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Responding to COVID-19 and beyond:

A framework for assessing early rehabilitation needs following treatment in intensive care

National Post-Intensive Care Rehabilitation Collaborative

Version 1

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Responding to Covid-19 and beyond:

A framework for assessing early rehabilitation needs following treatment in intensive care

National Post-Intensive Care Rehabilitation Collaborative

The National Post-Intensive Care Rehabilitation Collaborative is a multi-professional group from a wide range of backgrounds with expertise in the rehabilitation and support of patients following treatment in intensive care.

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Supported by: Ganesh Suntharalingam, Sandy Mather and Asha Abdillahi, Intensive Care Society	

The National Post-Intensive Care Rehabilitation Collaborative has assembled a collective that exemplifies the multi-professional ethic common to both modern intensive care and rehabilitation. We are committed to further action to improve functional outcomes for patients afflicted in the COVID-19 pandemic that will ultimately improve outcomes for all patients requiring rehabilitation support. Further work will undoubtedly present challenges and require collaboration across multiple partners and networks.

Index

Background

The COVID-19 pandemic has challenged critical care units across the United Kingdom. As of 28 May 2020, more than 9347 patients with confirmed COVID-19 have been admitted to critical care units in England, Wales and Northern Ireland over an eleven week period (1). Resources have been considerably constrained, affecting patient management strategies. Over 1285 patients were last reported as still receiving critical care and many more remain on inpatient wards.

Up to half of critical care patients experience physical, psychological and cognitive compromise, collectively known as Post-Intensive Care Syndrome or PICS (2). Some will recover quickly with few long-term sequalae, while others will follow a slower trajectory requiring ongoing support. At this point in time, there is no evidence to suggest that the burden of survivorship (PICS) is any different for patients with COVID-19. Some organ specific phenomena may emerge, but these will occur in conjunction with aspects of survivorship.

Outcomes for these patients can be improved when needs are identified sufficiently early to enable effective support to be put in place (3). However, there is significant variation in practice and available expertise across NHS Trusts. A need exists to develop a national framework that is applicable across all Trusts, to support hospitals that have scanty support services, reduce variation and improve patient outcomes.

In April 2020 the Intensive Care Society (ICS) convened a national group – the National Post-Intensive Care Rehabilitation Collaborative (subsequently referred to as the Collaborative) – consisting of over thirty multi-professionals. They convened over five sessions to generate discussion and make practical recommendations to facilitate early post-intensive care assessment and support. Representative groups included rehabilitation specialists; allied health professionals including physiotherapists, occupational therapists, speech and language therapists, dieticians, psychologists, related fields such as ear, nose and throat (ENT); patient representatives and the intensive care community. National bodies provided leadership - the Intensive Care Society, British Society of Rehabilitation Medicine and UCL Partners.

This report is the initial output of that group. The principles and pathways outlined here are transferrable for all patients following a critical care stay, no matter the precipitating illness. Following the multi-professional meetings outlined above, the principles and pathways were presented to patient representative groups to ensure that the approach remained patient centred. This was received positively, with a critical illness survivor commenting *“The plan of action looks good-…I just wish we had been given an opportunity like this at the time.”*

Alignment with emerging national Critical Care and Rehabilitation Guidance

It is acknowledged that the NICE guidance (CG83) from 2009 (3) established the principles and necessity to commence rehabilitation as soon as feasible in the critical care environment. The subsequent Quality Standards (2017) provided the critical care community with clear focus in the delivery of the NICE guidance, outlining the operational details

and measurements required. However, local and regional feedback has often reported complexity in sustaining the patient pathway across acute, community and primary care.

These challenges were recently reiterated through in a Faculty of Intensive Care Medicine (FICM) publication (5), where the necessity to provide follow-up outpatient services was reinforced. The multi-disciplinary nature of this service was emphasized, and a variety of delivery strategies were outlined including the use of virtual consultations for individuals and/or groups.

A recent publication within the rehabilitation medicine community (6) outlines the rehabilitation pathway across the range of current provision (Figure 1). This pathway includes critical care and locally developed “Step Down/Triage” units where patients can receive expert input to direct their onward care into further rehabilitation streams. This pathway aligns to the FICM pathway (Figure 2) where patients require screening and assessments to understand how to maximise their rehabilitation potential.

Both the BSRM and FICM articulate the uncertainty around the proportion of patients recovering from COVID-19 who will require the various rehabilitation pathways currently available and how best to screen patients for more detailed “profession specific” assessments. It is acknowledged that not all critical care services have access at all times to the highly skilled multi professional team required to assess and treat recovering patients The challenge is to ensure that patients can be screened in a functional, practical and feasible way in order to signal when specialist referrals are required.

This work seeks to support the critical care community with assessment tools that can be deployed at specific patient transition stages to 1) enable ongoing rehabilitation interventions, and 2) ensure the most appropriate professional is involved with each patient’s care in a timely and effective way.

Aims of this work

This work aims to provide guidance for:

- Improvement the early identification of rehabilitation needs in ICU patients in the acute setting by staff from all backgrounds
- Signposting to appropriate specialist assessment and investigation for patients in the context of the COVID-19 pandemic
- Improvement of the communication of these needs along the patient pathway, providing the patient and ongoing care providers with clear information and documentation of their rehabilitation needs in order to plan how these may be addressed **– the Rehabilitation Prescription.**

Potential sequelae of ICU admission for COVID-19

The collaborative working groups identified potential sequelae following an ICU admission for COVID-19 (Table 1) based on the emerging literature and early clinical observations. This is an indicative rather than an exhaustive list. Recent documents by both the BSRM (6) and FICM (5) have also outlined potential sequelae.

Table 1: Sequelae of COVID-19 post-ICU requiring rehabilitation response

Category	Presentation, pathophysiology and other disease drivers, complications, sequelae, or effects of therapy
Medical & Essential Care	**Respiratory** • Acute laryngeal injury, laryngeal dysfunction, expiratory central airway collapse, laryngotracheal stenosis • Pulmonary deconditioning, fibrosis, embolism or hypertension • Pneumothoraces • Prolonged weaning or long-term tracheostomy, tracheal stenosis **Renal and other multi-organ damage:** • Acute kidney injury resulting in ongoing need for renal replacement therapy • Reduced renal reserve with higher likelihood of late chronic kidney disease (needs prolonged monitoring) **Neurological:** • Neurological presentations include seizures, altered consciousness, stroke, hypoxic-ischaemic injury, autoimmune disease, and possible direct viral infection of CNS. Sequelae include motor, sensory, or language deficits, epilepsy, sleep-disordered breathing, or persistent disorders of consciousness **Cardiovascular:** • Left ventricular dysfunction and effort intolerance due to arterial thrombosis and myocardial injury (myocarditis/ cardiomyopathy/microvascular thrombosis) • Right ventricular dysfunction (pulmonary thromboembolism or associated severe [possibly progressive] lung injury)
Nutrition	**Nutritional compromise due to:** • Disease symptoms: anosmia with or without taste changes, loss of appetite, diarrhoea, nausea and/or vomiting • Clinical course during ICU: (causing muscle wasting or feeding difficulties) hyper-inflammation, the requirement for high levels of sedation, paralysis and proning, prolonged endotracheal intubation on upper aerodigestive tract disuse • ICU-acquired: dysphagia, delirium, weakness, breathlessness and the environment (staff in PPE, cutlery and crockery, upper limb weakness, specific food items and absence of family members)

Physical – movement	**Intensive care unit acquired weakness** • Myopathic, neuropathic and atrophic aetiology leading to impaired physical function and reduced exercise tolerance **Positional** • Brachial plexus injury • Foot drop associated with ICUAW and possible neuropraxia from prone positioning • Pressure effects e.g. sores, neuropraxia • Plantar flexion contractures **Pain** • Shoulder girdle pain due to joint stiffness & muscular weakness • Chronic pain **Other** • Breathlessness and fatigue with possible development of breathing pattern disorders • Urinary incontinence and sexual dysfunction
Communication, Cognition, Behaviour	**Dysphonia** • Intubation-related injury including oedema, ulceration, granuloma, vocal fold palsy, arytenoid dislocation); compromised respiratory function **Cognition** • Delirium may be particularly prominent (due to intensity of host inflammatory response, care from staff in PPE, deep sedation, isolation from relatives, rapid transfers) • Late cognitive deficits may be common, multifactorial in origin, and affect multiple cognitive domains • Prolonged disorders of consciousness
Psychosocial	**Mental Health** • About 50% of patients in ICUs suffer from hallucinations, delusions, low mood, panic or early flashbacks • Post-ICU, about 50% of patients have clinically significant symptoms of anxiety, depression or post-traumatic stress disorder • Exacerbation of pre-existing psychological difficulties may occur **Family and social considerations** • Isolation from relatives may exacerbate sequelae or the level of social support within communities and the shared experience of the COVID-19 outbreak may constitute a valuable protective factor
Fatigue & Pain	**Multiple mechanisms (see previous sections):** Chronic pain (observed in up to 70% of critical care survivors). Includes: • Worsening of pre-existing chronic pain due to medication changes • New-onset pain relating to acute organ injury or late scarring; hyperinflammatory host response; ICU acquired weakness and deconditioning; musculoskeletal sequelae or neural injury

The Patient Pathway

Early rehabilitation, while the patient is still on the intensive care unit (ICU), is recommended (3) (6). This rehabilitation should continue on step-down from ICU, with early intervention and the opportunity for further triage into post-acute rehabilitation pathways provided in the community setting (Figures 1 & 2).

Transitions of care – wherever they occur in the pathway - are critical, providing an important opportunity for assessment of rehabilitation need, communication and signposting to appropriate follow-up support. The consequences of missed opportunities at transition can be significant (3).

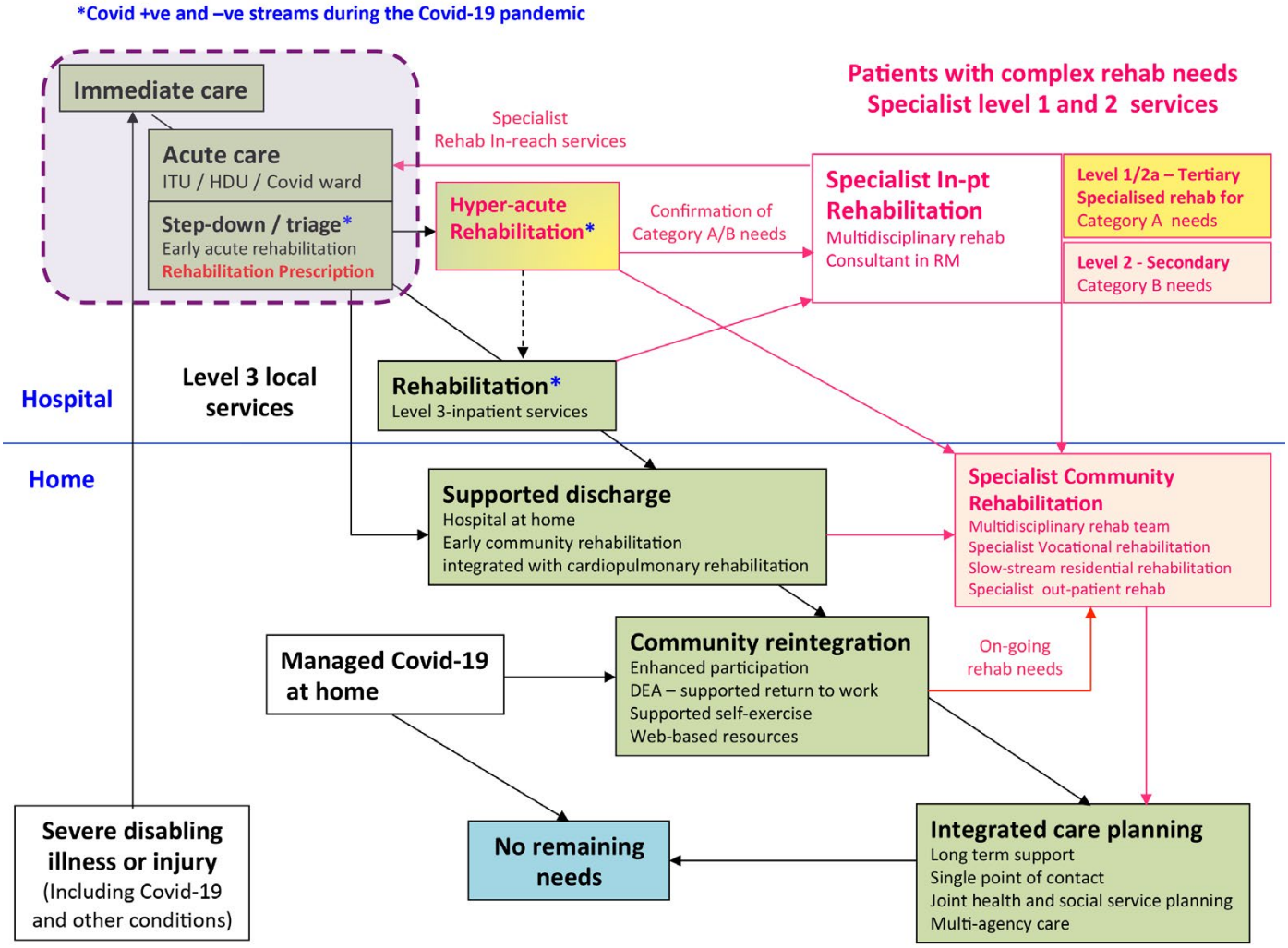
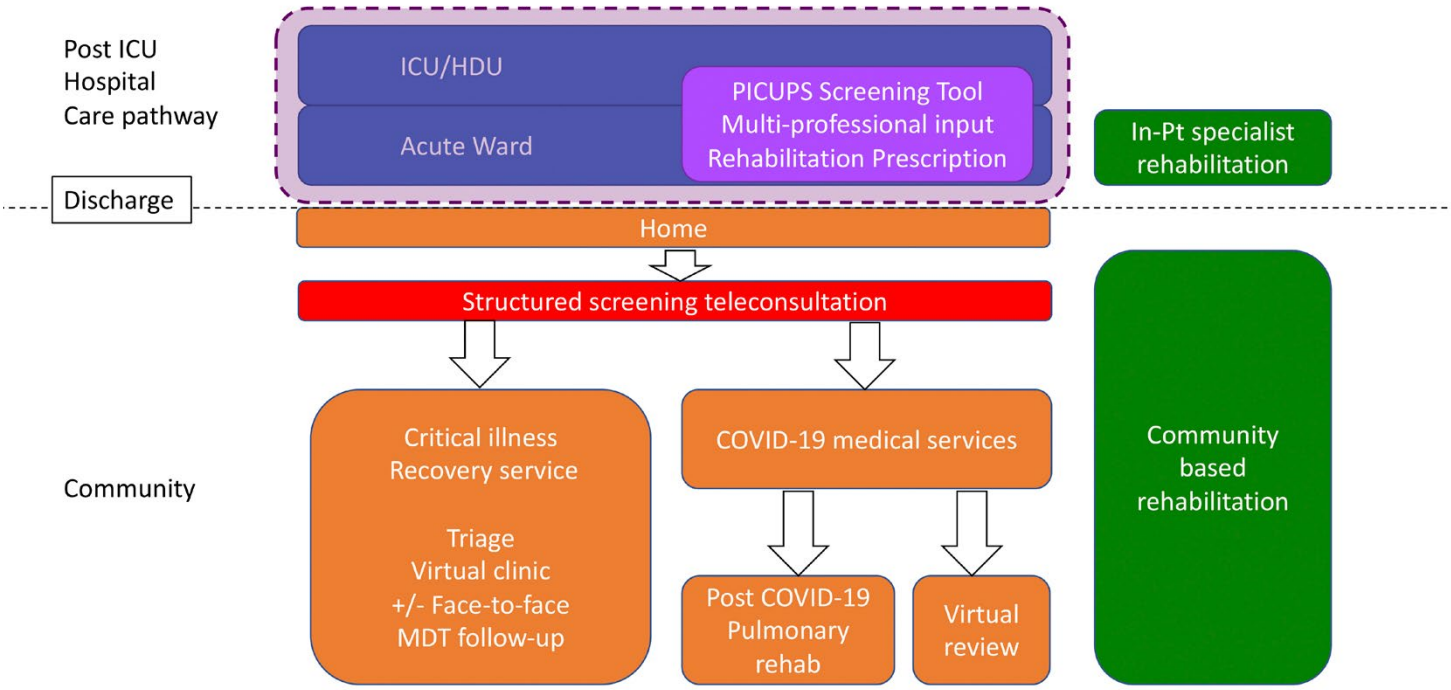


Figure 1: Focus of this document in relation to BSRM's 'Rehabilitation care pathways in the wake of COVID-19' (6)

Legend: The majority of patients have category C or D needs which can be met by the local level 3 services, led by allied health professions or by consultants in specialities such as care of the elderly, and experts in stroke, cardio-pulmonary rehabilitation and exercise medicine. Patients with more complex rehabilitation needs (category A or B) will require specialist rehabilitation, either in tertiary (Level 1) service with enhanced capacity to support patients with highly complex needs or in a local Level 2 specialist inpatient and specialist community service before re-joining the Level 3 pathway.

Compliance with existing frameworks



Adapted and simplified from "Recovery and Rehabilitation for Patients following the Pandemic" FICM Position Statement May 2020

Figure 2: FICM Hospital Care pathway highlighting the focus of this document at the patient transition stage between ICU/HDU and discharge from the acute ward

The two critical transition points presenting key opportunities for assessment, planning and rehabilitation within the early pathway, and addressed within this document, are:

1. At ICU step-down
2. At hospital discharge.

ICUs and acute wards expertise and resources in regards to rehabilitation are variable, both within and outside of the pandemic context, There is a need for a simple holistic assessment process – a screening tool – which can be applied by staff from all backgrounds with minimal trainings to all patients at transitions of care to **screen for functional deficits. This needs to** include triggers for further assessment and/or indicate when specialist support should be sought.

Screening tool development

The Collaborative worked with leading experts to support the development of two new functional screening tools, “Post ICU Presentation Screen (PICUPS)” and PICUPS Plus (appendix 1). A range of existing and validated metrics were used, acknowledging that the rapidity of the development in the light of the COVID-19 response will require an iterative refinement process.

The tool was constructed from adaptations of:

- UKROC toolset
- Chelsea Critical Care Physical Assessment (CPAX) Tool
- NHSE Standard Contract D02 supplement Levels of nursing care and supervision for tracheostomised patients
- Therapy Outcome Measures (TOMS)
- Modified Medical Research Council Dyspnoea Scale
- Airway-Dyspnoea-Voice-Swallow (ADVS)
- ADVS and International Dysphagia Diet Standardisation Initiative (IDDSI).

The PICUPS is a 13-item screening tool developed to support triage and handover of patients stepping down from critical care to the acute wards, and onwards into rehabilitation.

It is designed to be simple enough to be completed by staff from a range of backgrounds in order to:

- Inform the immediate plan for care on the acute ward (Figure 3)
- Identify problems that are likely to require further more detailed evaluation by members of the multi-disciplinary team and
- Inform development of the Rehabilitation Prescription in the acute care setting (including the Rehabilitation Complexity Scale) indicating the needs for rehabilitation at the next stage of care.

This information will additionally identify where patient needs are and are not being met. Used at population level, the information may assist with quantifying shortfalls in service provision, estimating the gap between need and capacity, informing future planning.

A high-level representation of a proposed assessment framework in the inpatient pathway from ICU is shown in Figure 3 and described on the next page.

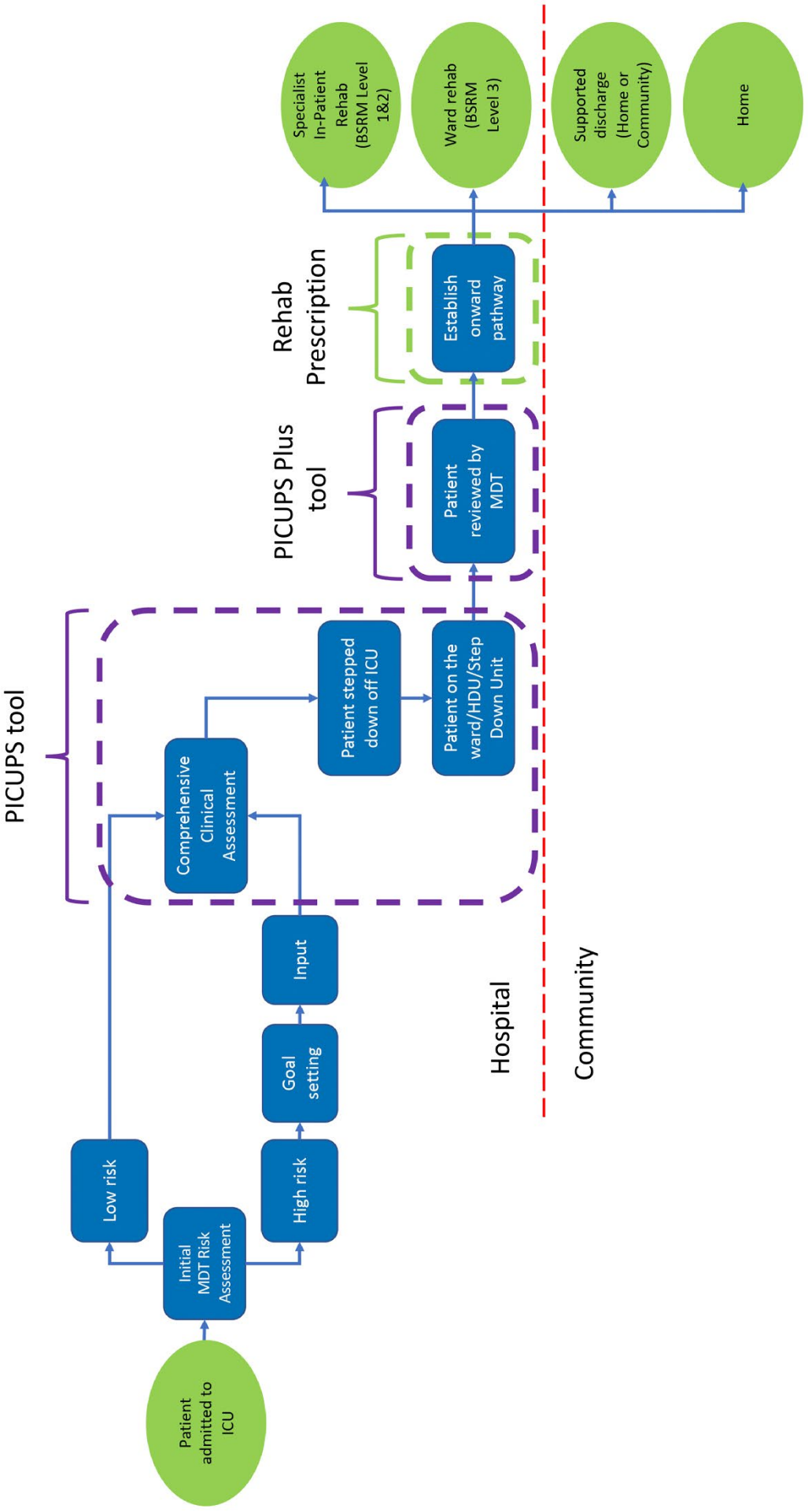


Figure 3: Rehabilitation assessment framework as part of the inpatient pathway from ICU

Transition 1: Stepdown from ICU

It is recommended that all patients who are transferred from a critical care area to an acute ward are screened using the **Post-ICU Presentation Screen (PICUPS)** within 24 hours prior to, or as close as feasible to arrival in the acute ward (Figure 4). Information gained in this screen should be used to support handover and subsequent care planning.

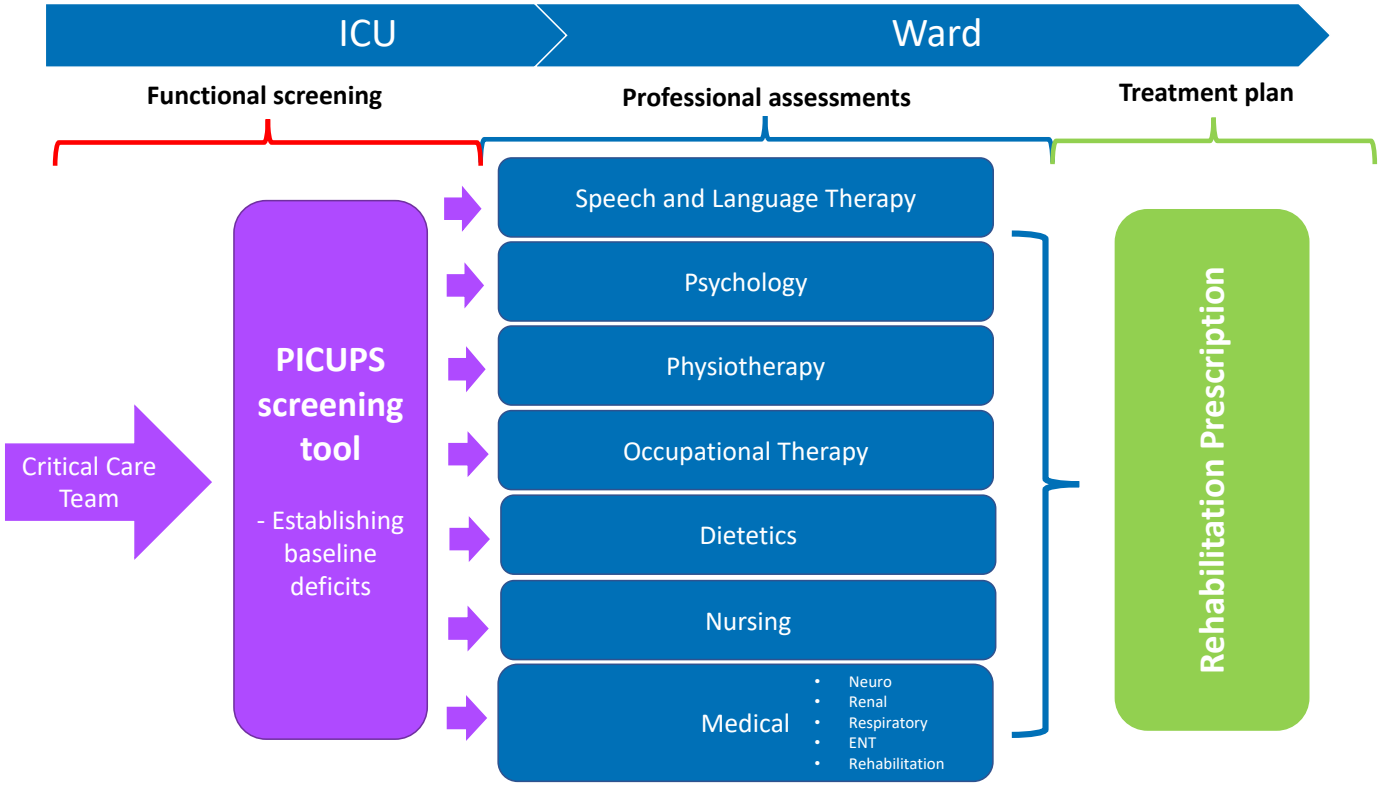


Figure 4: Rehabilitation screening and assessment on stepdown from ICU

Transition 2: On the acute ward prior to discharge

As soon as possible after step-down to the acute ward patients should be assessed by the relevant disciplines as sign-posted by the PICUPS tool. The **PICUPS Plus** tool can assist with this process. It is composed of additional optional items that may be used depending on the individual presentation. It is designed to identify potential higher-level items that may need to be addressed as patients progress towards discharge from acute care.

The **PICUPS Plus** tool can also further assist refinement of **the Rehabilitation Prescription (RP)** prior to discharge (Figure 5). For example, a patient without a tracheostomy who was previously intubated and extubated on ICU who has ICU-acquired dysphagia, dysphonia or upper airway dysfunction may not be routinely referred to Speech and Language Therapy (SLT), but the Dyspnoea/Voice/Swallowing items on the PICUPS Plus will identify these problems and trigger referral to SLT for further evaluation and intervention.

It is not expected that all items in the PICUPS Plus will be relevant to everyone, but that individual components may be used as relevant.

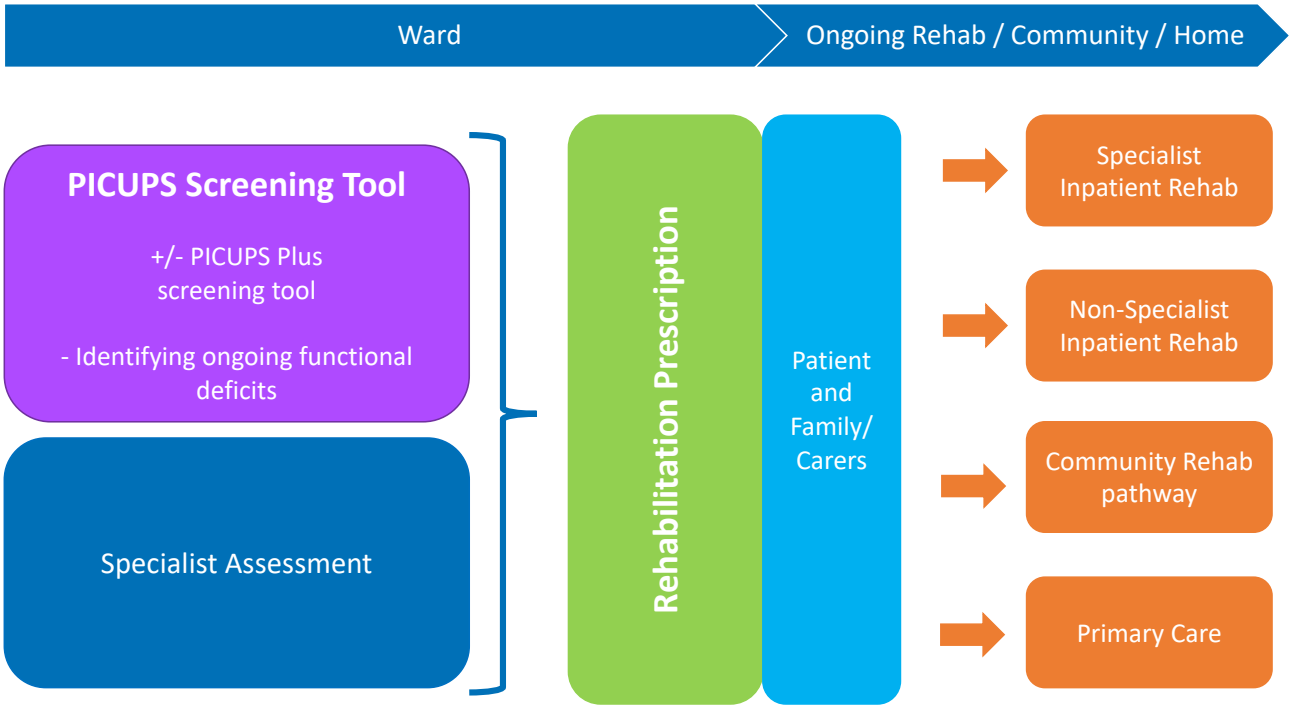


Figure 5: Ward-based care to discharge & Rehabilitation Prescription

Specialist Assessments

Results of screening using the PICUPS and PICUPS Plus, as well as other clinical needs, will be used to trigger targeted assessments by specialists in each of the relevant fields of care. Best practice for specialist assessment, and subsequent treatment where relevant, are being developed linking to the assessment tools and where they can be accessed.

In addition, for those COVID-19 patients who continue to have complex needs for rehabilitation at the point of discharge from acute care a Rehabilitation Prescription should be prepared:

https://www.bsrm.org.uk/downloads/covid-19bsrmissue2-11-5-2020-forweb11-5-20.pdf

The Rehabilitation Prescription

As the patient progresses towards discharge from acute care, information from the PICUPS tools and the targeted specialist assessments by members of the multi-disciplinary team (see below), feed in to the development of an individualised Rehabilitation Prescription (RP). This approach of utilising a RP was identified by FICM for the value it has provided to the Trauma Networks where, *"Rehabilitation Prescription was successfully used to capture met and unmet needs for rehabilitation following discharge from Major Trauma Centres"* (5). An important contribution of using a RP is that it prompts development of a plan, as well as a conversation with each patient regarding the ongoing journey of recovery and rehabilitation.

The RP identifies each individual's need for rehabilitation and specifies how these will be met after discharge from the acute ward and as they move on to the next stage of the pathway. Those who make a very rapid recovery may have few needs, but others may require ongoing rehabilitation in the community (e.g. from cardiopulmonary rehabilitation, psychological support, monitored exercise programmes etc). Before referral to those programmes patients should have the appropriate investigations to ensure they can participate safely (e.g. testing of cardiac and respiratory function, provision of suitable orthoses to protect joints that are vulnerable, due to muscle weakness).

A small number of patients will have more complex needs requiring further inpatient rehabilitation before they can make the transition to the community. The RP is a free text tool that sets out the rehabilitation needs, and the recommendations / referrals that have been made to address them. **The RP travels with the patient and should be reviewed and updated at appropriate intervals to record actions undertaken to implement the recommendations.**

The RP is accompanied by a minimum dataset of which the key elements as follows:

- Does the patient have on-going needs for rehabilitation? Yes / No
    - If yes, a rehabilitation needs checklist is completed to describe the needs under three categories: physical, cognitive and psychosocial
- Are they being transferred to the appropriate facility? Yes / No
    - What type of rehabilitation does the patient need?
    - What is their discharge destination?
    - What is the reason for variance?
- A brief description of further needs for rehabilitation.

Using the RP prior to hospital discharge, and for those patients who are not identified as having needs initially but are recognised 1-2 months after recovery from the acute illness, will allow the patient's rehabilitation pathway to be planned. It will also allow recurrent review of rehabilitation needs at population level in order to target services.

Proof of principle for the RP comes from the Major Trauma Networks where its use is now established. The minimum RP dataset is now mandated for collection in the Trauma Audit and Research Network (TARN) registry. A national clinical audit (7) linked data from the national clinical registries for trauma and specialist rehabilitation and used the RP to track patients and determine whether they received the rehabilitation they needed, and to evaluate the outcomes following major trauma. It demonstrated the feasibility of this approach to quantify any gaps in capacity to meet demand for rehabilitation.

The same principle can be applied in the post-ICU arena and the minimum dataset has been slightly adapted for this purpose.

Alignment with other relevant guidelines and standards

For UK Critical Care communities, the translation of both CG83 and the subsequent Quality Standards (QS 158) remains the gold standard of both practice and aspiration. Within the rehabilitation medicine community, the BSRM standards of Specialist Rehabilitation following in the Acute Care Pathway (2014) outlines the value and role that rehabilitation medicine consultants and teams can play in supporting acute care.

The deployment of a structured screening tools (PICUPS and PICUPS Plus) in conjunction with the development of a Rehabilitation Prescription, will enable some alignment with both the NICE quality standards (QS 158) and BSRM standards for acute care pathways (Table 2).

Table 2: Compliance with national standards and framework

National Framework	Locally developed process	PICUPS Tool	PICUPS Plus	Rehabilitation Prescription
NICE CG83 - Rehabilitation after critical illness in adults (2009/2017)				
Quality Standard 1: Adults in critical care at risk of morbidity have their rehabilitation goals agreed within 4 days of admission to critical care or before discharge from critical care, whichever is sooner.	✓			
Quality Standard 2: Adults at risk of morbidity have a formal handover of care, including their agreed individualised structured rehabilitation programme, when they transfer from critical care to a general ward.		✓		
Quality Standard 3: Adults who were in critical care and at risk of morbidity are given information based on their rehabilitation goals before they are discharged from hospital.			✓	✓
Quality Standard 4: Adults who stayed in critical care for more than 4 days and were at risk of morbidity have a review 2 to 3 months after discharge from critical care.	✓			
BSRM Core standards for Specialist Rehabilitation following in the Acute Care pathway (2014)				
RM Consultants should be closely involved both at a clinical level and in the planning and delivery of all Major acute care pathways (including critical care, neurosciences and stroke) to support and direct rehabilitation for patients with complex needs.		✓		✓
Patients who have (or are likely to have) on-going complex physical, cognitive, communicative or psychosocial disability (category A or B needs) should be assessed by an RM Consultant (or their designated deputy) prior to discharge from the acute unit.		✓		✓
The RM consultant should be involved from an early stage in the patient's acute care pathway to: assess patients with complex rehabilitation needs; participate in the planning and execution of their interim care and rehabilitation; expedite referral and transfer for on-going rehabilitation as soon as they are fit enough.		✓		✓

Conclusions

There have previously been a number of separate efforts to develop standards for rehabilitation following ICU, notably by the ICS, FICM and the BSRM. The National Post-Intensive Care Rehabilitation Collaborative is a co-operative body of expertise representing a breadth of stakeholder organisations across multiple disciplines to establish a unified approach with applicability across all NHS institutions as the NHS reboots after the COVID-19 pandemic. Our immediate priority are those surviving from COVID-19, but the longer-term ambition is to improve rehabilitation for all post ICU patients going forward. The recommendations in this document, and the national datasets that it generates, will also provide a valuable foundation for future improvements in ICU after-care. This would include enabling audit and service evaluation, to understand population-level needs, optimise current care and address the current gaps in provision across the range of services (inpatient and community, specialist and non-specialist). The data that are generated will also support much needed research into the epidemiology, mechanisms, treatment, and health economics of ICU Survivorship.

The PICUPS tools and Rehabilitation Prescription are available in paper form for immediate integration into hospital assessment and rehabilitation pathways.

Next Steps

There is now an imperative to move on to the next phases of work for the Collaborative:

- Using the tool in clinical practice to improve the clinical care of COVID-19 patients
- Refining the PICUPS and PICUPS Plus tools through patient and public involvement, implementation, feedback and iteration
- Sharing and aligning this work to that of other networks developing longitudinal rehabilitation pathways for COVID-19 patients and beyond
- Developing a national dataset incorporating PICUPS and the Rehabilitation Prescription to better understand longer term outcomes of ICU patients and the national need for rehabilitation support and services

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References

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4. Adapted from the Therapy Outcome Measures (TOMS). Enderby, P., John, A. (2019) Therapy Outcome Measure User Guide. Croydon: J & R Press Ltd
5. Adapted from the Modified Medical Research Council Dyspnoea Scale
6. Adapted from Airway-Dyspnoea-Voice-Swallow (ADVS) scale (Nouraei, S., et al Clin Otolaryngol. 2017;42(2):283-294) and Grade, Roughness, Breathiness, Asthenia, Strain (GRBAS) Perceptual Voice Rating Scale
7. Adapted from ADVS and International Dysphagia Diet Standardisation Initiative (IDDSI)

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