NICE National Institute for Health and Care Excellence

Appendix A: Stakeholder consultation comments table

2018 surveillance of Rehabilitation after critical illness in adults (2009)

Consultation dates: 11 to 24 May 2018

Do you agree with the proposal to not update the guideline?			
Stakeholder	**Overall response**	**Comments**	**NICE response**
British Association of Critical Care Nurses	Yes	No comments provided	Thank you for your response.
Sheffield Teaching Hospitals NHS Foundation Trust	No	We acknowledge the stated proposal not to update the guideline at this time but to review following publication of scopes of two other planned clinical guidelines. As such we agree with the rationale not to update the guideline at present but with the intention to conduct an exceptional surveillance review at later date following other planned publications.	Thank you for your comments and for agreeing with the no update (at present) decision. In relation to ensuring information is given to GPs after discharge and promoting routine GP follow-up post-discharge, please note that the current recommendation 1.1 on key principles of care states that key elements of the coordination of care are to "Liaise with primary/community care for the functional reassessment at 2–3 months after the patient's discharge from critical care. Ensure

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		However, we feel there are number of areas which require attention and would urge the GDG to take these comments under review. We recommend the additions to the existing guideline concerning the provision of information (a) specifically to GPs following the patients discharge from hospital, and (b) specifically available to support children with relatives in critical care. In addition to a comment above regarding provision of information specifically to the patient's GP, we would welcome recommendations that promote routine GP follow-up after hospital discharge for patients following an episode of critical illness. As part of the follow-up review process at 2-3 months after discharge we would suggest specific attention is recommended to addressing return to work (for those whom it is applicable). We acknowledge previously highlighted barriers or limitations to prescribing that one or several specific clinical outcome measures are used for all patients. However, we do feel there is place to state that "outcomes should be measured for a number of core domains: physical function including ADL function;	information, including documentation, is communicated between hospitals and to other hospital-based or community rehabilitation services and primary care services." We have noted your suggestion on recommendations concerning information to support children with relatives in critical care; and this will be considered in the exceptional surveillance review, if it is not covered within the scopes of "Rehabilitation for chronic neurological disorders including traumatic brain injury" and "Rehabilitation after traumatic injury". Thank you for your comment concerning return to work. There is a NICE guideline on Workplace health: long-term sickness absence and incapacity to work (NICE guideline PH19) which would include actions taken to address the needs of employees who have been absent due to a critical illness. This guideline is planned for an update, and we will pass your comments on to the guideline development team responsible for the NICE guideline PH19 update. Thank you for your suggestions concerning outcomes that should be assessed. Physical functioning, including activities of daily living, and psychological wellbeing are currently covered in recommendations 1.20 and 1.23. Neurocognitive functioning is alluded to in the examples provide in Table 1 when discussing checking for neurological injury. While patient reported outcome measures (PROMS) are not explicitly discussed, we have recommend (as part of the surveillance process) that Intermediate

		neurocognitive function; psychological wellbeing; patient-reported quality of life; patient experience". We would welcome greater detail and clarification on commissioning guidance for the rehabilitation pathway.	care including reablement (NICE guideline NG74) is cross-referenced in recommendation 1.21. NICE guideline NG74 highlights the need to take a person-centred approach to assessment and delivery of care, including the use of PROMS.
The Association of Chartered Physiotherapists in Respiratory Care (ACPRC)	No	We acknowledge the stated proposal not to update the guideline at this time but to review following publication of scopes of two other planned clinical guidelines. As such we agree with the rationale not to update the guideline at present but with the intention to conduct an exceptional surveillance review at later date following other planned publications. However, we feel there are number of areas which require attention and would urge the GDG to take these comments under review. We recommend the additions to the existing guideline concerning the provision of information (a) specifically to GPs following the patients discharge from hospital, and (b) specifically available to support children with relatives in critical care. In addition to a comment above regarding provision of information specifically to the patient's GP, we would welcome recommendations that promote routine GP	Thank you for your comments and for agreeing with the no update, at present, decision. In relation to ensuring information is given to GPs after discharge and promoting routine GP follow-up post-discharge, please note that the current recommendation on key principles of care states that key elements of the coordination of care are to "Liaise with primary/community care for the functional reassessment at 2–3 months after the patient's discharge from critical care. Ensure information, including documentation, is communicated between hospitals and to other hospital-based or community rehabilitation services and primary care services." We have noted your suggestion on recommendations concerning information to support children with relatives in critical care; and this will be considered in the exceptional surveillance review, if it is not covered within the scopes of "Rehabilitation for chronic neurological disorders including traumatic brain injury" and "Rehabilitation after traumatic injury". Thank you for your comment concerning return to work. There is a NICE guideline on Workplace health: long-term sickness absence

		follow-up after hospital discharge for patients following an episode of critical illness. As part of the follow-up review process at 2-3 months after discharge we would suggest specific attention is recommended to addressing return to work (for those whom it is applicable). We acknowledge previously highlighted barriers or limitations to prescribing that one or several specific clinical outcome measures are used for all patients. However, we do feel there is place to state that "outcomes should be measured for a number of core domains: physical function including ADL function; neurocognitive function; psychological wellbeing; patient-reported quality of life; patient experience". We would welcome greater detail and clarification on commissioning guidance for the rehabilitation pathway.	and incapacity to work (NICE guideline PH19) which would include actions taken to address the needs of employees who have been absent due to a critical illness. This guideline is planned for an update, and we will pass your comments on to the guideline development team responsible for the NICE guideline PH19 update. Thank you for your suggestions concerning outcomes that should be assessed. Physical functioning, including activities of daily living, and psychological wellbeing are currently covered in recommendations 1.20 and 1.23. Neurocognitive functioning is alluded to in the examples provide in Table 1. While patient reported outcome measures (PROMS) are not explicitly discussed, we have recommend (as part of the surveillance process) that Intermediate care including reablement (NICE guideline NG74) is cross-referenced in recommendation 1.21. NICE guideline NG74 highlights the need to take a person-centred approach to assessment and delivery of care, including the use of PROMS.
British Dietetic Association (Critical Care Specialist Group)	No	We feel that the NICE guidelines should be updated particularly in relation to nutrition as nutrition issues receive relatively little attention in the existing guideline. While there is still only a small amount of research that has been done in this area it is known that malnutrition is prevalent among critically ill patients, and in one study	Thank you for your comments. Please note that as there is an existing NICE guideline on Nutrition support in adults (NICE guideline CG32) that is cross-referenced in NICE guideline CG83 (recommendation 1.6) and which covers caring for adults who are malnourished or at risk of malnutrition in hospital, this would not be considered as an area for update

		was found in 43% of general ICU admissions (1) The nutritional status of patients frequently deteriorates further during the ward phase of care (2). Studies by Merriweather (3) and Rowles et al (4) found oral intake to be inadequate in the post-ICU phase. Failure to meet nutritional requirements is likely to have a negative impact on muscle mass and physical or functional ability (5) For the post ICU patient, good nutritional care is fundamental to the recovery process. The process of nutritional recovery has multiple linked elements including appetite, physical ability to eat, personal preferences and emotional influences. Superimposed on these are the systems that deliver nutrition to patients. If all these form links in a chain that lead to nutritional recovery it is entirely possible that a single break in the chain could disrupt the benefits from all the other elements. The importance of these factors influencing nutritional intake should be recognised and addressed in ICU survivors in order to maximise nutritional intake 1.Giner M, Laviano A, Meguid MM, Gleason JR. In 1995 a correlation between malnutrition and poor outcome in critically ill patients still exists. Nutrition. 1996;12(1):23-	within NICE guideline CG83. We have noted your comments about ICU survivors and an individualised model of care to address organisational and patient related factors that influence nutritional recovery and will ensure this is addressed when NICE guideline CG32 has its next surveillance review; and that the references you have provided are considered.

		29. http://www.ncbi.nlm.nih.gov/pubmed/8838832. Accessed April 20, 2018. 2. Nematy M, O'Flynn JE, Wandrag L, et al. Changes in appetite related gut hormones in intensive care unit patients: a pilot cohort study. Crit Care. 2006;10(1):R10. doi:10.1186/cc3957 3. Merriweather JL. Exploration of the factors that influence nutritional recovery following critical illness : a mixed methods study. July 2014. https://www.era.lib.ed.ac.uk/handle/1842/9571. Accessed April 20, 2018. 4. Rowles A, Langan A, Bear DE. SUN-P019: Oral Intake and Appetite in the Intensive Care Unit. Clin Nutr. 2016;35(Suppl 1):S51. doi:10.1016/S0261-5614(16)30362-4 5. Bear DE, Wandrag L, Merriweather JL, Connolly B, Hart N, Grocott MPW. The role of nutritional support in the physical and functional recovery of critically ill patients: a narrative review. Crit Care. 2017;21(1):226. doi:10.1186/s13054-017-1810-2	

		6. Merriweather J, Smith P, Walsh T. Nutritional rehabilitation after ICU - does it happen: a qualitative interview and observational study. J Clin Nurs. 2014;23(5-6):654-662. doi:10.1111/jocn.12241 Work with ICU survivors suggests that improvements in nutritional rehabilitation require an individualised model of care to address the identified organisational and patient related factors that influence nutritional recovery (3). This approach challenges the traditional approach to nutritional care and requires service re-design to address the multiple potential barriers to nutritional recovery. This is not specifically covered in the NICE Guidelines 'Nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition' which are referred to in NICE83. It is known that poor appetite and nausea are barriers to eating in ICU patients (7). A qualitative study identified multiple factors that contributed to patients' failure to achieve nutritional goals (6,8). Analysis of sequential interviews and observations revealed a number of themes including nutritional care delivery failures such as the inflexibility of hospital meals, failure to deliver nutritional supplements and lack of staff knowledge about critical illness related issues. Patient related	

		factors that emerged included physiological and psychosocial issues such as poor appetite, early satiety, taste changes, low mood and depression. Patients also experienced social isolation and struggled with lack of familiar food and routine. The identified factors that influence nutritional recovery interlink serving to increase the complexity of nutritional problems for this patient group. 7. Peterson SJ, Tsai AA, Scala CM, Sowa DC, Sheean PM, Braunschweig CL. Adequacy of Oral Intake in Critically Ill Patients 1 Week after Extubation. J Am Diet Assoc. 2010;110(3):427-433. doi:10.1016/j.jada.2009.11.020 8. Merriweather JL, Salisbury LG, Walsh TS, Smith P. Nutritional care after critical illness: a qualitative study of patients' experiences. J Hum Nutr Diet. 2016;29(2):127-136. doi:10.1111/jhn.12287 We note that that an exceptional surveillance review is proposed to be undertaken once the guidelines 'Rehabilitation for chronic neurological disorders including traumatic brain injury' and Rehabilitation after traumatic injury' have been published but our concern is	

		that they may also contain limited attention to nutritional issues.	
Do you have any comments on areas excluded from the scope of the guideline?			
Stakeholder	**Overall response**	**Comments**	**NICE response**
British Association of Critical Care Nurses	No	No comments provided	Thank you for your response.
Sheffield Teaching Hospitals NHS Foundation Trust	Yes	The current guideline does not adequately address the key governance aspects of care delivery. We feel it should be within the scope of this guideline to recommend services should have agreed local guidance/policy governing when early physical rehabilitation/early mobilisation may be safely. Additionally, we feel it should be within the scope of this guideline to make recommendations on the overarching skills & competency requirements for staff delivering rehabilitation following critical illness. and training/education of staff involved in the rehabilitative process. Additionally, we feel it should be within the scope of this guideline to make recommendations on the overaching strategy to training/education of staff involved in the rehabilitation process or pathway. A specific aspect of physical morbidity which is not addressed in the current guideline is the assessment of	Thank you for your comments. Recommendations concerning when early physical rehabilitation/early mobilisation is safe would be included in the scope, under “Optimum timing for assessment and intervention to treat physical and non-physical dysfunction, including psychological and cognitive dysfunction, associated with critical illness.’ NICE guidelines no longer provide recommendations concerning skills, training or education that staff are expected to have. It is expected that staff are trained/educated in a way to ensure that what is recommended can be achieved. Thank you for your comment on reduced bone density/increased risk of fractures following a critical illness. If there is evidence to indicate that patients should be referred for screening of acquired osteoporosis/osteopenia as a result of their critical illness, then

		reduced bone density and increased fracture risk following a period of critical illness. A number of papers have been published on this particular matter. We would advise that consideration is given to the need to refer patients for screening of acquired osteoporosis/osteopenia as a result of their critical illness event. This may be at discharge from hospital or several months after discharge. We feel it would be within the scope of this guideline to make recommendations on a strategy to improve large scale data collation on outcomes following critical illness. Currently, there are limitations to the profile of the Case Mix Programme conducted by the Intensive Care National Audit & Research Centre (ICNARC) as insufficient data is collected on long-term outcomes following an episode of critical illness (eg. return to employment; social care costs; hospital readmission rates; presence of physical or non-physical morbidity at critical care or hospital discharge or at later timepoints following hospital discharge). There are recommendations or models which may be drawn from other similar areas of healthcare (eg. UK Rehabilitation Outcomes Collaborative; WHO International Classification of Functioning). Services should be encouraged through published recommendations to put systems and processes into place to achieve large-scale collation and analysis of data	this would be within scope under "effective components of rehabilitation strategies". Thank you for your suggestions on data collection, however data collection requirements are not currently within scope of the guideline.

		surrounding rehabilitation outcomes following critical illness.	
The Association of Chartered Physiotherapists in Respiratory Care (ACPRC)	Yes	The current guideline does not adequately address the key governance aspects of care delivery. We feel it should be within the scope of this guideline to recommend services should have agreed local guidance/policy governing when early physical rehabilitation/early mobilisation may be safely. Additionally, we feel it should be within the scope of this guideline to make recommendations on the overarching skills & competency requirements for staff delivering rehabilitation following critical illness. and training/education of staff involved in the rehabilitative process. Additionally, we feel it should be within the scope of this guideline to make recommendations on the overaching strategy to training/education of staff involved in the rehabilitation process or pathway. A specific aspect of physical morbidity which is not addressed in the current guideline is the assessment of reduced bone density and increased fracture risk following a period of critical illness. A number of papers have been published on this particular matter. We would advise that consideration is given to the need to refer patients for screening of acquired osteoporosis/osteopenia as a result of their critical illness event. This may be at discharge from hospital or several months after discharge.	Thank you for your comments. Recommendations concerning when early physical rehabilitation/early mobilisation is safe would be included in the scope, under “Optimum timing for assessment and intervention to treat physical and non-physical dysfunction, including psychological and cognitive dysfunction, associated with critical illness.’ It would be up to services to use related recommendations to inform local policy. NICE guidelines no longer provide recommendations concerning skills, training or education that staff are expected to have. It is expected that staff are trained/educated in a way to ensure that what is recommended can be achieved. Thank you for your comment on reduced bone density/increased risk of fractures following a critical illness. If there is evidence to indicate that patients should be referred for screening of acquired osteoporosis/osteopenia as a result of their critical illness, then this would be within scope under “effective components of rehabilitation strategies”. Data collection requirements are not currently within scope of the guideline.

		We feel it would be within the scope of this guideline to make recommendations on a strategy to improve large scale data collation on outcomes following critical illness. Currently, there are limitations to the profile of the Case Mix Programme conducted by the Intensive Care National Audit & Research Centre (ICNARC) as insufficient data is collected on long-term outcomes following an episode of critical illness (eg. return to employment; social care costs; hospital readmission rates; presence of physical or non-physical morbidity at critical care or hospital discharge or at later timepoints following hospital discharge). There are recommendations or models which may be drawn from other similar areas of healthcare (eg. UK Rehabilitation Outcomes Collaborative; WHO International Classification of Functioning). Services should be encouraged through published recommendations to put systems and processes into place to achieve large-scale collation and analysis of data surrounding rehabilitation outcomes following critical illness.	
British Dietetic Association (Critical Care Specialist Group)	No	No comments provided	Thank you for your response.
Do you have any comments on equalities issues?			
Stakeholder	**Overall response**	**Comments**	**NICE response**

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees

British Association of Critical Care Nurses	No	No comments provided	Thank you for your response.
Sheffield Teaching Hospitals NHS Foundation Trust	Yes	We wish to highlight an inequality in rehabilitation provision and accessibility between those severe disability as a result of [non-traumatic injury] critical illness versus severe disability as a result of traumatic injury. Those with severe disabling illness or injury following trauma have more clearly identified access to 'specialist rehabilitation services' (eg. Brain Injury, Spinal Injury, Burns). However, many patients will acquire equally severe and complex disability following critical illness not related to trauma. At present, this guidance does not support access to 'specialist rehabilitation services' following critical illness. We feel this specific aspect should be addressed and a clearly identifiable pathway should be advocated for a defined subgroup of this population so they make access specialist rehabilitation services as defined in relevant trauma guidance. This would not be the case for all patients, only a proportion.	Thank you for your comments concerning access to specialist rehabilitation services. However, we think the guideline recommendations do support access to specialist rehabilitation services for all patients following a critical illness, whether resulting from a traumatic injury or not, where appropriate. Recommendation 1.1: "To ensure continuity of care, healthcare professional(s) with the appropriate competencies should coordinate the patient's rehabilitation care pathway". This specifies that "The healthcare professional(s) may be intensive care professional(s) or, depending on local arrangements, any appropriately trained healthcare professional(s) from a service (including specialist rehabilitation medicine services) with access to referral pathways and medical support (if not medically qualified)." Recommendation 1.25: Based on the functional reassessment. Refer the patient to the appropriate rehabilitation or specialist services if: o the patient appears to be recovering at a slower rate than anticipated, according to their rehabilitation goals, or o the patient has developed unanticipated physical and/or non-physical morbidity that was not previously identified.

			Evidence for specialist rehabilitation services for people with non-traumatic critical illnesses may be looked at as part of the exceptional review that will be conducted once the scopes for the 'Rehabilitation for chronic neurological disorders including traumatic brain injury' and 'Rehabilitation after traumatic injury' NICE guidelines are available. However it is outside the scope of NICE guideline CG83 to address service configuration and delivery of strategies.
The Association of Chartered Physiotherapists in Respiratory Care (ACPRC)	Yes	We wish to highlight an inequality in rehabilitation provision and accessibility between those severe disability as a result of [non-traumatic injury] critical illness versus severe disability as a result of traumatic injury. Those with severe disabling illness or injury following trauma have more clearly identified access to 'specialist rehabilitation services' (eg. Brain Injury, Spinal Injury, Burns). However, many patients will acquire equally severe and complex disability following critical illness not related to trauma. At present, this guidance does not support access to 'specialist rehabilitation services' following critical illness. We feel this specific aspect should be addressed and a clearly identifiable pathway should be advocated for a defined subgroup of this population so they make access specialist rehabilitation services as defined in relevant trauma guidance.	Thank you for your comments concerning access to specialist rehabilitation services. However, we think the guideline recommendations do support access to specialist rehabilitation services for all patients following a critical illness, whether resulting from a traumatic injury or not, where appropriate. Recommendation 1.1: "To ensure continuity of care, healthcare professional(s) with the appropriate competencies should coordinate the patient's rehabilitation care pathway". This specifies that "The healthcare professional(s) may be intensive care professional(s) or, depending on local arrangements, any appropriately trained healthcare professional(s) from a service (including specialist rehabilitation medicine services) with access to referral pathways and medical support (if not medically qualified)." Recommendation 1.25: Based on the functional reassessment.

		This would not be the case for all patients, only a proportion.	Refer the patient to the appropriate rehabilitation or specialist services if: o the patient appears to be recovering at a slower rate than anticipated, according to their rehabilitation goals, or o the patient has developed unanticipated physical and/or non-physical morbidity that was not previously identified.
British Dietetic Association (Critical Care Specialist Group)	No	No comments provided	Thank you for your response.

Department of Health and Social Care

I wish to confirm that the Department of Health and Social Care has no substantive comments to make, regarding this proposal.

Royal College of Nursing

This is just to let you know that the feedback I have received from nurses caring for people undergoing rehabilitation after critical illness suggests that there is no additional comments to submit to inform on the surveillance consultation of the above guidelines.