National Institute for Health and Clinical Excellence

Critical illness rehabilitation
Scope Consultation Table
17 April – 15 May 2008

Order No	Stakeholder	Section number	Comments	Response
1	Arrhythmia Alliance		This organisation was approached but did not respond.	
2	Association for Chartered Physiotherapists in Respiratory Care (ACPRC)		This organisation was approached but did not respond.	
3	Association of Catholic Nurses of England and Wales		This organisation was approached but did not respond.	
4	Association of the British Pharmaceuticals Industry,(ABPI)		This organisation was approached but did not respond.	
5	Barnsley Hospital NHS Foundation Trust		This organisation was approached but did not respond.	
6	Barts and The London NHS Foundation Trust		This organisation was approached but did not respond.	
7	Bedfordshire PCT		This organisation was approached but did not respond.	
8	Birmingham & the Black Country Critical Care Network		This organisation was approached but did not respond.	
9	Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
10	Bournemouth and Poole PCT		This organisation was approached but did not respond.	
11	Brighton and Sussex University Hospitals NHS Trust		This organisation was approached but did not respond.	
12	British Association for Counselling and Psychotherapy		This organisation was approached but did not respond.	
13	British Association of Cardiac Rehabilitation		This organisation was approached but did not respond.	
14.0	British Association of Critical Care Nurses	4.1.1	Is ITU an appropriate term to use? How is ITU defined? Should the population in the scope include ICU or should it include all critical care areas. Or should the population refer to the level of patient i.e. Level 3 patients or Level 2 patients.	Noted. Further specifications have been made in section 4.1.1 to 'level 2 and 3 Critical Care
14.1	British Association of Critical Care Nurses	4.2	We have similar comments to above. How is "Intensive Care Units" being defined?	Noted. Further specifications have been made in section 4.1.1 to 'level 2 and 3 Critical Care

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14.2	British Association of Critical Care Nurses	4.4	Key outcome measures should include: Return to work and Number of visits to GP.	The perspective on outcomes applied in this guideline will be all direct health effects whether for patients or, where relevant, other individuals (principally carers). The perspective adopted on costs will be that of the NHS and PSS and any analysis will consider all relevant resource use within that perspective. If the inclusion of a wider set of costs or outcomes is considered important and expected to significantly influence the results from any economic modelling undertaken, additional analyses will be carried out.
14.3	British Association of Critical Care Nurses	Appendix A	How will the question regarding the needs to carers be answered? Is there enough quality evidence available to answer this question?	Noted. The answers will be guided by evidence review and GDG consensus.
15	British Dietetic Association		This organisation was approached but did not respond.	
16	British Heart Foundation		This organisation was approached but did not respond.	
17	British National Formulary (BNF)		This organisation was approached but did not respond.	
18	British Orthopaedic Association		This organisation was approached but did not respond.	
19.0	British Pain Society	General	Anecdotally, pain, both widespread and localised, can be a major problem following critical illness. Neuropathic pain can be particularly difficult to treat. The aetiology of the pain is often unclear and could result from immobility, positioning, drug treatment, multi-organ failure, etc. Little or no research data are available. This is an area that requires investigation.	Noted. Detailed guidance on the management of pain is outside the scope of these guidelines, but would be included under assessment for physical factors as the cause of, or related to rehabilitation needs.
19.1	British Pain Society	3 – f)	ITU follow-up clinics should assess for and flag up any on-going issues of Chronic Pain. Post surgical pain results in chronic pain in 5-25% (depending on definition) of patients. ITU patients are likely to have had multiple procedures and this figure could be higher. WA Macrae, HTO Davies. Chronic Postsurgical Pain. Epidemiology of Pain: Eds Ian Crombie et al. International Association for the Study of Pain. IASP Press, Seattle 1999.	Noted. This will be guided by the evidence review and will be captured under the key outcome measure of Health-related Quality of Life.
19.2	British Pain Society	4.4 – e)	Key Outcomes – Health related QoL will identify any on-going incapacity due to severe pain. If present, it contributes a significant impact to decreased QoL and economic cost.	Thank you.

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20.0	British Psychological Society, The	General	This guideline has the potential to address unmet need in the rehabilitation of ITU patients. It is positive to see that all aspects of rehabilitation are intended to be covered by this guideline including psychosocial morbidity. This is particularly important as it is becoming increasingly evident from the literature that such patients are at risk of developing both short and long term adverse psychological reactions which can have an impact on the rate of physical rehabilitation as well as limiting quality of life and economic activity directly.	OK.
20.1	British Psychological Society, The	Section 3	The list of psychological conditions that may effect ITU patients in section 3 c is far from exhaustive and we would make the point that there is a considerable chance that there will also be co-morbidity (i.e. depression and PTSD for e.g).	Thank you. The issue of co-morbidity will be guided by the evidence review.
20.2	British Psychological Society, The	Section 4.2 b	It would be helpful if in section 4.2 b that relates to the settings covered by this guideline, if it is made explicit that all settings where psychological rehabilitation is delivered are to be included - this is hinted at but needs to be clearly stated. The way in which clinical input from psychologists and others providing psychological assessment and care into ITU is delivered is very variable (and in many places non-existent). Consequently, this guideline should explicitly seek to map and explore existing service models for the delivery of psychological care in this context and ensure that it is inclusive in its coverage.	The guideline will identify the effective components of rehabilitation strategies. It will not address the service configuration and delivery of the strategies. However, implementation tools will be developed to assist local Trusts to set up their own services.
20.3	British Psychological Society, The	General and Section 4.3a	There appears to be a potential over focus on the use of 'screening tools' for psychological assessment and consideration should also be given to clinical assessment (this is probably most relevant to section 4.3 a).	The structured clinical question in Appendix A does include both 'screening and assessment tools'. Recommendations on which screening and/or assessment tools to be used will be guided by the evidence review and GDG consensus.
20.4	British Psychological Society, The	General	The clinical questions section would also benefit from further exploration of the available psychological interventions. In considering assessment, further emphasis is required on identifying risk factors given that it is a well established finding that vulnerability to PTSD for example is linked to a variety of demographic factors and more importantly to prior history of	Noted. Risk stratification will be incorporated in the review of evidence as stated in section 4.3a. However, it is outside the remit of the scope in terms of reviewing risk factors/prediction models around each relevant morbidity. Regarding available specific psychological interventions, the guideline will refer to

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			trauma and psychological distress.	other already published NICE guidelines such as Depression (CG23), PTSD (CG26) and Anxiety (CG22). Extra information on other NICE relevant guidelines has been added in section 4.6.1
21.0	British Society of Rehabilitation Medicine & JSC Rehabilitation Medicine	General	This draft scope has been well prepared and reflects the views of a lively workshop held in Manchester on March 28th. It reports on the significant unmet rehabilitation needs of this group of patients who have physical, cognitive and psychological impairments attributable to their critical illness. Developers of the guidelines are encouraged to construct pathways that support the referral of people with unmet rehabilitation need after a critical illness to specialists in Rehabilitation Medicine. These doctors have the specialist competencies to address complex neuropsychological and physical impairments, and have the skills required to work in teams able to address these needs, and the knowledge to refer on when necessary to vocational or educational colleagues.	Noted.
21.1	British Society of Rehabilitation Medicine & JSC Rehabilitation Medicine	Section No 3	It refers in section 3(g) to the evidence on the successful use of structured, self-directed rehabilitation strategies to aid physical and psychological recovery but acknowledges that the strategies currently used vary widely It also, in 3(h) and (i) acknowledges the need to collect accurate information on impairment and disability to guide treatment and agrees that there are currently no evidence based guidelines to guide best practice.	Noted.
21.2	British Society of Rehabilitation Medicine & JSC Rehabilitation Medicine	Section 4	Section 4 describes the areas that will be addressed and those that will be excluded. It excludes those receiving palliative care, those who had critical care for a neurological or neurosurgical condition, and those who received critical care and did not develop critical illness. The last exclusion is something of an oxymoron and requires clearer definition. The second exclusion is more worrying	Noted. Section 4.1.2b has been modified to reflect this.

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			because nationally, access to expert neurorehabilitation resources for individuals with neurological illness who have survived an ICU illness is not always available, and the needs of this group are often not recognised until some time after the acute illness, often when they have failed to reintegrate successfully into their social or working lives. This is an opportunity to capture the needs of this group who have had a neurological illness, perhaps a sub arachnoid haemorrhage or meningitis, who have made a full physical recovery but have hidden neuropsychological deficits. If identified by screening at a suitably early point in time they should be referred on to specialist neurorehabilitation services to allow access to an MDT and neuropsychology assessment and treatment, that may allow them to make a success of their return to their social and vocational activities. It is a wrong assumption that their needs are already met by existing pathways. Key outcome measures and economic aspects are part of the scope and must take careful advice to allow the best selection of reliable and validated measures for this group of people. Although the preferred unit of cost effectiveness according to the guidelines manual is the QALY, the limitations of this measure are well known, particularly with reference to a population with significant levels of disability and some thought should be given to evaluating cost of care needs and their provision before and after interventions, and functional levels of activity before and after that are not usually captured by these or other popular health measures such as the Short Form 36. Developers of the guidelines are encouraged to construct pathways that support the referral of people with unmet rehabilitation need after a critical illness to specialists in Rehabilitation Medicine .	
22	British Thoracic Society		This organisation was approached but did not respond.	

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23	BUPA		This organisation was approached but did not respond.	
24	Cambridge University Hospitals NHS Foundation Trust		This organisation was approached but did not respond.	
25	Central Manchester and Manchester Childrens University Hospitals		This organisation was approached but did not respond.	
26	Chelsea & Westminster Acute Trust		This organisation was approached but did not respond.	
27	Cheshire PCT		This organisation was approached but did not respond.	
28.0	College of Occupational Therapists	2b and 4.1.2	From the scope it is clear that specific clinical subgroups will not be included, e.g. neurosurgical conditions and elective surgery. However, this contradicts previous critical care recommendations (Critical Care Without Walls) and many trusts are moving at bringing together all critically ill patients, rather than separating them into specialism. This will improve the care and use of resources (beds and staffing) for level 2 and 3 patients. It is therefore important that some aspects of neuro related NSF's and guidelines are considered during the guideline development process. An example may be the NSF for LTC (neuro) as many of the issues that patients with critical illness experience are addressed within this NSF. Although there is a variety of other NSF's they do not necessarily consider the psychological impact of a critical care experience and a traumatic, un-expected/sudden life-threatening event. Currently there are no specific guidelines for managing trauma patients (spinal, orthopaedic, plastics etc) however they are a large group of patients that will be seen in a critical care context and addressing their needs will be essential.	The guideline will identify the effective components of rehabilitation strategies. It will not address the service configuration and service delivery model of the strategies. However, implementation tools will be developed to assist local Trusts to set up their own services.
28.1	College of Occupational Therapists	3b	Physical morbidity does not only relate to muscle loss but also ongoing **fatigue and reduced exercise tolerance** impacting on participating on all aspects of every day activities and normal life. Activity analysis and fatigue management/ energy conservation should be considered for all these patients to facilitate an effective and efficient return to previous level of function where possible.	Noted. The evidence review will cover the aspect of daily functional status which should cover not only muscle loss but also other factors that affect physical activity.
28.10	College of Occupational Therapists	4.2. b	Are trauma patients included in this group of patients? There may	Yes. The guideline includes trauma patients. Section

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			need to be more clarity on the Healthcare setting as some ICUs have high throughput of cardiac, renal and respiratory patients. There is no specific pathway for neurological conditions, e.g. GBS and this client group should be considered. The NSF for LTC and the strategy for managing LTC Patients need to be considered when differentiating the healthcare setting as many people will be excluded from the guideline implications if it only focuses on medical and general surgery.	4.1.2b has also been modified to reflect this.
28.11	College of Occupational Therapists	4.4. b	Return to work (carer and patient) and the financial implications of this and the reduction in long-term care could be included here.	The perspective on outcomes applied in this guideline will be all direct health effects whether for patients or, where relevant, other individuals (principally carers). The perspective adopted on costs will be that of the NHS and PSS and any analysis will consider all relevant resource use within that perspective. If the inclusion of a wider set of costs or outcomes is considered important and expected to significantly influence the results from any economic modelling undertaken, additional analyses will be carried out.
28.2	College of Occupational Therapists	3c	3b impact on psychological issues. Although this is a well-recognised area of concern the psychological support services for patients and families remain absent. Engagement in rehabilitation as an inpatient or outpatient is often limited due to these complex psychological issues. The relationship between sedative protocols and psychological and cognitive morbidity requires further research to develop robust approaches with fewer complications.	Noted. This will be explored by GDG during the guideline development process.
28.3	College of Occupational Therapists	3d	3b directly impacts on 3c and 3d as fatigue can either mask or highlight cognitive and psychological issues and should be considered together and not in isolation. Cognition is not formally assessed, although there are measurements out there that can be used, however at this stage is does not have predictive outcome information. Sedation, previous mental health issues and new psychological issues need to be considered together.	Noted. This will be guided by the evidence review and further exploration by the GDG during the guideline development process.

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28.4	College of Occupational Therapists	3e	The focus of the critical care outreach teams need to be expanded to enable this early rehabilitation approach and consider physical and psychological issues of the patient and the carers/families. Step down from ICU to HDU or a general ward causes a lot of anxiety to both patient and carers and there is limited to no support with this transition. Anxiety limits patients' participation in rehabilitation and a holistic approach to theses issues are essential. Ward rehabilitation by generic therapists may not be standard practice in all hospitals, where discharge planning often takes priority. Incorporating rehabilitation standards into the guidelines will be challenging. *(Other barriers to consider is the way in which consultants from varied specialties interpret suggestions made by CC outreach teams on how to manage their patients post CC on the ward – from previous experience this has been very challenging).*	Noted. These issues will be discussed by the GDG during the guideline development process.
28.5	College of Occupational Therapists	3f	While this is happening in some clinics the process is often merely a problem identification and onward referral process. Actual intervention requires more time and resources and this is not always possible in regional follow up clinics. Recommendations are required that will justify the role and importance of this approach in follow up clinics where intervention is limited but by addressing the issues the patient may have a better outcome. Referrals may be made but actual intervention is dependent on the community resources available and evaluation of economical aspects will be very difficult.	Noted. The NICE Implementation team will consider these issues.
28.6	College of Occupational Therapists	3g	Other aspect to consider is the use of tele rehabilitation and a program similar to the 'expert patient program'. Support groups have proven to be very beneficial and these three strategies should be included in the evidence review to improve long-term outcome of both families and carers.	Noted. This will be guided by evidence review.
28.7	College of Occupational Therapists	3i	An occupational therapy evidence based protocol has been developed for assessment and intervention with patients during	Noted. The technical team expects to pick this up from the systematic review.

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			and after a critical care episode and this can be made available to the guideline group.	
28.8	College of Occupational Therapists	General	Evidence review around environmental aspects impacting on recovery may need to be reviewed as the environment from ICU to HDU, ward and home changes significantly and will impact on outcome. Recommendations relating to this will be helpful, especially where psychological and cognitive issues are evident (e.g. PTA & delusions).	It is outside the remit of the scope to review this. Although important, the technical team considered that the issue of environmental changes from hospital to patient's home should be addressed through a routine continuous care plan based on person-centred approach, following any recommended assessment and intervention strategies.
28.9	College of Occupational Therapists	4.1.2. b	Although there is agreement that these groups are separate they will experience similar physical and psychological issues and it will be good practice if the guidelines are considered with these pathways as well, especially relation to family support. **Same comment as made in point 1 (also relating to 2b).** From the scope it is clear that specific clinical subgroups will not be included, e.g. neurosurgical conditions and elective surgery. However, this contradicts previous critical care recommendations and many trusts are moving at bringing together all critically ill patients, rather than separating them into specialism. This will improve the care and use of resources (beds and staffing) caring for level 2 and 3 patients.	Noted. Section 4.1.2b has been modified to reflect this.
29	Coloplast Limted		This organisation was approached but did not respond.	
30	Commission for Social Care Inspection		This organisation was approached but did not respond.	
31	Connecting for Health		This organisation was approached but did not respond.	
32	Coventry and Warwickshire Cardiac Network		This organisation was approached but did not respond.	
33	Department for Communities and Local Government		This organisation was approached but did not respond.	
34	Department of Health		This organisation responded and said that they have no comments to make.	
35	Department of Health, Social Security and Public Safety of Northern Ireland		This organisation was approached but did not respond.	
36	Derbyshire Mental Health Services NHS Trust		This organisation was approached but did not respond.	

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37	East & North & West Hertfordshire PCTs		This organisation was approached but did not respond.	
38	East Kent Hospitals NHS Trust		This organisation was approached but did not respond.	
39	Gloucestershire Hospitals NHS Trust		This organisation was approached but did not respond.	
40	Guys and St Thomas NHS Trust		This organisation was approached but did not respond.	
41	Harrogate and District NHS Foundation Trust		This organisation was approached but did not respond.	
42	Health Commission Wales		This organisation was approached but did not respond.	
43	Healthcare Commission		This organisation was approached but did not respond.	
44	Hertfordshire Partnership NHS Trust		This organisation was approached but did not respond.	
45	Herts & Beds Critical Care Network		This organisation was approached but did not respond.	
46	Hill-Rom		This organisation was approached but did not respond.	
47.0	ICUsteps	4.1.1	We welcome the inclusion in the scope of all adult patients with rehabilitation needs following a period of critical illness. Our concern is that the wording as it stands states that adults with rehabilitation needs are included in the scope but does not state explicitly that all ICU patients should be assessed for rehabilitation needs. Though we believe this is the intention of the scope, we would prefer it made clear that the assessment and evaluation of rehabilitation needs covered in section 4.3 a) applies to every patient admitted to intensive care.	Noted. This will be guided by the evidence review and health economics modelling. Therefore the scope is not specific at this point.
47.1	ICUsteps	General	The Background and Clinical Need for the Guideline summarise the current situation faced by patients recovering from a period of critical illness very well. The key outcome measures are thorough as are the clinical questions covered in appendix a. We welcome the scope as a solid foundation for this guideline and look forward to reviewing and commenting on the recommendations the GDG produce in due course.	Thank you.
48	Institute of Biomedical Science		This organisation was approached but did not respond.	
49	Intensive Care Aftercare Network (i-canuk)		This organisation was approached but did not respond.	
50	Intensive Care National Audit & Research Centre (ICNARC)		This organisation was approached but did not respond.	
51	Intensive Care Society		This organisation was approached but did not respond.	
52	Kirklees PCT		This organisation was approached but did not respond.	
53	Lancashire Teaching Hospitals Acute		This organisation was approached but did not respond.	

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	Trust			
54	Leeds PCT		This organisation was approached but did not respond.	
55	Long Term Medical Conditions Alliance		This organisation was approached but did not respond.	
56	Medicines and Healthcare Products Regulatory Agency (MHRA)		This organisation was approached but did not respond.	
57.0	Medway NHS Trust		This organisation was approached but did not respond.	
57.1	Medway NHS Trust	4.11	• I am please that a decision has been made to have all patients with rehabilitation needs after the long debates we had after the scoping exercise • However how are we going to decide who has rehabilitation needs • These needs must include physical as well as psychological needs	Noted.
57.2	Medway NHS Trust	4.1.2 b	• There will be some patients who are following an elective pathway and who may not develop a critical illness as such, but may well have psychological issues relating to their stay in ITU which will effect their rehabilitation. We need to be able to capture these patients.	Noted. The Scope is aiming to capture this group of patients and Section 4.1.2b has also been modified to reflect this.
57.3	Medway NHS Trust	4.2	• The healthcare settings need to include high dependency unit. In the previous version the term used was Critical Care Units. Why was this changed?	Further specifications have been made in section 4.1.1 to 'level 2 and 3 Critical Care'. The scope intends to be patient-focused (ie. those who would benefit most from rehabilitation), instead of being unit-focused.
57.4	Medway NHS Trust	4.3c	• Excellent that the role of carers has been identified	Thank you.
57.5	Medway NHS Trust	4.4d	• Will need to be sure that readmissions to hospitals are not as result of other things such as chronic conditions	Noted. Further specification has been added in section 4.4c.
57.6	Medway NHS Trust	4.4	• As part of outcome measures do the effects of caring for these patients for the carers need to be considered??	Yes. As stated in section 4.3c, *'Where available, evidence on the role of the carer, and interventions aimed at the carer, will be reviewed.'*
57.7	Medway NHS Trust	Appendix A	• Good clear clinical questions	Thank you.
58.0	Mid Trent Critical Care Network	2a	Change ITU to Critical Care, it was agreed at the scoping meeting in Manchester NOT to refer to ITU but replace with critical care	Modification and further specifications have be made in section 4.1.1 to 'level 2 and 3 Critical Care'.

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58.1	Mid Trent Critical Care Network	3a	There is inconsistency with ICU/ITU and critical care	Noted. Changes has been made.
58.2	Mid Trent Critical Care Network	3f	Again replace ICU/ITU, the modern term now is critical care as many units combine their ICU/HDU facilities.	Noted. Changes has been made
58.3	Mid Trent Critical Care Network	4.1.1	As above plus, no time limit, 'a stay' could mean 2 hours or 20 days, is there a time period?	Further specifications have been made in section 4.1.1 to 'level 2 and 3 Critical Care' so that it is patient-focused (ie. those who would benefit most from rehabilitation), instead of being time-focused.
58.4	Mid Trent Critical Care Network	4.4f	Return to work as an outcome, number of GP visits as an outcome? These are what commissioners are looking at and this is the criteria they use for funding.	The perspective on outcomes applied in this guideline will be all direct health effects whether for patients or, where relevant, other individuals (principally carers). The perspective adopted on costs will be that of the NHS and PSS and any analysis will consider all relevant resource use within that perspective. If the inclusion of a wider set of costs or outcomes is considered important and expected to significantly influence the results from any economic modelling undertaken, additional analyses will be carried out.
58.5	Mid Trent Critical Care Network	Appendix A	There is little quality information regarding the needs of carers/families, whilst this is important I do not know how this will be obtained without further audit, research.	Noted. This will be guided by the systematic review and GDG consensus.
59	Milton Keynes PCT		This organisation was approached but did not respond.	
60	MRSA Action UK		This organisation was approached but did not respond.	
61	National Patient Safety Agency (NPSA)		This organisation was approached but did not respond.	
62	National Public Health Service - Wales		This organisation was approached but did not respond.	
63	National Spinal Injuries Centre		This organisation was approached but did not respond.	
64	National Treatment Agency for Substance Misuse		This organisation was approached but did not respond.	
65	NCCHTA		This organisation was approached but did not respond.	
66	NHS Plus		This organisation was approached but did not respond.	
67	NHS Purchasing & Supply Agency		This organisation was approached but did not respond.	
68	NHS Quality Improvement Scotland		This organisation was approached but did not respond.	
69	Norfolk, Suffolk and Cambridgeshire Critical Care Network		This organisation was approached but did not respond.	

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70	North East & Cumbria Critical Care Network		This organisation was approached but did not respond.	
71	North Trent Critical Care Network		This organisation was approached but did not respond.	
72	North West London Critical Care Network		This organisation was approached but did not respond.	
73	North Yorkshire and York PCT		This organisation was approached but did not respond.	
74	Northumbria Healthcare NHS Foundation Trust		This organisation was approached but did not respond.	
75.0	Nottingham University Hospitals NHS Trust	2a	Change ITU to Critical Care, it was agreed at the scooping meeting in Manchester NOT to refer to ITU but replace with critical care	Modification and further specifications have be made in section 4.1.1 to 'level 2 and 3 Critical Care'.
75.1	Nottingham University Hospitals NHS Trust	2f	Again replace ICU/ITU, the modern term now is critical care as many units combine their ICU/HDU facilities.	Noted. Changes has been made
75.2	Nottingham University Hospitals NHS Trust	4.1.1	As above plus, no time limit, 'a stay' could mean 2 hours or 20 days, is there a time period?	Further specifications have been made in section 4.1.1 to 'level 2 and 3 Critical Care' so that it is patient-focused (ie. those who would benefit most from rehabilitation), instead of being time-focused.
75.3	Nottingham University Hospitals NHS Trust	4.4f	Return to work as an outcome, number of GP visits as an outcome? These are what commissioners are looking at and this is the criteria they use for funding.	The perspective on outcomes applied in this guideline will be all direct health effects whether for patients or, where relevant, other individuals (principally carers). The perspective adopted on costs will be that of the NHS and PSS and any analysis will consider all relevant resource use within that perspective. If the inclusion of a wider set of costs or outcomes is considered important and expected to significantly influence the results from any economic modelling undertaken, additional analyses will be carried out. Number of GP visits will be looked at in the evidence review but is not considered as a key outcome.
75.4	Nottingham University Hospitals NHS Trust	Appendix A	There is little quality information regarding the needs of carers/families, whilst this is important I do not know how this will be obtained without further audit, research.	Noted. This will be guided by the systematic review and GDG consensus.
76	Nutricia Clinical Care			
	Oxford Radcliffe Hospitals NHS Trust	GENERAL	We welcome NICE's recognition of the need for such a document to address these highly prevalent and lifestyle limiting issues	Thank you.

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			following critical illness. The scope is comprehensive and will highlight this under recognised and under researched area of patients needs. Concerns regarding the patient's ability to return to the workforce and the burden of prolonged emotional instability appear to be included. We hope that emphasis will be placed on how to deal with patients who utilise services out of the area (tertiary referrals) and continue to require access to these services on repatriation. Access to support services is problematic and the current model of delivery leaves many patients wanting for basic needs (i.e access to PT/OT on discharge for resulting musculoskeltal issues associated with CIP).	The guideline will identify the effective components of rehabilitation strategies. It will not address the service configuration and service delivery model of the strategies. However, implementation tools will be developed to assist local Trusts to set up their own services.
77	Paediatric Intensive Care Society		This organisation was approached but did not respond.	
78	Pennine Acute Hospitals NHS Trust		This organisation was approached but did not respond.	
79	Pernicious Anaemia Society, The		This organisation was approached but did not respond.	
80.0	Renal Association, The	General	With respect to the definition of the group of patients to be considered for rehabilitation whilst it would be ideal to be able to offer rehabilitation to all patients irrespective of their length of stay on the ICU. However there must be an element of pragmatism. At present there does not seem to be any particularly good screening tools for identifying those patients benefiting the most from rehabilitation. This was why there was so much discussion around the definition of the group to be covered by the guideline. If there are limited financial resources then it would seem more pragmatic to identify a group of patients who would benefit the most from rehabilitation. At present it does not appear to be clear which group of patients this would be.	Further specifications have been made in section 4.1.1 to 'level 2 and 3 Critical Care'
80.1	Renal Association, The	General	There has not been much discussion on the rehabilitation required for patients with organ specific disease. The incidence of acute kidney injury (AKI) has been estimated to occur in as many as 30% of ICU admissions. The mortality in this	Noted. This Scope is for General Rehabilitation after critical illness, the Scope is not set out to address organ-specific rehabilitation.

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			patient group ranges from 50-80%. These patients will include those who recover kidney function prior to requiring renal replacement therapy as well as those who did require renal replacement therapy. It should be recognized that the incidence of AKI is dependent upon the definition used and has been underreported in the past.	
80.2	Renal Association, The	General	From a recent four-year audit performed at St James's University Hospital 14% (n = 509) of ICU admissions required renal replacement therapy for AKI. ICU mortality was 55% (n = 282). 24% (n = 55) of patients discharged from the ICU were transferred for continuing care under renal specialists on the renal unit. Only 8% (n =5) of hospital survivors were dependent upon renal replacement therapy.	Noted. This Scope is for General Rehabilitation after critical illness, the Scope is not set out to address organ-specific rehabilitation.
80.3	Renal Association, The	General	From a renal physicians perspective caring for patients with critical illness on the ICU with established end-stage renal disease (ESRD) or (AKI) I would make the following specific recommendations for the group to consider: 1. Patients with complete recovery of kidney function following AKI probably do not require anything more specific than the general rehabilitation package that will be devised by NICE. 2. Patients with AKI whose renal function fails to recover completely but who are left with significant chronic kidney disease (I suggest CKD stage 4,5) as part of the rehabilitation package should be referred to a renal physician for continued assessment and care. These patients will need specialist dietary/nutritional support and advice. These patients need to be managed carefully in terms of their fluid balance and electrolytes.	Noted. This Scope is for General Rehabilitation after critical illness, the Scope is not set out to address organ-specific rehabilitation.

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			It is important these patients are identified and managed as per the NICE guidelines (draft) to slow the subsequent progression of renal disease. 3. Patients with AKI who remain dialysis dependent will require transfer to a renal unit for continuing renal replacement therapy. They will need the general rehabilitation package and require dietary/nutritional support. Careful management of fluid balance and electrolytes will be important in their rehabilitation. Failure of recovery of function will require preparation for long-term dialysis and early referral to a vascular surgeon (or transplant surgeon if peritoneal dialysis is considered). It is important to facilitate the establishment of long-term vascular access through a arteriovenous fistula. Continued dialysis through central venous catheters place the patient at risk of line sepsis in the future. Psychological support may be necessary to enable the patient to come to terms with long-term chronic disease. 4.Patients with established ESRD prior to admission to the ICU will need transfer to a renal unit and continuing nutritional support. There may be other issues regarding vascular access (potential loss of functioning arteriovenous fistula) that needs to be considered in terms of their rehabilitation and early referral to a vascular surgeon for assessment.	
81	Robert Jones & Agnes Hunt Orthopaedic & District Hospital NHS Trust		This organisation was approached but did not respond.	
82	Royal Brompton & Harefield NHS Trust	4.4 Key outcome measures	The outcome measures, LOS & mortality, are not very useful when looking at the rehabilitation aspect. I propose the Functional Independence Measure is used as this addresses clinical progression / improvement appropriately and is better than the Bartel Index.	Noted. The guideline intends to look at further impacts and long term outcomes in terms from rehabilitation therefore hospital length of stay and mortality are included. .The choice of which tools to be used for this particular outcome will be guided by the evidence review and GDG consensus.

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83	Royal College of General Practitioners		This organisation was approached but did not respond.	
84.0	Royal College of Nursing	3c	We agree that counselling and some times psychotherapy/ psychiatry support would help the patient's early recovery.	Noted.
84.1	Royal College of Nursing	3h	Use of Barthel index, Hospital Anxiety and Depression Scale and impact of Events scale are useful tools to assess the physical and psychological problems.	Noted. The choice of which tools to be used to assess physical and psychological morbidity will be guided by the evidence review and GDG consensus.
84.2	Royal College of Nursing	General	This document guideline is very useful in general. But it does not seem to address issues of the age of the patient. The care may be more specific if the patient is elderly (age 75 and above) with multiple problems.	Thank you. The question of specific subgroups will be guided by the evidence review.
85	Royal College of Paediatrics and Child Health		This organisation was approached but did not respond.	
86	Royal College of Pathologists		This organisation was approached but did not respond.	
87.0	Royal College of Physicians of London	General	The College believes the draft scope has been well prepared and reflects the views of the workshop held in Manchester on March 28th.	Thank you.
87.1	Royal College of Physicians of London	General	Key outcome measures and economic aspects are part of the scope and must take careful advice to allow the best selection of reliable and validated measures for this group of people. Although the preferred unit of cost effectiveness according to the guidelines manual is the QALY, the limitations of this measure are well known, particularly with reference to a population with significant levels of disability and some thought should be given to evaluating cost of care needs and their provision before and after interventions, and functional levels of activity before and after that are not usually captured by these or other popular health measures such as the Short Form 36.	Noted. The methods guide acknowledges that there are well documented methodological problems with QALYs and acknowledge that this is also true of other approaches. If there are not sufficient data to estimate QALYs gained, an alternative measure of effectiveness may be considered.
87.2	Royal College of Physicians of London	General	Developers of the guidelines are encouraged to construct pathways that support the referral of people with unmet rehabilitation need after a critical illness to specialists in Rehabilitation Medicine.	Noted. This guideline aims to review the effectiveness and cost-effective of screening/assessment tools and interventions for general rehabilitation after critical illness. The guideline does not cover service guidance but will make recommendations on appropriate

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				referrals.
87.3	Royal College of Physicians of London	4	This section describes the areas that will be addressed and those that will be excluded. It excludes those receiving palliative care, those who had critical care for a neurological or neurosurgical condition, and those who received critical care and did not develop critical illness. The last exclusion is something of an oxymoron and requires clearer definition. The second exclusion is more worrying because nationally, access to expert neurorehabilitation resources for individuals with neurological illness who have survived an ICU illness is not always available, and the needs of this group are often not recognised until some time after the acute illness, often when they have failed to reintegrate successfully into their social or working lives. This is an opportunity to capture the needs of this group who have had a neurological illness, perhaps a sub arachnoid haemorrhage or meningitis, who have made a full physical recovery but have hidden neuropsychological deficits. If identified by screening at a suitably early point in time they should be referred on to specialist neurorehabilitation services to allow access to an MDT and neuropsychology assessment and treatment, that may allow them to make a success of their return to their social and vocational activities. It is a wrong assumption that their needs are already met by existing pathways.	Noted. Section 4.1.2b has been modified to reflect this.
88	Royal College of Psychiatrists		This organisation was approached but did not respond.	
89	Royal College of Radiologists		This organisation was approached but did not respond.	
90.0	Royal College of Speech and Language Therapists	General	The RCSLT welcomes the draft scope document and looks forward to reviewing the guidelines later in the year.	Noted.
90.1	Royal College of Speech and Language Therapists	3 (b)	Muscle mass is also lost for patients who are not swallowing or communicating.	Noted. Changes have been made to reflect this in section 3
90.2	Royal College of Speech and Language Therapists	3 (c)	There is a recognised impact of being unable to communicate, to express needs etc	Noted. Changes have been made to reflect this in section 3
90.3	Royal College of Speech and Language Therapists	3 (e)	SLT input into rehabilitation is recognised as having an impact on length of stay and maximising rehabilitation potential both in terms of nutrition and hydration and communication.	This will be guided by the evidence review on the effectiveness and cost-effectiveness of rehabilitation strategies.
90.4	Royal College of Speech and Language Therapists	3 (f)	Follow up clinics are vital but currently PCTs do not wish to apply for them.	Noted. This guideline aims to review the effectiveness and cost-effective of screening/assessment tools and

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			The RCSLT recommends that this guideline include evidence for follow-up clinics.	interventions for general rehabilitation after critical illness. The guideline does not cover service guidance but provision of appropriate services (rather than specific clinics) will be recommended.
90.5	Royal College of Speech and Language Therapists	4.1.2 (b) and ref to 4.3	This point assumes that rehabilitation to these specialist groups is currently optimal, however it is widely variable across different sites. This is also an artificial distinction / grouping as many patients who require critical care for a neurological or neurosurgical condition are situated on general ITUs and should come under the remit of this guideline. These are precisely the particular patients who require cognitive / psychological input!	Noted. Section 4.1.2b has been modified to reflect this.
90.6	Royal College of Speech and Language Therapists	4.3 (b)	The RCSLT recommends that communication and swallowing are included in the specifics of physical, psychological and cognitive dysfunction.	Noted. Changes have been made to reflect this in section 3
90.7	Royal College of Speech and Language Therapists	4.3 (d)	The information needs of adults must include communication and swallowing problems.	Noted. Changes have been made to reflect this in section 3
91	Royal Liverpool and Broadgreen NHS Trust		This organisation was approached but did not respond.	
92	Royal Society of Medicine		This organisation was approached but did not respond.	
93	SACAR		This organisation was approached but did not respond.	
94	Sandwell PCT		This organisation was approached but did not respond.	
95	Scottish Intercollegiate Guidelines Network (SIGN)		This organisation was approached but did not respond.	
96.0	Sheffield PCT	General	When do we need to consider the Mental Capacity Act implications in the person's recovery period? E.g If the person has been unconscious and decisions' were made in their best interests Due to lasting disability and incapacity do they need to be assessed for continuing care and do they have capacity to do so?	Noted. This will be covered in the Introduction section of the guideline.
96.1	Sheffield PCT	General	Need to consider most appropriate treatment in the least invasive setting E.g. is an intermediate care setting or someone's own home more	The guideline will identify the effective components of rehabilitation strategies. It will not address the service configuration and service delivery model of the

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			appropriate than a hospital setting for ongoing rehabilitation? What parameters within a risk assessment should we use to determine place of care and should this involve primary and secondary care multi disciplinary staff to achieve optimal outcomes for recovery?	strategies. However, implementation tools will be developed to assist local Trusts to set up their own services.
96.2	Sheffield PCT	General	Need to consider longer term care planning and where the responsibility lies eg should it form part of Quality outcomes framework for GPs when next revised? Or Should PCTs consider this in their workforce planning with commissioners?	The guideline will identify the effective components of rehabilitation strategies. It will not address the service configuration and service delivery model of the strategies. However, implementation tools will be developed to assist local Trusts to set up their own services.
97.0	Sheffield Teaching Hospitals NHS Foundation Trust	General	There is no mention of nutritional screening or assessment of weight loss and needs to include support / information for GPs and Community Teams in the scope.	Where appropriate, the guideline will cross reference to another published NICE guideline: Nutrition support in adults (CG32). Extra information on relevant other NICE guidelines has been added in section 4.6.1.
97.1	Sheffield Teaching Hospitals NHS Foundation Trust	3i & 4.3b	The timing of assessment and intervention is a crucial element and some reference needs to be made about the role of the MDT in the ITU in providing early assessment and intervention, for example, individual patient case management.	The guideline will identify the effective components of rehabilitation strategies. It will not address the service configuration and service delivery model of the strategies. However, implementation tools will be developed to assist local Trusts to set up their own services.
98	Sherwood Forest Hospitals NHS Foundation Trust		This organisation was approached but did not respond.	
99	Social Care Institute for Excellence (SCIE)		This organisation was approached but did not respond.	
100	Society of British Neurological Surgeons		This organisation was approached but did not respond.	
101	South Manchester University Hospitals NHS Trust		This organisation was approached but did not respond.	
102	South Tees Hospitals NHS Trust		This organisation was approached but did not respond.	
103	Southport & Ormskirk Hospital NHS Trust		This organisation was approached but did not respond.	
104.0	Surrey Wide Critical Care Network	General	Need clarity with regard to the provision of psychological rehab and the minimal qualification required. This is often done by ICU nurses as there is no one else available.	Noted. The guideline will define the skills needed to carry out rehabilitation but will not make recommendation on who with what qualification should be delivering the rehabilitation. This is the role of The Royal Colleges to set up professional standards.

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104.1	Surrey Wide Critical Care Network	General	The guideline needs to define a minimum standard of expertise in dealing with mental health issues	Noted. The guideline will define the skills needed to carry out rehabilitation but will not make recommendation on who with what qualification should be delivering the rehabilitation. This is the role of The Royal Colleges to set up professional standards.
104.2	Surrey Wide Critical Care Network	General	Needs to be more specific in relation to length of stay in ICU	Further specifications have been made in section 4.1.1 to 'level 2 and 3 Critical Care' so that it is patient-focused (ie. those who would benefit most from rehabilitation), instead of being time-focused.
104.3	Surrey Wide Critical Care Network	General	Needs to be more specific with regard to ongoing care in relation to long term problems like renal failure, liver disease, etc	Noted. This will be guided by evidence review and GDG consensus. Therefore, the Scope is not specific at this point.
104.4	Surrey Wide Critical Care Network	General	Needs to define strategies for follow up clinics/counselling/access for investigation into other complications	Noted. This will be guided by evidence review and GDG consensus. Therefore, the Scope is not specific at this point.
104.5	Surrey Wide Critical Care Network	General	Needs to define access to dieticians, speech and language therapists, physiotherapists, etc	Noted. This will be guided by evidence review and GDG consensus. Therefore, the Scope is not specific at this point.
104.6	Surrey Wide Critical Care Network	General	Overall impression is that the scope seems "woolly" and needs definition and specificity	Noted. This will be guided by evidence review and GDG consensus. Therefore, the Scope is not specific at this point.
105.0	Sussex Critical Care Network	General	Overall a very welcome piece of work and will hopefully produce some useful guidelines to move this important topic forward	Thank you.
105.1	Sussex Critical Care Network	General	When rehabilitation strategies are discussed throughout the document, would it be beneficial to include 'communication' and 'swallow dysfunction' when outlining 'physical, psychological and cognitive dysfunction'? This is based on patients being at risk of communication difficulties and swallow dysfunction following critical illness.	Noted. Changes have been made to reflect this in section 3
105.2	Sussex Critical Care Network	General	As its recovery from critical illness not intensive care, is it right to specify a spell on ICU? We would suggest replacing references to ITU or Intensive Care with Critical Care to avoid confusion	Noted. The technical team will revise the Scope.
105.3	Sussex Critical Care Network	3D	Would the term 'executive functions' be more appropriate than 'problem solving' to encapsulate the broader range of cognitive dysfunctions?	Noted. The technical team will revise the Scope.
105.4	Sussex Critical Care Network	3H	Would it be beneficial to include 'cognitive and communication	Noted. Changes have been made to reflect

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			problems' in addition to 'psychological and physical problems'? Relevant cognitive tools may include the Rivermead Behavioural Memory Test.	communication issue in section 3.
105.5	Sussex Critical Care Network	4.1.2b	We would question that neurosciences can be omitted on the assumption that rehabilitation is already part of their care pathway. They actually provide one of the biggest rehabilitative challenges locally.	Noted. Section 4.1.2b has been modified to reflect this.
106.0	Tees Valley and South Durham Critical Care Network	4.3 e	Very helpful as few believe that the care they are delivering is ineffective	Noted.
106.1	Tees Valley and South Durham Critical Care Network	Overall	A very good and concise scoping document	Thank you.
107	The Intercollegiate Board for Training in Intensive Care Medicine		This organisation was approached but did not respond.	
108	University Hospital Birmingham NHS Foundation Trust		This organisation was approached but did not respond.	
109	Walsall Hospital NHS Trust		This organisation was approached but did not respond.	
110	Walton Centre for Neurology & Neurosurgery		This organisation was approached but did not respond.	
111	Welsh Assembly Government		This organisation was approached but did not respond.	
112	Welsh Scientific Advisory Committee (WSAC)			
113.0	York Hospitals NHS Foundation Trust	**1**	Guideline title- Rehabilitation **after** period of critical illness- the word after needs clarifying-what stage of rehabilitation is being covered.	Further specifications have been made in section 4.1.1 to 'level 2 and 3 Critical Care'. Regarding timing for rehabilitation, this will be guided by the evidence review (as question 4 in appendix A).
113.1	York Hospitals NHS Foundation Trust	**3 c)**	Role of patient diaries not mentioned-needs to be big role in psychological rehabilitation.	Noted. This will be guided by evidence review and GDG consensus.
113.10	York Hospitals NHS Foundation Trust	**General**	The rehabilitation of critically ill patients is a very long and complex process that needs breaking down and this needs to be made much clearer which parts of the process that will be covered and addressed separately. E.g. 1) Day one ICU and acute critical illness and early identification of rehabilitation needs and early rehabilitation on ICU. 2) Progressing and managing transition from ICU to ward rehabilitation. 3) Managing discharge and follow up rehabilitation of patients following critical illness. 4) Community	Currently as stated in section 3f and 3g – rehabilitation strategies differ in nature and the composition varies widely. The technical team expects the evidence review will provide clearer picture of what is meant by rehabilitation strategies and the optimal timing for rehabilitation. Moreover, the guideline will only identify the effective components of rehabilitation strategies. It will not address the service configuration and service

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			rehabilitation. Each of these stages need addressing separately as they will have very different needs in terms of assessment and rehabilitation strategies.	delivery model of the strategies. However, implementation tools will be developed to assist local Trusts to set up their own services.
113.2	York Hospitals NHS Foundation Trust	**3 e)**	What is meant by rehabilitation strategies after discharge from critical care? What setting, ward? Community? What is meant by rehabilitation strategies, need to be clearer, is it goal setting?	Noted. As stated in section 3f and 3g – rehabilitation strategies differ in nature and the composition varies widely. The technical team expects the evidence review will provide clearer picture of what is meant by rehabilitation strategies.
113.3	York Hospitals NHS Foundation Trust	**4.1.1**	Specify age covered under adult.	The question of specific age-related subgroups (ie. elderly patients) will be guided by the evidence review.
113.4	York Hospitals NHS Foundation Trust	**4.2 a)**	High dependency unit not specified	Further specifications have been made in section 4.1.1 to 'level 2 and 3 Critical Care'. The scope intends to be patient-focused (ie. those who would benefit most from rehabilitation), instead of being unit-focused.
113.5	York Hospitals NHS Foundation Trust	**4.3 a), b)**	Appears to describe a process of assessing patients post critical illness. Assessment however needs to be started on day of admission, looking at assessment from day one of critical illness and diagnostic and assessment tools need to be appropriate for assessing critically ill patients from day one.	Noted. The technical team will revise the Scope to reflect this.
113.6	York Hospitals NHS Foundation Trust	**4.4 a)**	Is Mortality an appropriate outcome measure? Are we not looking more at quality of life, readmissions etc.	Noted. The technical team will revise the Scope to reflect this.
113.7	York Hospitals NHS Foundation Trust	**General**	Scope appears to look at identifying and screening patients in retrospect who have developed a rehabilitation need secondary to a period of critical illness **but** doesn't appear to address assessing rehabilitation needs **during** the ICU stay and critical illness.	The 'optimal timing' of when identification should be carried out will be guided by evidence review.
113.8	York Hospitals NHS Foundation Trust	**General**	Does not appear to cover risk assessing of the critically ill patient for early rehabilitation. Is this guideline meant to guide the early rehabilitation of the critically ill patient on ICU?	Noted. Risk stratification will be incorporated in the review of evidence as stated in section 4.3a. However, it is outside the remit of the scope in terms of reviewing risk factors/prediction models around each relevant morbidity.

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113.9	York Hospitals NHS Foundation Trust	**General**	The term 'Rehabilitation strategy' is not specific enough and needs breaking down. Is it development of multidisciplinary paperwork as part of a pathway? Is it a specific MDT careplan? Is it a personalised care plan for community self management of rehabilitation? A rehabilitation strategy will take a very different form depending on at what point the rehabilitation process the strategy is being developed for.	Noted. As stated in section 3f and 3g – rehabilitation strategies differ in nature and the composition varies widely. The technical team expects the evidence review will provide clearer picture of what is meant by rehabilitation strategies. Moreover, the guideline will only identify the effective components of rehabilitation strategies. It will not address the service configuration and service delivery model of the strategies. However, implementation tools will be developed to assist local Trusts to set up their own services.