitation After Critical Illness' (available at http://publications.nice.org.uk/rehabilitation-after-critical-illness-cg83). This profiled the importance of this area of clinical practice aiming to improve the standards of care and previously unmet clinical needs of this patient group. NICE CG83 advocated a continuum of multidisciplinary rehabilitation along the recovery pathway from within the ICU to the ward and following hospital discharge, albeit these recommendations were largely based on expert consensus due to the lack of published evidence [8]. Specifically, at the point of hospital discharge, it is recommended that patients are referred to appropriate rehabilitation services if ongoing needs are identified. At 2-3 months following hospital discharge, a review and functional reassessment of the patient should be undertaken to determine the extent of recovery and additional rehabilitation input in the event of a slower than anticipated recovery or identification of new physical and/or psychological morbidity [8].

Despite the intentions, widespread clinical implementation of these guidelines has been challenged by the limited evidence underpinning the recommendations, as well as sparse detail provided to characterise the optimum type, intensity, frequency and duration of exercise therapy and rehabilitation interventions [9]. Furthermore, critical care survivors experience inadequate and disjointed multidisciplinary care following hospital discharge with inconsistent service provision, which can be strongly influenced by local resources and geographical location [10].

Failure to implement national guidelines or respond to published evidence is not uncommon. Disparity between the prevalence of conditions such as chronic cardiorespiratory disease, diabetes mellitus and sleep-related disorders, and availability of recommended services for their management, is evident across the UK [11-13]. Previous surveys relating to provision of critical care rehabilitation have focussed on ICU follow-up [14] or physiotherapy practice within the ICU [15-17]. Two recent surveys reported on NICE CG83, but these were limited in content and detail [18 19]. The aim of the current study was to comprehensively determine, across the UK, implementation of NICE CG83 during the post hospital discharge period with detailed characterisation of available follow-up and rehabilitation services, and including establishing barriers to service provision.

METHODS

Details for all adult ICUs across the UK (England, Scotland, Wales and Northern Ireland) were obtained via two central registries; the Intensive Care National Audit and Research Centre (ICNARC) and the Scottish Intensive Care Society Audit Group (SICSAG). A total of 240

organisations were identified (85 university teaching (UT) hospitals and 155 district general (DG) hospitals). Specialist-only and private ICUs were excluded were from survey.

The authors designed a predominantly closed-question survey (Web file 1) to evaluate clinical practice regarding follow-up and rehabilitation services for survivors of critical illness post hospital discharge. Demographic details were requested regarding number, type and bed-capacity of critical care areas at each organisation. In addition, detail of service provision including follow-up, content, delivery and evaluation of rehabilitation programmes was requested, and barriers to offering services were sought if none were currently in operation. The majority of questions allowed respondents to select from multiple options with space available for free-text comments throughout. These options were not ranked, nor were respondents asked to mark their response in terms of perceived importance or grading, with the exception of asking respondents to detail the main limiting barrier to service availability. The survey was piloted using three senior physiotherapy clinicians and clinical-academics (ICU clinical experience ranging 7-14 years) at two tertiary referral university teaching hospitals in London, UK. Constructive critique of survey design, content, structure, user-acceptability and time for completion was requested, following which further refinement was undertaken.

In March 2013, the survey and a covering letter of invitation to participate were distributed by post to the senior physiotherapist for critical care at each of the organisations with an included ICU. Stamped, self-addressed envelopes (SAEs) were enclosed for return of completed surveys. Surveys were coded to identify responses. Throughout the period of survey distribution a variety of strategies were employed to assist with survey promotion

and enhance rates of completion and return. Six weeks following initial survey distribution, a reminder letter was sent by post to non-responders with a second copy of the survey and further SAEs. A further six weeks later, telephone calls were made to remaining non-responders. Direct contact was attempted with the senior critical care physiotherapist to determine willingness to participate, who were offered the choice of telephone or email completion of the survey. Respondents were also contacted via email or telephone if there were missing data.

Data Handling

In line with guidance produced by the UK National Research Ethics Service (available at http://www.nres.nhs.uk/) the project was deemed an evaluation of service provision, and therefore ethical approval was not required. Completion and return of the survey was considered indicative of willingness to participate in the survey and implied consent. All data were stored in standard spreadsheets, transcribed from hard copies of returned surveys. Due to the nature of the study and data collected, descriptive statistics were used to analyse quantitative responses including number, percentage and 95% confidence intervals where appropriate, and additional qualitative review of free-text comments made. A response rate of 65% rate was considered *a priori* to provide a representative sample.

RESULTS

Responding institutions

One hundred and eighty-two of the 240 distributed surveys were returned, indicating an overall response rate of 75.8% (95%CI 70.4 to 81.2) (*Figure 1*). Specifically, nearly three-quarters of all surveys distributed to both university teaching (UT) and district general (DG)

hospitals were returned (66/85, 75% and 115/155, 74.2% respectively) indicating that the groups of respondents were a representative sample of the original cohort of organisations. One survey was returned blank with the respondent indicating that they lacked sufficient time for completion. Demographic data for the hospitals surveyed are reported in *Table 1.* The majority were district general (DG) hospitals with ICUs and high dependency units (HDUs) managing mixed general medical and surgical patient casemixes. A large number of responses reported 'combination' units accepting both Level 3 and 2 patients (*Table 2*).

Five respondents reported that available rehabilitation programmes at their organisations were the direct result of active research studies (*Figure E1, Web only file 2*). These responses were excluded as the aim of the survey was to characterise current clinical practice rather than research activity. These five respondents completed the section asking for barriers to offering a clinical service had the research study not been implemented.

Table 1. Demographics of respondent organisations

Characteristic	n (%)
Response rate according to UK country	
England	145 (75.1)
Scotland	20 (87.0)
Wales	12 (80.0)
Northern Ireland	5 (55.6)
Type of hospital	
University teaching	66 (36.5)
District general	115 (63.5)
Total number of Critical Care Units*	
Level 3 (ICU)	112
Level 2 (HDU)	170
Combination Level 3 and 2 units	98
Total number of Critical Care Beds*	
Level 3 (ICU)	1007
Level 2 (HDU)	1090
Combination Level 3 and 2 units	1354
Frequency of reported types of patients admitted to Critical Care Unit*#	
General	230
Surgical	52
Medical	38
Cardiac/Cardiology/Cardiothoracic	35
Neurological	22
Respiratory	17
Trauma	14
Renal	5
Burns	4
Liver	4
ENT	3
Other~	10

n=181 responses (except for response rate according to country, n=192 resonses). Critical care units and bed numbers refers to the total number within respondent organisations overall e.g. one organisation may have multiple critical care areas. *n=2 non-responses. #Data presented indicates frequency of reported occurrence of type. Multiple responses could be given. ~Other e.g. haematology, infectious disease, maxillo-facial, vascular.

Abbreviations: ICU = intensive care unit. HDU = high dependency unit. ENT = ear, nose, throat.

Table 2. Classifications of level of clinical care provided to patients

Level	Classification
0	Patients whose needs can be met through normal ward care in an acute hospital.
1	Patients at risk of their condition deteriorating, or those recently located from higher levels of care, whose needs can be met on an acute ward with additional advice and support from the critical care team.
2	Patients requiring more detailed observation or intervention including support for a single failing organ system or post-operative care and those 'stepping down' from higher levels of care.
3	Patients requiring advanced respiratory support alone or basic respiratory support together with support of at least two organ systems. This level includes all complex patients requiring support for multi-organ failure.

From Comprehensive Critical Care, DH, 2000 [20]

Post hospital discharge follow-up clinical services

Forty-eight organisations (27.3%, 95%CI (20.7 to 33.9)) reported availability of follow-up of post critical illness patients at 2-3months following hospital discharge (*Figure E1, Web only file 2*). Thirty-two (66.7%) of these were from DG hospitals and 16 (33.3%) from university teaching (UT) hospitals. Forty-five organisations offering follow-up were located in England, two in Scotland, one in Northern Ireland and none in Wales. Two respondents did not provide details of follow-up provision. Of the remaining responses (n=46), ICU follow-up clinics were the most frequently reported form of follow-up (n=39, 84.8%) (*Table 3*). Eleven respondents reported more than one form of follow-up was in place.

Table 3. Follow-up services for critical care survivors post hospital discharge

Form of follow-up	**n (%)**
ICU follow-up clinic	39 (84.8)
Rehabilitation class	10 (21.7)
Other	6 (13.0)
Did not specify	2 (4.3)
Postal survey	1 (2.2)
Telephone call	1 (2.2)
Medical outpatient appointment	0 (0)
Multidisciplinary team member	**n (%)**
Physiotherapist	43 (89.6)
Critical Care nurse	42 (87.5)
Critical Care doctor	31 (64.6)
Psychologist	10 (20.8)
Dietician	2 (4.2)
Occupational therapist	2 (4.2)
Content of follow-up	**n (%)**
HRQL	40 (83.3)
Psychological status	39 (81.3)
Medical status	34 (70.8)
Nursing-related issues	29 (60.4)
Exercise capacity	28 (58.3)
Diet/nutrition	24 (50.0)
Other	9 (18.8)

For follow-up, n=frequency of reported occurrence out of 46 responses. Multiple forms of follow-up could be indicated. Other included informal coffee morning, patient support group, physiotherapy outreach, ad hoc appointments with ICU nursing staff. For multidisciplinary team members, n=frequency of reported occurrence out of 48 responses. Multiple team members could be listed. For follow-up content, n=frequency of reported occurrence out of 48 responses. Multiple content could be listed. Other included 'problem-based' or 'patient-dependent' discussion

Abbreviation: ICU = intensive care unit. HRQL = health-related quality of life.

Forty-three (89.6%) respondents reported that physiotherapists were part of the multidisciplinary team (MDT) involved in follow-up of post critical illness patients. However, just under one-third of these, n= 13 (30.2%), reported that this was on an *ad hoc* referral basis only. Other MDT members involved in follow-up are detailed in *Table 3*. In five cases access to critical care doctors, occupational therapists, psychologists or dieticians was also reported to be on a referral basis only. Critical care nurses were the most consistently featured MDT members and occupational therapists and dieticians were rarely involved in follow-up. The scale of MDT involvement ranged from one member (10.4%) to five members (2.0%), with three being the most common (43.8%). No other healthcare professionals, other than those listed, were documented to be part of the MDT.

Nearly half of those with follow-up services included a functional reassessment for comparison with assessment conducted at the time of hospital discharge (n = 20, 42.6%). *Table 3* details other aspects of follow-up assessments; health-related quality of life (n = 40, 83.3%) and psychological status (n= 39, 81.3%) were the most frequently reported items. Exercise capacity and nursing-related issues were included in approximately half of cases.

Availability of post hospital discharge rehabilitation programmes

Twelve organisations reported a rehabilitation programme was available following hospital discharge for post critical illness patients (6.8%, 95% CI (3.1 to 10.5)) (*Figure E1, Web only file 2).* Two reported that their programme was only available on an *ad hoc* basis only. Of the remaining ten programmes implemented on a regular basis, 4 (40%) were conducted at UT hospitals and 6 (60%) at DG hospitals), and all based at organisations in England. All had

also reported offering a follow-up service, with eight of these in the form of an ICU follow-up clinic.

Senior ICU physiotherapists led all available rehabilitation programmes, with the exception of one led by a rehabilitation physiotherapist. The majority (n=9) were hospital-based, outpatient programmes, specific for post critical illness patients. Exercise was a component of all programmes including cardiovascular, muscle strength, balance and functional activities. Exercise prescription was usually based on clinician judgement, and on occasion using results of physical assessment of walking capacity of function. Clinical and physiological parameters were used to monitor exercise intensity during sessions. Less than half of all programmes (n=4) included education sessions. Measures used to evaluate effectiveness of these rehabilitation programmes varied greatly with exercise capacity and health-related quality of life most commonly reported.

Further detail on the leadership, format and structure, content and monitoring and evaluation of available post hospital discharge rehabilitation programmes can be found in Web only file 2.

Barriers to delivery of post hospital discharge rehabilitation programmes

Respondents were requested to report the barriers to delivery of post hospital discharge rehabilitation programmes from a non-hierarchical list including clinical, pragmatic, managerial and administrative options. From the reasons selected, respondents were also requested to confirm the main reason. From a potential 171 responses, there were seven non-responses to both parts of this question (n=164), and a further 8 non-responses to

specifying the main barrier (n=156). 91% (n = 149) of respondents reported lack of funding as one barrier to offering a post hospital discharge rehabilitation programme, and 75% reported lack of staff (Table 4). Only 2.4% of respondents reported that a lack of evidence and less than 1% of respondents reported time constraints as barriers to implementing a post hospital discharge rehabilitation programme. 6% (10/164) of respondents reported only one barrier, 20% (33/164) reported two barriers and 73% (120/164) reported greater than two barriers.

Table 4. Barriers to post hospital discharge rehabilitation programmes for survivors of critical illness

Barrier	Frequency reported overall, n (%)	Frequency reported as main barrier, n (%)
Lack of funding	149 (90.9)	99 (63.5)
Lack of sufficient staff	128 (78.0)	17 (10.9)
Resources prioritised to other patient groups/clinical areas	71 (43.3)	4 (2.7)
Not considered required service at managerial level	66 (40.2)	22 (14.1)
Lack of available space	50 (30.5)	2 (1.3)
Insufficient patient numbers to justify	35 (21.3)	11 (7.1)
Extra-contractual (out-of-area) patient caseload	15 (9.1)	0 (0.0)
Lack of trained staff	13 (7.9)	0 (0.0)
No evidence	4 (2.4)	0 (0.0)
Not sure what to include in a programme	2 (1.2)	0 (0.0)
Other (time constraints)	1 (0.6)	1 (0.6)

For frequency of reported barriers overall, n=164 responses. For frequency of reporting as main barrier, n=156 responses. (n=182 responses, excluding one blank response, ten non-applicable responses relating to rehabilitation programmes in regular operation, seven non-responses to both parts of this question, and a further eight non-responses to specifying the main barrier).

Alternative rehabilitation programmes

57.3% (98/171) of respondents reported that in the absence of a specific post hospital discharge rehabilitation programme for survivors of critical illness at their organisation, patients were referred into alternative rehabilitation streams, including pulmonary rehabilitation (PR) (62/98, 63.3%) and cardiac rehabilitation (38/98, 38.8%) (e.g. those patients post cardiac surgery and post myocardial infarction) and various community-based services (59/98; 60.2%). Free-text comments from respondents regarding barriers to offering rehabilitation programmes and the use of alternative rehabilitation streams for ICU survivors following hospital discharge can be found in the Data Supplement (E3).

DISCUSSION

These data from the first comprehensive UK survey highlight the limited implementation of NICE CG83 and the poor delivery across the UK of post hospital rehabilitation services for survivors of critical illness. Indeed, of one-hundred and eighty-two surveys returned, less than one-third of all institutions surveyed provided any form of follow-up for these patients. Of major clinical concern is that only 5% of respondents reported the provision of a regular rehabilitation programme for critical illness survivors, a major focus of CG83. A lack of funding was the most frequently reported and main barrier to service availability. Furthermore, lack of managerial support for this type of service and prioritisation of resource allocation to other clinical areas were reported as barriers by over 40% of the respondents. These data indicate that inadequate clinical infrastructure exists for hospitals and community teams to successfully adhere to NICE CG83. The limited impact of NICE guidance on clinical practice is not unique to critical care rehabilitation and is, rather

disappointingly, a theme observed in other areas of healthcare that have been subject to the development of NICE guidelines.

Implementation of NICE CG83 across the UK

The lack of implementation of NICE CG83 evident from these data could have reflected poor motivation on the part of clinicians to actively engage in the delivery of recommendations. However, the key barriers to service delivery were reported as lack of funding, limited resources and infrastructure with reduced priority at managerial level. In the modern National Health Service (NHS), such obstacles to the application of NICE CG83 are at either a clinical commissioning or clinical operational level, or both, rather than at the level of the clinicians. Interestingly, the paucity of data to support the effectiveness of post ICU rehabilitation was not perceived as a barrier by the vast majority of clinicians, and highlights the complexities in the management and clinical delivery of a critical care rehabilitation service. A conflict between clinicians, managers and commissioners has developed as the lack of high level clinical evidence supporting NICE CG83 provides a major challenge to the funding of a critical care survivor rehabilitation service by both managers and commissioners. Of note, the survey identified five respondents who reported availability of post hospital discharge rehabilitation services as part of existing research studies ([21-23], examining the effect of various exercise-based interventions delivered in outpatient settings to post critical illness patients following hospital discharge. At present, only abstract data are available from one of these studies, that demonstrate a significant improvement in exercise capacity and balance as a result of the intervention [24]. Further data from this, and other similar studies, will assist in establishing the evidence-base post critical illness rehabilitation.

Alternatives to post hospital discharge rehabilitation programmes

Rehabilitation for survivors of critical illness is a complex intervention [25], that requires further translational work and clinical trials to provide the evidence [26-28]. Until these data are available, the unmet clinical need will remain evident and unaddressed. Referral into established rehabilitation programmes, such as cardiac and pulmonary rehabilitation, offers one potential resolution with over 50% of respondents reported the use of other rehabilitation programmes for the critical care survivors, and this may further be influenced by the designated speciality of the ward destination of patients following ICU discharge. Indeed the up-to-date guidelines for pulmonary rehabilitation [29], advocate individualised patient management and these interventions could be easily adapted for patients recovering from critical, albeit that additional referrals places an increased burden these services. However, whilst valuable resources, these programmes are disease-specific and may not fully address the range of impairments demonstrated by survivors of critical illness as part of 'post intensive care syndrome' [5].

The clinical usefulness of post ICU clinics

Post-ICU clinics provided the majority of available follow-up services in the current survey. Profiled in the late 1990s and early 2000s following updating of the NHS agenda for critical care [20 30], these clinics have been reported by patients to play a valuable contribution to their physical, emotional and psychological recovery [31]. However, trial data have failed to demonstrate clinical effectiveness or cost benefit [32]. An alternative approach to the conduct and purpose of post ICU clinics would be to robustly monitor over time the trajectory of recovery of ICU survivors with onward referral into specific speciality care where identified as required. Wide variability in responses regarding post hospital discharge

rehabilitation programmes for ICU survivors severely limits any consensus on the optimum approach for these services. The marked heterogeneity of the patient population makes it increasingly likely that a bespoke, individualised approach, akin to the approach of personalised medicine, may be more appropriate.

Barriers to implementation of national guidelines

The implementation of, and adherence to, a clinical guideline can be inconsistent [33 34]. The limited detail in terms of the rehabilitation programme in the guideline *per se* as well as local conditions such as staff infrastructure, organisation and resource were the main source of restriction to implementation of NICE CG83 in the current survey [35]. This is the first survey to investigate reasons behind failure to implement such a national guideline and offer significant insight into the requirements necessary for successful clinical application of recommendations designed to enhance patient care. Whilst the goals of NICE CG83 were important and raised the profile of this area of clinical practice the influence will be short-lived without further investment in support systems at operational and staffing level. Disappointingly, this scenario appears to be mirrored in other common clinical conditions. Although evidence supports the use of early pulmonary rehabilitation (PR) following acute exacerbation of chronic obstructive pulmonary disease (AECOPD) to enhance exercise capacity, health status and reduce hospital readmissions [29 36-38], recent data suggest that only one-third of eligible patients are referred to early PR programmes and less than 10% of all hospital discharges for AECOPD complete early post-hospitalisation PR [12]. This implementation failure is also observed following the NICE guidance on the management of obstructive sleep apnoea [39] with a recent national mapping exercise highlighting a significant mismatch between predictive healthcare requirements, based on prevalence of

known associated risk factors, and delivery of related services [13]. Furthermore, the 2012 NHS Atlas of Variation in Healthcare for People with Diabetes [11] revealed substantial numbers of patients were not in receipt of the basic clinical standards of care. The barriers to the implementation of these guidelines are specific to each clinical area, but there are generic barriers, such as lack of adequate funding and resource, that need to be considered carefully. However, it must be highlighted that robust clinical trial and other data are required to support a guideline if it is to be commissioned within the NHS and delivering a guideline prematurely will lead to implementation failure, despite major enthusiasm by clinicians.

Critique of the method

A major strength of this survey is the employment of a variety of strategies to optimise completion, resulting in a 76% response rate. Nonetheless, survey non-response is a challenge to the robustness of the current findings, introducing bias through the potential for non-responders to differ significantly from responders [40 41]. Despite this, one must consider this as a most satisfactory return indicating external validity [41 42]. Furthermore, the sample of respondents was representative of the original cohort. The high response rate may represent the clinical concern of the respondents in terms of poor implementation of NICE CG83, in particular, as the core standards for care of the critically ill patient have been recently published highlighting rehabilitation as an important core clinical care standard [43].

Postal questionnaires can be preferable for conducting surveys of large populations over a wide geographical range, offering a cost-efficient as well as time-efficient format with often

improved response rates in comparison to alternative routes such as telephone interview or email [44]. Furthermore, an email or internet-based platform would have been restricted in the current study due to lack of available electronic contact details for named critical care physiotherapy clinicians, and where postal distribution offered a more standardised approach for monitoring and identifying respondents. Nonetheless, we acknowledge that in the current technology climate, many respondents may have preferred this option for survey participation. We utilised both email and telephone contact at later stages of survey distribution as a more feasible and less cost-prohibitive means to target previous non-responders with good effect. Despite encountering some difficulty with locating designated senior clinicians [45], this resulted in a relatively high conversion rate of 36% of non-responders. However, we recognise that it was not possible to control who was responsible for actual completion of the postal surveys returned, and that this may have been by more junior staff depending on local staffing arrangements, perceived importance and time constraints of senior clinicians. However, we also specified in the accompanying cover letter that respondents be in a position to comment on the content of the survey, and therefore this may have been appropriate for different personnel.

The current survey took advantage of a range of design and formatting strategies to enhance completion, additionally including a personalised cover letter and stamped addressed envelopes [41 42 46]. Survey review was undertaken during piloting with three senior physiotherapy clinical-academics, and we aimed to minimise additional burden to potential respondents by not utilising a larger sample at this stage. Furthermore, we adopted an approach to survey distribution in keeping with that suggested to minimise non-response [47]. However, the current survey lacked sufficient demographic or other data

regarding non-responders to attempt comparison between the two groups [40 41], although 95% confidence intervals are narrow supporting the respondents as representative sample of the whole respondent population.

We identified ICUs for inclusion based on data provided by two national registries (ICNARC and SICSAG). Whilst specialist-only and private institutions were excluded, assuming that rehabilitation services offered to these patient cohorts may be influenced by disease-specific or institutional status-related factors, we acknowledge that future survey data acquired from these organisations may add further benefit to characterising service provision. We adopted a more rigorous approach to data acquisition than previous similar surveys that were country-specific [18] or excluded key regions [19], albeit these authors examined NICE CG83 implementation across the patient pathway and results observed at the post hospital discharge stage mirrored those of the current study.

The current study focussed on post hospital discharge management as it is at this stage that patients may be more likely to experience insufficient input for reasons such as lack of available services, repatriation back to other geographical regions or follow-up under non-ICU teams [48]. In contrast to previous surveys, we examined barriers to service availability in detail to gain further insight regarding this. Furthermore, rehabilitation for ICU survivors following hospital discharge has been the focus of recent research interest with randomised controlled trial data now available [49]. The current survey could be critiqued for being discipline-specific. However, it was considered that senior critical care physiotherapy clinicians would be well-informed as key members of the multi-disciplinary team involved in

management of ICU survivors, to comment on follow-up and rehabilitation service provision at their institutions.

CONCLUSION

These data from this first comprehensive UK survey of post hospital discharge rehabilitation programmes for critical illness survivors have demonstrated a low reported prevalence and, more importantly, this survey has showed a failure to implement NICE CG83. Lack of clinical prioritisation and funding was reported by the clinicians as the major cause for the failure to implement the guideline, but the paucity of evidence that supported the guideline must be regarded as a major contributor to the limited engagement between clinicians, managers and commissioners to deliver NICE CG83. Without clinical and cost effectiveness evidence for such a programme, it would be a significant challenge to commission such a service in an NHS that is driven to commission both clinical and specialist services with an established evidence base. The focus of the clinicians must be to ensure that clinical guidelines have a robust and strong evidence base to maximise their implementation and this will result in an enhancement in patient care that will be both clinical and cost effective.

ACKNOWLEDGEMENTS

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CONTRIBUTORS

BC, LD and NH contributed to the conception and design of the study. BC and AD analysed the data. BC and NH interpreted the data. BC drafted the manuscript and all authors critically revised for significant intellectual content and insight. All authors had full access to all of the data and can take responsibility for the integrity and accuracy of data analysis. Furthermore all authors gave final approval of the manuscript version for publication. BC and NH are responsible for the overall content as guarantors.

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COMPETING INTERESTS

All authors have completed the Unified Competing Interest Form at www.icmje.org.coi_disclosure.pdf (available from the corresponding author) and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years; no spouse, partner or children have any financial relationships that may be relevant to the submitted work; and no other non-financial interests that may be relevant to the submitted work.

ETHICAL APPROVAL

Ethical approval was not required for this study.

DATA SHARING

No additional data available.

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What is already known on this topic

Survivors of critical illness demonstrate impairment of physical function, psychological well-being, cognitive function and health-related quality of life that are recognised clinical features of the post intensive care syndrome.

In the UK, rehabilitation following critical illness as a continuum that spans the whole patient pathway of recovery has been recommended in national guidance.

What this study adds

Limited implementation of NICE CG83 is evident across the UK in terms of clinical follow-up and rehabilitation programmes.

Establishing robust evidence to support national guidelines will maximise implementation to ensure clinical and cost-effective patient care is delivered.

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FIGURE LEGENDS

Figure 1. Flow-chart of survey distribution stages, response rates and promotional activities

Abbreviations: iCSP = interactive Chartered Society of Physiotherapy. ACPRC = Association of Chartered Physiotherapists in Respiratory Care.

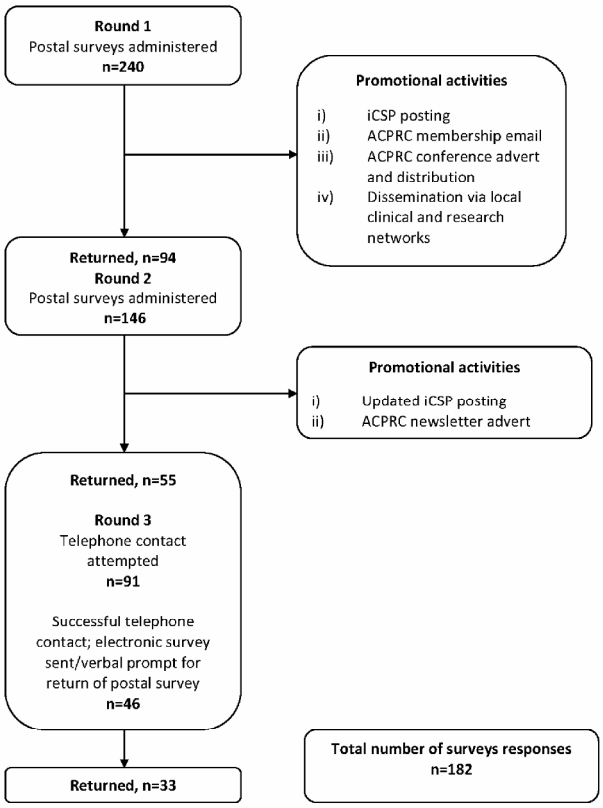

Figure 1. Flow-chart of survey distribution stages, response rates and promotional activities

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A UK Survey of Rehabilitation Following Critical Illness: Implementation of NICE Clinical Guidance 83 (CG83) Following Hospital Discharge

DATA SUPPLEMENT - REHABILITATION SURVEY

REHABILITATION FOR SURVIVORS OF CRITICAL ILLNESS FOLLOWING HOSPITAL DISCHARGE

Many thanks for taking the time to complete this survey. It should take 10-20 minutes depending on the level of detail provided. Space is given for further information as necessary. There are some initial questions asking about your hospital and critical care unit(s), a short section asking about practice in relation to the third phase of rehabilitation outlined in CG83 (summarised below), and then greater detail surveying local rehabilitation services, if available, for survivors of critical illness following discharge from hospital.

It is anticipated that one potential outcome from this survey would be to compile a database of available rehabilitation services for patients across different areas of the country.

If you would be happy to be contacted with regard information you have provided in this survey please include your details below. These details will not be passed on to any third person.

AIMS

- To identify provision of post hospital discharge follow-up of critical illness patients in line with NICE CG83 guidelines
- To characterise specific rehabilitation services provided following hospital discharge for survivors of critical illness
- To investigate physical and non-physical components of rehabilitation programmes offered
- To establish outcome measures used to evaluate rehabilitation programmes
- To investigate factors influencing availability of these rehabilitation services

Details

Name:

Position:

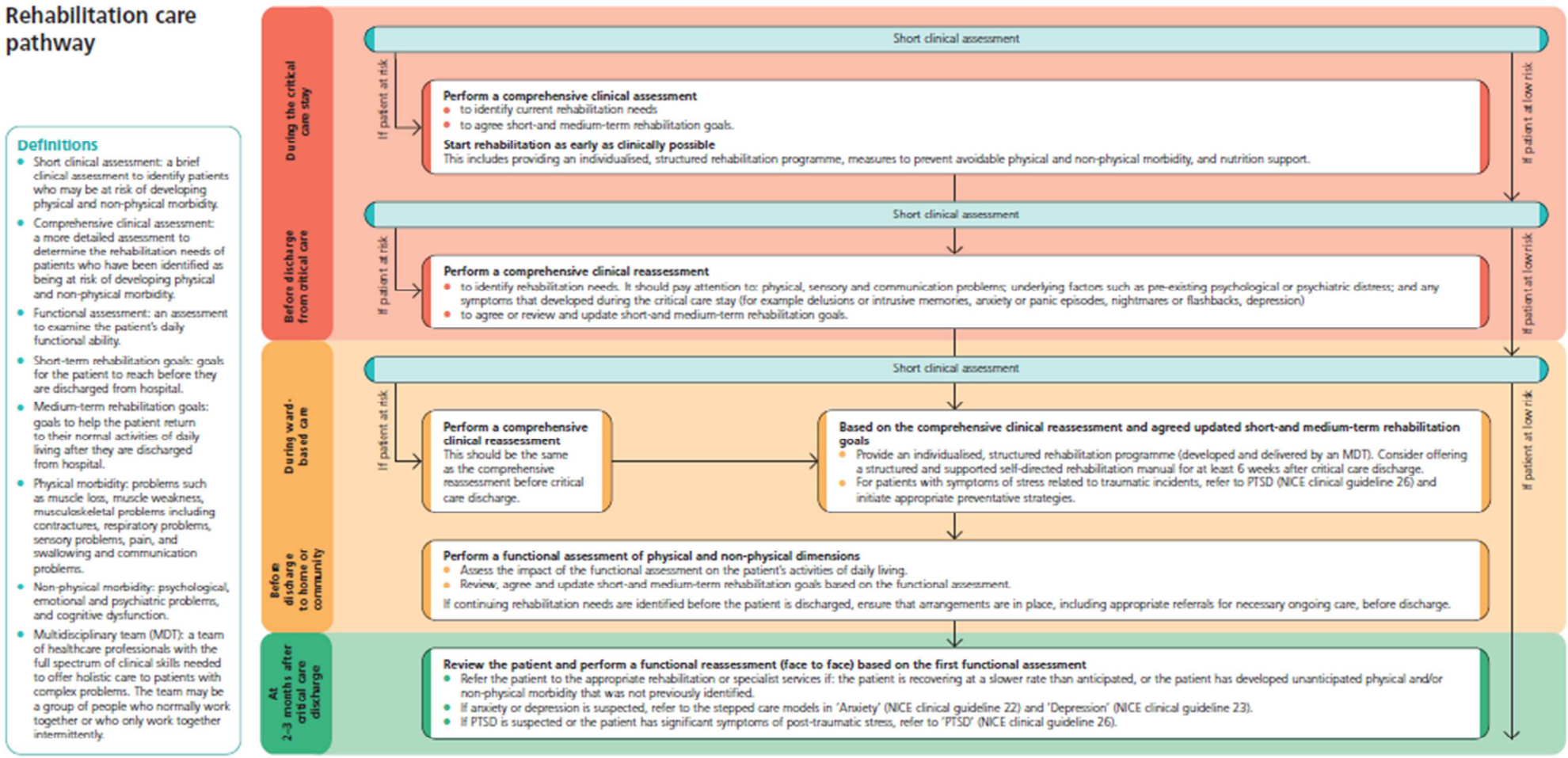
Name of Hospital:

Email:

Phone:

Bronwen Connolly, Clinical Research Fellow, Lane Fox Respiratory Unit, St.Thomas' Hospital, Westminster Bridge Rd, London, SE1 7EH.

Rehabilitation care pathway



Full guideline available at http://publications.nice.org.uk/rehabilitation-after-critical-illness-cg83

RFCI Survey, v3, March 2013.

Bronwen Connolly, Clinical Research Fellow, Lane Fox Respiratory Unit, St.Thomas' Hospital, Westminster Bridge Rd, London, SE1 7EH.

SECTION 1 YOUR CRITICAL CARE SERVICES

1) Is your hospital a: Teaching (University) hospital □

District General hospital □

Other □

2) Please indicate the number, size and speciality of any critical care areas in your hospital (include all individual intensive care unit (ICU, Level 3), high dependency unit (HDU, Level 2) and/or combined Level areas)

CC area	Level	Speciality	Beds
1			
2			
3			
4			
5			
6			
7			
8			
9			
10			

Bronwen Connolly, Clinical Research Fellow, Lane Fox Respiratory Unit, St.Thomas' Hospital, Westminster Bridge Rd, London, SE1 7EH.

SECTION 2 FOLLOW-UP FOR POST CRITICAL ILLNESS PATIENTS (with reference to CG83)

Are you involved in follow-up for post critical illness patients 2-3 months after discharge?

YES □ **(please go to Question 1.)** **NO** □ **(please go to SECTION 3)**

1. What form does this follow-up take:

ICU follow-up clinic □

Medical outpatient appointment (as part of other medical follow-up) □

Telephone call □

Postal survey □

Rehabilitation class □

Other (please specify)

.....

2. Who is involved in this follow-up?

Physiotherapist	□	Occupational Therapist	□
Critical Care Nurse	□	Critical Care Doctor	□
Psychologist	□	Dietician	□

Other (please specify)

.....

3. Does this follow-up involve a functional reassessment based on previous assessment at hospital discharge?

YES □ NO □

4. What else is covered in this follow-up?

Exercise capacity	□	Health-related quality of life	□
Psychological status	□	Nursing-related issues	□
Medical status	□	Diet/nutrition	□

Other (please specify)

.....

Bronwen Connolly, Clinical Research Fellow, Lane Fox Respiratory Unit, St.Thomas' Hospital, Westminster Bridge Rd, London, SE1 7EH.

SECTION 3 REHABILITATION SERVICES FOLLOWING CRITICAL ILLNESS

Does your hospital offer a rehabilitation programme following hospital discharge specifically for post critical illness patients as part of *routine* clinical practice?

(separate to generic services such as intermediate care, supported discharge, hospital-at-home or similar)

YES □ **(please go to Question 1.)** **NO** □ **(please go to Question 19.)**

---

1. Who is responsible for leading this rehabilitation programme?

Physiotherapist	□	Critical Care Doctor	□
Occupational Therapist	□	Critical Care Nurse	□
Speech and Language Therapist	□	Exercise/sports therapist	□
Other (please give detail)	□		

.....

2. If a physiotherapist, is this.....

ICU physiotherapist	□	Rehabilitation physiotherapist	□

Current banding/position .....

Duration of ICU rehabilitation experience .....

3. How do you select patients for inclusion into the programme?

		Assessment measure (if applicable)
Duration of mechanical ventilation in ICU	□	.....
Duration of ICU admission	□	.....
Duration of hospital admission	□	.....
Physical function at ICU discharge	□	.....
Muscle strength at ICU discharge	□	.....
Exercise capacity at ICU discharge	□	.....
Health-related quality of life at ICU discharge	□	.....
Physical function at hospital discharge	□	.....
Muscle strength at hospital discharge	□	.....

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Exercise capacity at hospital discharge □ .....

Health-related quality of life at hospital discharge □ .....

Not applicable – all post ICU patients are eligible □ .....

Other/comments (please give detail)

.....

FORMAT OF DELIVERY

4. Is your programme:

Home-based □ Hospital-based □ Community-based □

Other/comments (please give detail)

.....

5. In your programme, do patients exercise:

Under supervision □ Independently □ Combination □

Do you use an accompanying rehabilitation or exercise manual YES □ NO □

Other/comments (please give detail)

.....

6. Is your programme:

A stand-alone programme for post critical illness patients □

Part of existing rehabilitation services including patients with other disease groups □

If so which

.....

Other/comments (please give detail)

.....

7. At what time point post hospital discharge does the programme commence:

Immediately post hospital discharge □ One week post hospital discharge □

Two weeks post hospital discharge □ One month post hospital discharge □

2-3 months post hospital discharge □

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Other/comments (please give detail)

.....

.

Does your service have a waiting list: YES □ NO □

If so, how long? .....

STRUCTURE

8. How many sessions are in the rehabilitation programme e.g. 12 sessions, 16 sessions?

.....

9. How often are the sessions?

Weekly □ Twice-weekly □ Fortnightly □

Other

.....

10. How long is each session?

30 minutes □ 45minutes □ 1 hour □

Other

.....

11. Is this a: Rolling programme □ Stand alone □

12. How many patients are in the group? .....

What is the staff:patient ratio? .....

13. Do patients exercise in a: Pre-determined circuit □ Patient-specific plan □

Other

.....

CONTENT

14. Does your rehabilitation programme include an exercise component

YES □ (please continue) NO □ (please go to Question 17.)

What exercises are included (please tick all that apply)?

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Cardiovascular		Strength		Balance		Functional	
Step-ups	□	Lower limb	□	Static	□	Sit-to-stand	□
Treadmill	□	Upper limb	□	Dynamic	□	Timed Up and Go	□
Static bike	□	Free weights	□			Walking	□
Cross-trainer	□	Theraband/ resisted	□				

Other/comments (please give detail)

.....

How are these exercises prescribed?

Results of walking tests	□	Results of balance assessment	□
Results of physical function assessment	□	Repetition maximum principle	□
Target heart rate	□	Target Borg (please specify range)	□
Clinician judgement	□		

Other/comments (please give detail)

.....

15. How do you monitor and/or progress exercise intensity during the exercise session?

Heart rate targets	□	SpO_2	□	Borg	□
Visual analogue scale	□	Clinical observation/judgement of patient			□
Patient verbal feedback	□	No formal monitoring			□

Reassessment of baseline measures □

Other/comments (please give detail)

.....

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16. Does your rehabilitation programme include an education component

YES □ NO □

If YES....what topics are included

Subject		Delivered by (please list MDT member)
Exercise	□	.....
Stress management	□	.....
Nutrition	□	.....
Return to work	□	.....
Energy conservation	□	.....
Medications	□	.....
What to expect of recovery	□	.....
Motivational coaching/training	□	.....

Other (please give detail)

.....

EVALUATION

17. What outcome measures do you use with patients participating in your rehabilitation programme?

Strength-based e.g. repetition maximum, maximum weight □

Please specify.....

Exercise capacity e.g. field walking tests (e.g. 6 Minute Walk Test, cardiopulmonary exercise testing
(VO_2max) □

Please specify.....

Health-related quality of life e.g. SF-36 survey, Hospital Anxiety and Depression scale□

Please specify.....

Mental/cognitive assessment e.g. Montreal Cognition Assessment □

Please specify.....

Bronwen Connolly, Clinical Research Fellow, Lane Fox Respiratory Unit, St.Thomas' Hospital, Westminster Bridge Rd, London, SE1 7EH.

Functional performance e.g. Timed Up and Go, Short Physical Performance Battery □

Please specify.....

Other (please specify)

.....

18. Any other comments regarding your post critical illness rehabilitation programme?
.....

.....

.....

NO AVAILABLE REHABILITATION SERVICE

19. If the answer to offering a rehabilitation service/programme at the start of this section was' NO' please give details as to limiting factors for availability of these services.....

	All reason (tick all that apply)	**Main reason** (tick one only)
Lack of sufficient staff numbers	□	□
Lack of suitably trained staff	□	□
Lack of available space/venue	□	□
No evidence to suggest benefit	□	□
Lack of funding	□	□
Not considered required service at managerial level	□	□
Insufficient patient numbers to justify	□	□
Not sure what to include in a rehabilitation programme	□	□
Resources prioritised to other patient groups/clinical areas	□	□
Extra-contractual (out-of-area) patient caseload	□	□

Other (please specify)

.....

20. Do you refer ICU patients routinely into other rehabilitation programmes/services, either in-patient or community-based?

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YES □ (please continue) NO □ (please go to Question 21.)

Pulmonary rehabilitation □ Cardiac rehabilitation □

Exercise on prescription (or similar) □ Community gym sessions □

Other (please specify)

.....

21. Does your organisation offer a post hospital discharge rehabilitation programme to survivors of critical illness as part of a research study?

YES □ NO □

If able, please provide contact detail for lead researcher

.....

(End of survey – many thanks for completing)

Rehabilitation Following Critical Illness: The Failure to Implement NICE Clinical Guidance 83 (CG83) in the UK

DATA SUPPLEMENT

E1. Post hospital discharge follow-up services and rehabilitation programmes

Figure E1 reports available follow-up services and rehabilitation programmes for survivors of critical illness post hospital discharge.

E2. Detail on characteristics of available post hospital discharge rehabilitation programmes for survivors or critical illness

Leadership of, and enrolment into, post hospital discharge rehabilitation programmes

In the majority of cases (n=9) this was a senior ICU physiotherapist (median (IQR) duration ICU experience 7.0 (4.0-13.0) years). A rehabilitation physiotherapist led one programme. One programme reported additional involvement of an occupational therapist and a fitness instructor with three including critical care nurses. There were no other MDT members reported. Limited data were provided regarding enrolment criteria of patients into available rehabilitation programmes (*Table E1*).

Table E1. Enrolment criteria for post hospital discharge rehabilitation programmes

Eligibility criteria	n (%)	Detail of assessment measure
Duration mechanical ventilation	7 (70.0)	>5 days; >4 days; >3 days; 48hours
Duration ICU Admission	3 (30.0)	>5 days; >4 days
Duration hospital admission	2 (20.0)	"lengthened"
Physical function at ICU discharge	2 (20.0)	"reduced from pre-admission"
Muscle strength at ICU discharge	2 (20.0)	No detail provided
Exercise capacity at ICU discharge	2 (20.0)	No detail provided
HRQL at ICU discharge	0	-
Physical function at hospital discharge	4 (40.0)	No detail provided
Muscle strength at hospital discharge	3 (30.0)	No detail provided
Exercise capacity at hospital discharge	3 (30.0)	No detail provided
HRQL at hospital discharge	1 (10.0)	No detail provided
All patients eligible	1 (10.0)	"any ITU stay"
Other	2 (20.0)	"those with profound weakness or functional limitation regardless of LOS"; "screen for low or high risk throughout ICU/hospital stay. If high risk, exercise plan, goals and rehab class if suitable. All plus 2 day ICU are automatically sent SF8 and depending on score, either 1:1 follow up or group follow-up"

n=10 responses. Multiple criteria could be reported per response.

Abbreviations: ICU/ITU = intensive care/therapy unit. HRQL = health-related quality of life. LOS = length of stay. SF8 = Short Form-8 (health-related quality of life survey).

Format and structure of post hospital discharge rehabilitation programmes

Of the ten rehabilitation programmes, nine were hospital-based and one was home-based. Patients exercised under supervision in four programmes, and with a combination of supervised and independent exercise in the remaining six. Only one programme used an accompanying rehabilitation manual, however three others reported providing printed, individualised home exercises for patients. All programmes were designed specifically for post critical illness patients. None were combined with existing disease-specific services such as pulmonary or cardiac rehabilitation. Programmes started immediately (n=4), at one week (n=1), within two weeks (n=3), within one month (n=1) and at 2-3 months (n=1) post hospital discharge. The number of sessions in each programme varied from 6 to 12, excluding assessment sessions. Data were absent for two programmes. Three programmes had the capacity and flexibility to allow patients to continue until individual goals or target physical function level had been achieved. Typically sessions ran weekly (n=7) or twice-weekly (n=3). All programmes included sessions of one hour duration. Eight programmes were 'rolling' programmes and patients could start and finish the programme at any point in time. One was stand-alone such that cohorts of post critical illness patients all started and completed programmes together. No enrolment, initiation timing, frequency or duration data were reported for one programme.

Content and monitoring of post hospital discharge rehabilitation programmes

All rehabilitation programmes included an exercise component, involving a combination of cardiovascular, muscle strength, whole body balance and functional activity (*Table E2*). Nine programmes incorporated at least two different forms of exercise prescription during the programme usually based on clinician judgement, sometime informed by results of walking

tests and physical function assessment. All programmes included at least two forms of patient monitoring during exercise sessions, based on a range of physiological and clinical factors. Seven programmes used target rates of perceived exertion with four programmes using oxygen saturation levels and 3 programmes monitoring heart rate. In contrast, patient-related parameters were adopted in 8 programmes which monitored exercise performance based on verbal feedback of the patient, 6 based on clinician judgement of the patient and 2 based on visual analogue scales undertaken by the patient.

Surprisingly, less than half of all programmes included an education component (n=4). A range of topics were covered including exercise, stress management and relaxation, nutrition, return to work, energy conservation, medications, recovery following critical illness, smoking cessation, managing breathlessness and breathing control, delivered predominantly by physiotherapists but with additional input from occupational therapist and nursing colleagues.

Group size

Group size and staff-to-patient ratio was also highly variable between the 10 post rehabilitation programmes. One programme incorporated a 1:1 staff-to-patient ratio whilst another adopted a flexible approach that depended on the complexity of the patient and individual rehabilitation needs. Across the remaining programmes group sizes ranged from 5 to 14 patients with one qualified staff member for every 3 patients. Seven of the ten programmes adopted patient-specific exercise plans, whilst the remaining three reported that patients exercised in a pre-determined circuit.

Table E2. Exercise component and evaluation of post hospital discharge rehabilitation programmes

Category of exercise	Specific exercise	n (%)
Cardiovascular	Static bike	10 (100.0)
	Step-ups	9 (90.0)
	Treadmill	7 (70.0)
	Cross-trainer	2 (20.0)
Strength	Lower limb	10 (100.0)
	Upper limb	10 (100.0)
	Theraband/resistance	9 (90.0)
	Free weights	7 (70.0)
Balance	Dynamic	9 (90.0)
	Static	5 (50.0)
Functional	Sit-to-stand	8 (80.0)
	Walking	6 (60.0)
	Timed Up And Go	2 (20.0)
Outcome	**Detail of outcome measure**	**n (%)**
HRQL	SF-36, HADS, EQ5D, FIM, SF-8	10 (100.0)
Exercise capacity	6MWT; ISWT	9 (90.0)
Other	Achievement of patient-specific goals; BMI; Impacts of Events Score	3 (30.0)
Functional	TUAG; patient-specific goals	2 (20.0)
Strength	2 minute step-ups	1 (10.0)
Mental/cognitive	-	0

For exercise component and outcome measures, n=frequency of reported occurrence out of 10 responses. Multiple options could be listed per response.

Abbreviations: HRQL = health-related quality of life. 6MWT = Six Minute Walk Test. ISWT = Incremental Shuttle Walk Test. SF-36 = Short Form 36. HADS = Hospital Anxiety and Depression Scale. EQ5D = EuroQol 5 Dimensions. FIM = Functional Independence Measure. SF-8 = Short Form 8. TUAG = Timed Up And Go. BMI = body mass index.

Evaluation of post hospital discharge rehabilitation programmes

Four of the programmes reported reassessment of baseline measures as a form of evaluation of the programme. However, subjective clinician judgement was the most commonly utilised form of evaluation followed by the objective changes in walking tests and physical function. Physiological parameters, such as target perceived rate of exertion and heart rate, and results of balance assessments were used infrequently in the evaluation of the response to the rehabilitation programme. Exercise capacity and health-related quality of life outcome measures were the most commonly utilised. Interestingly, none of the programmes incorporated the use of the repetition maximum principle to prescribe strengthening exercises.

E3. Individual comments made by respondents regarding barriers to offering post hospital rehabilitation discharge services and use of alternative rehabilitation streams.

The following free-text comments were made by respondents regarding barrier to offering specific post hospital discharge rehabilitation programmes and further elucidate the themes of funding restriction, resource allocation/availability (Including staffing) and strategic management priorities as key limiting factors. (Note: words in italics added by the author for full interpretation):

> "...we at times struggle to fight for staff for in pt rehab (*in-patient rehabilitation*) let alone fight for a budget for op (*out-patient*) care

> "...we run a voluntary f-u (*follow-up*) clinic but have had to withdraw the rehab (*rehabilitation*) and psych (*psychology*) elements due to no (sic) support from therapy managers

"...despite extensive work the business case was declined

"...a rehab (*rehabilitation*) programme was run for 12m using charitable funds money. Ongoing funding was not secured as it was not deemed a Trust priority

"...historically no service available, no need established by current ICU services

"...and not considered required at managerial level; Some years ago charitable funding was available to open follow-up clinic to include rehab (*rehabilitation)* service but Trust board refused the 2 year funding as they could not commit to continuing to fund the service once the charitable monies expired. So the reason we didn't introduce the service at that time was a mix of funding and managerial issues. Currently I would think staffing would be another issue.

"...previously ran post ICU rehab (*rehabilitation*) class but had to stop because reduced staffing (prioritising in-pt) and difficult to get numbers (no transport provided)

"...The main barriers to this aspect are time constraints, lack of staff and funding alongside limited knowledge of potential co-morbidities following ICU stay. Critical Care follow up clinics do not take place in an adequate time frame in this trust and as such many people do not attend, therefore we are missing potential problems. Additionally the clinic is not an MDT run clinic, limiting clinical identification of potential problems.

"...absence of vertical integration of health and social care

"...not so much not considered as required - sure the team believe it's required just not enough resources

"6.5WTE PT (*6.5 whole-time equivalent physiotherapists*) in team covering 7 different ward specialities, 3x critical care areas, resp o/p (*respiratory out-patients*), resp pts (*respiratory patients*) in A&E/admissions

Other comments described the interaction between acute and primary care services, which in some cases offer a route for ongoing rehabilitation input, and clinical and logistical factors for consideration in determining need for specific critical care services:

"...inpt (in-patient) and outpt (out-patient) services are provided by two separate organisations, therefore although the inpt (*in-patient*) team would like to provide a service the community team will not lend support

"...pt (*patient*) needs met by other community services available

"...not sure if we would have individual class therefore combined with PR (*pulmonary rehabilitation*); we would like to set one-up

"...numbers are very small and tends to be post-op (*post-operative*); back to baseline 5/7 (*at five days*). not seen need to provide service separate to our IRS (*in-patient rehabilitation or integrated respiratory service*)

"...We have a follow up clinic run by our CCORT (*critical care outreach team*), but no physical rehab (*rehabilitation*) post D/C (*discharge*) home (unless needing regular community physio (*physiotherapy*) input)

"...very structured in hospital critical care rehab (*rehabilitation*) service to maximise pt (*patient*) status at hospital d/c (*discharge*), has significantly reduced LOS (*length of stay*), readmissions to critical care, QOL (*quality of life*) scores and ongoing co-morbidity/health problems. Insufficient numbers for group rehab (*rehabilitation*) specific to CCD (*critical care disease*) post d/c (*discharge*)

"...patients who need long-term rehab (*rehabilitation*) are followed up by community staff

"...we use PR (*pulmonary rehabilitation*) programme for many post ITU patients

"...cardiac patients go to CR (*cardiac rehabilitation*)

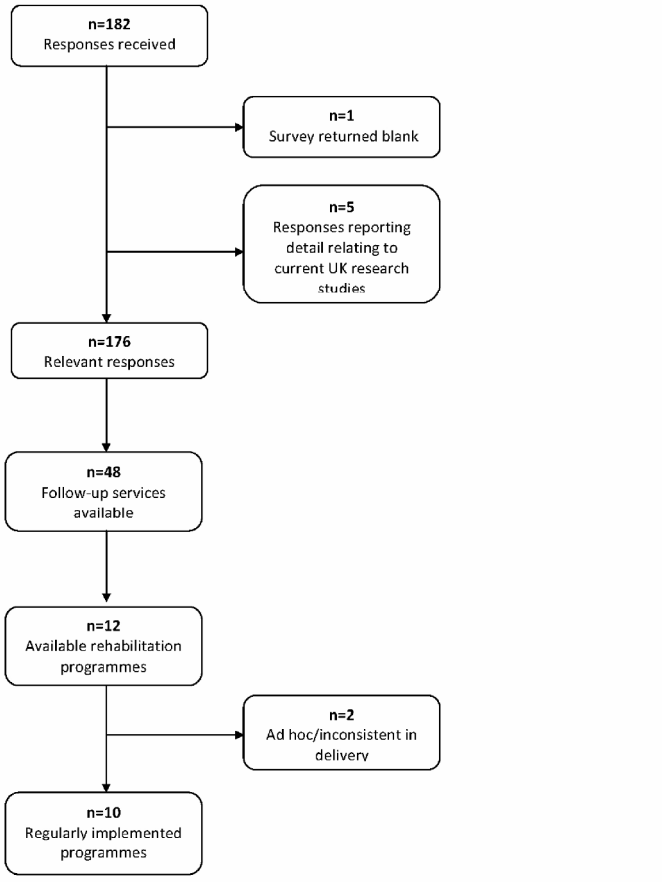

Figure E1. Flow-chart outlining available follow-up services and rehabilitation programmes for survivors of critical illness post hospital discharge

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Figure E1. Flow-chart outlining available follow-up services and rehabilitation programmes for survivors of critical illness post hospital discharge
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