

FICM Position Statement and Provisional Guidance:

Recovery and Rehabilitation for Patients Following the Pandemic

May 2020

POSITION STATEMENT AND PROVISIONAL GUIDANCE:

RECOVERY AND REHABILITATION FOR PATIENTS FOLLOWING THE PANDEMIC

The purpose of this document

The Coronavirus (COVID-19) Pandemic has put a strain on NHS critical care services. Whilst recovering from the acute phase of the pandemic, we need to think of the aftermath and seek solutions to provide effective recovery and rehabilitation services for affected patients and their families. This is a unique opportunity to elevate public understanding of the impact of critical illness on outcomes and recovery.

There has been much work related to the evolution of recovery pathways following critical illness. COVID-19 presents a real opportunity to ensure full implementation of existing hospital and community based rehabilitation services for people recovering from critical illness, and to identify areas requiring further development in the post-COVID-19 era.

The Life After Critical Illness (LACI) work stream of the Faculty was halfway to being delivered when the pandemic struck. This position statement and provisional guidance has been produced to support the pandemic and provide a national framework for future Critical Illness Recovery Services. It is intended that the Life After Critical Illness Working Party (LACIWP) of the Faculty will then expedite completion of the workstream document which we will modify as necessary, if additional learning is evident from the pandemic.

It is imperative that the NHS in all four nations urgently looks at, and plans for, the aftermath of this pandemic. This will require existing Critical Illness Recovery Services across the UK to be reviewed and expanded, and likely novel approaches taken to respond to the significant increase in need for these services. It also requires a full review of workforce capacity longer term to ensure this work is sustainable and effective.

In England, the Adult Critical Care Clinical Reference Group (ACC-CRG) review of a national block (blended) payments model for all adult critical care services needs to consider how the outcome element could be best utilised to achieve sustainable funding in light of this pandemic. Northern Ireland, Scotland and Wales will need to ensure similar national commissioning discussions are completed to enable the development of these services in a timely fashion.

Authors: *Dr Carl Waldmann (Chair), Dr Joel Meyer (Deputy Chair), Dr Andy Slack (Deputy Chair)*

Managing editor: *Mr Daniel Waeland*

Reviewers: *Dr Anthony Bastin, Dr Suzanne Bench, Ms Penelope Firshman, Ms Melanie Gager, Dr Julie Highfield, Dr Christina Jones, Ms Mo Peskett, Dr Tara Quasim, Dr Kate Regan, Ms Helen Sanger, Mr Gordon Sturmeay, Professor Lynne Turner-Stokes, Ms Dorothy Wade, Ms Catherine White, Dr Elizabeth Wilson*

Project management and design: *Ms Anna Ripley*

On behalf of the Life After Critical Illness Working Party - May 2020

1 EVOLUTION OF CRITICAL ILLNESS AFTERCARE SERVICES

In the evolution of Intensive Care, the specialty concerned itself with maximising the rates of those discharged alive from intensive care or the hospital. There was little in the literature about what happened to survivors of critical illness after they left hospital^{1,2}.

In 1989, a Kings Fund report highlighted that ‘there is more to life than measuring death’³. Following on from this there were several attempts in the UK to establish outpatient follow-up programmes, some of which were successful. However, due to a lack of funding and because of the perceived lack of an evidence base to justify funding or their existence, many failed to be sustainable. Some centres did manage to evolve rehabilitation and outpatient follow-up services for patients after critical illness/injury. However, unlike specialities such as Trauma, Cardiology, Respiratory Medicine, and Stroke Medicine, where rehabilitation pathways are now quite well-established, Intensive Care has been unable to develop a specific rehabilitation pathway.

In an attempt to justify the establishment of aftercare programmes for these patients, documents started to appear both in the Audit Commission report (1999)⁴ and the Modernisation Agency’s Comprehensive Critical Care report (2000)⁵.

In 2009, NICE⁶ provided guidance with the headline statement *“Given the individual impact on patients, and ripple effects on families and society in general, poor-quality rehabilitation and impaired recovery from severe illness should be regarded as a major public health issue.”* (NICE CG83). Unfortunately, this only achieved limited traction. In 2015, the Scottish Intensive Care Society Quality Improvement Group published guidance, making critical care rehabilitation one of its Quality Indicators⁷. In 2017, NICE published its Quality Standard (NICE QS 158)⁸, and since then there has been more of a concerted effort for all intensive care services nationally to provide rehabilitation and follow up. However, there still remains the problem of how to fund such services. To date this has been primarily achieved by local intensive care units (ICU) developing and submitting a business case to local commissioners. Unfortunately, these often fail due to a lack of supportive clinical evidence and a challenging financial climate in the NHS.

It is clear that recovery from critical illness is complex. Since 2010, the term **Post Intensive Care Syndrome (PICS)** has been increasingly utilised to describe the complex long-term sequelae of critical illness, affecting both survivors and their families. PICS has three key patient-centred domains at its core that can be impacted by critical illness; the physical, the cognitive and the psychological domains, the latter affecting both patient and family⁹.

The question of who should provide intensive care aftercare services has stimulated debate about whether it should be intensivist led or otherwise^{10,11}. The argument for these services being provided by the intensive care staff is hard to contest, with numerous benefits for patients as well as for staff. These include feedback from patients and caregiver (family) to ICU staff to influence changes in practice within the ICU, the enabling of revalidation for healthcare professionals and provision of a narrative of individual patients’ outcomes for staff, which can improve morale. The ICU multidisciplinary team are expertly placed to understand, interpret and plan the recovery phase of the patients’ illness and signpost them appropriately to other hospital or community based specialities. The patient feedback for these critical illness recovery clinics consistently highlights the benefit of hearing a narrative account of their ICU stay along with the review and normalisation of their ICU delirium experience. Some patients will have very severe on-going disability following

discharge requiring specialist inpatient or community-based rehabilitation¹². Others require a variety of community-based rehabilitation/ support services including cardiopulmonary rehabilitation, sports and exercise medicine, psychological, vocational support etc. All of these services need to be working in coordinated networks to optimise the care of patients who have been critically ill.

The development of the critical illness aftercare service has been in the forefront of the Faculty of Intensive Care Medicine's strategy and formed a part of the publication in 2017 of Critical Futures¹³. Life After Critical Illness (LACI) was deemed to be an important work stream for the Faculty to undertake. The work stream group was convened pre-COVID-19 and in November 2019 the Faculty founded the Life After Critical Illness Working Party (LACIWP) to work across multiple organisations and professions. A draft document has been commenced, and continues to move forward with contributors, aiming to:

- present a UK wide survey of current practice;
- provide an outline of existing service models, incorporating vignettes of good practice and examples of successful business cases; and
- outline future research proposals to evaluate existing services and outcomes of individuals after critical illness including data collection.

In addition to UK-wide members of the Faculty, organisations affiliated to LACI include:

- British Psychological Society
- British Society of Rehabilitation Medicine
- Chartered Society of Physiotherapy
- ICUsteps
- Royal College of General Practitioners
- Royal College of Occupational Therapists
- UK Critical Care Nursing Alliance

These organisations reflect the requirement for close collaboration across a spectrum of multidisciplinary organisations when exploring the optimal approach to planning and delivering recovery services. We will also be consulting the UK Clinical Pharmacy Association Critical Care Group and the British Dietetic Association for our final full pathway.

Data on long term patient outcomes from Intensive Care is limited, especially the impact on patients' and their relatives' Quality of Life. Patient-centred outcomes including returning to employment or studies, need for further medical care, and everyday tasks such as driving need to be collected.

Critical illness is a family crisis and the impact on a family or the informal caregivers has been clearly identified with PICS-Family (PICS-F). The family may experience their own mental health problems with depression, anxiety and PTSD and then there is the patient care workload once their relative returns home. Consequently, the information from patients and relatives has informed the basis of quality improvement projects for ICUs, particularly, but not exclusively in the area of communication. Research including a Kings Fund project, Experience Based Co Design has also informed and led to quality improvements in critical care.¹⁴⁻¹⁸

2 MODELS OF CARE

Inpatient phase and discharge

Critical illness recovery has an individualised trajectory for each patient that is unpredictable and requires continual input from the multi-disciplinary team (MDT) to tailor the rehabilitation process. The severity and duration of critical illness along with pre-ICU co-morbidities, clinical and social frailty all heavily influence an individual's rehabilitation potential.

Rehabilitation commences early within the ICU, enabling liberation from mechanical ventilation, continuing with targeting patient-centred recovery goals which may take weeks, months or several years to achieve.

A proportion of critically ill patients acquire substantial new deficits during their critical illness (i.e. trauma, stroke) that may require specialised bed-based rehabilitation services e.g. neurorehabilitation and ongoing specialist rehabilitation in the community. Guidelines developed by the British Society of Rehabilitation Medicine¹⁹⁻²⁰ advocate early involvement of a consultant in Rehabilitation Medicine and the use of a Rehabilitation Prescription to identify on-going rehabilitation needs as patients are ready to leave ICU, HDU and acute care settings, in order to direct them on to the appropriate rehabilitation services and expedite this transition. A proof of principle has been provided within the major trauma networks, where the Rehabilitation Prescription was successfully used to capture met and unmet needs for rehabilitation following discharge from the Major Trauma Centre²¹.

Another group of critically ill patients may require input from a discharge-to-assess 'D2A' team or an equivalent that usually consists of an occupational therapist, physiotherapist and a support planner (adult social care). They identify patients suitable for hospital discharge within 24hrs of referral. Once 'medically optimised', patients are discharged home with a planned assessment within 24hrs. Ongoing care needs are managed at home with Short Term Assessment and Re-ablement Services (STARS), equipment and voluntary services. This discharge process has been heavily utilised in some institutions during the COVID pandemic. However, the community-based interventions are usually only for a few weeks and many patients are discharged from these services at the end of the programme. For some, significant impairments can persist for months, years or sometimes a lifetime. Continued co-ordination of often complex care needs is required.

The majority of patients follow a recovery trajectory that enables discharge home without an immediate need for input from community services. A proportion of these, however, may present with long-term sequelae at a later stage and need to re-access services as those needs arise.

Outpatient phase

Critical illness recovery outpatient clinics have become crucially important given the complexity of PICS and the limited ability of general practitioners to cope with all the needs of the patient after discharge home irrespective of how the discharge process occurred.

Several diverse models for provision of outpatient Critical Illness Recovery Services have evolved across the UK in recent years (see table below). LACIWP identified five main outpatient service archetypes – hybrids of these models are also considered. Service models are strongly influenced by

the needs of the local case-mix, available resources, and by the professional background of the founding practitioner(s) i.e. nurse, therapist, doctor.

ARCHETYPE	IN-PERSON OPTION	VIRTUAL OPTION
(i) 1:1 uni-professional appointment	Yes	Yes (1:1 video call or phone call)
(ii) Panel MDT	Yes (all MDT members in one room)	Yes (MDT videoconference or phone call with individual patient)
(iii) Carousel MDT	Yes (each MDT member in separate room)	Yes (sequential 1:1 video call or phone call)
(iv) Group or cohort	Yes (secondary care or community)	Yes (group videoconference or phone call)
(v) Drop-in café	Yes	Yes

The most prevalent format to date has been the traditional in-person outpatient clinic (either (i), (ii), or (iii)). This offers the interpersonal quality of professional consultation plus opportunity for clinical examination and measurement and same-day investigations, if required. Onsite attendance presents the patient with an opportunity to re-visit the critical care unit to environmentally contextualise the experience of care and meet ICU staff. Group in-person models such as (iv) and (v) that incorporate the benefits of informal peer support have recently gained traction. There have also been reports of successful drop-in-café for bereaved families.

During this pandemic four factors – (1) the surge in numbers with COVID-19 related critical illness, (2) the heightened risk of COVID-19-distinctive PICS sequelae, (3) the importance of psychological / psychiatric input to support patients, families and staff, and (4) the relative homogeneity of the admission case mix – are helping to crystallise thought and strategy around recovery services. Furthermore, social measures and visiting restrictions imposed during the COVID-19 pandemic are disrupting our conventional clinical practice and providing an imperative to deliver virtual clinics. This is opportune because the time, space and cost of in-person outpatient clinics have recently been increasingly challenging to justify. Travel to the appointment is also saved. COVID-19 is driving urgent innovation and expansion of recovery services in the virtual technology space.

The range of healthcare professionals involved in delivering the assessments and interventions is illustrated in Figure 1.

Figure 1.



* Typically an Intensive Care Consultant with input from Rehabilitation Medicine Consultant where available.

Primary care and Community services have a very significant part to play in supporting both patient and family across the recovery trajectory. In the coming year, GPs are likely to encounter a substantial expansion in ICU survivor caseload. This highlights a requirement to improve links and information sharing between primary care and secondary/tertiary care. The changes to the NHS Standard Contract for 2017-19 define the responsibility of the provider of commissioned services and these are key for any provider of an outpatient service to ensure good practice for patient care and to maintain a good working relationship with local GPs²².

The spotlight thrown on intensive care by the COVID-19 pandemic and the shifting clinical landscape has given impetus to LACIWP's work. This position statement and provisional guidance aims to provide a national framework for future Critical Illness Recovery Services including best practice principles and recommendations for service delivery following hospital discharge which can be found in **Appendix 1**.

3 CRITICAL ILLNESS AFTERCARE SERVICES FOLLOWING COVID-19

Patients who have survived COVID-19 related critical illness during a resource-limited COVID-19 pandemic surge may have distinct challenges for recovery. Whilst clinicians are becoming familiar with acute management and some specific complications of COVID-19 illness it is clear that the medium and long-term sequelae of this disease remain unknown.

Critical illness sequelae to consider during COVID-19:

MEDICAL

Cardio-respiratory

- Breathing – physiological impairment, persistent lung injury, dysfunctional breathing and potential heart failure / myocarditis symptoms
- ILD follow up and repeat imaging, pulmonary function tests and echocardiography
- Residual cough
- Thrombosis – micro and macro – including pulmonary hypertension assessment
- Steroid cumulative effects on bones / GI tract; and ongoing steroid use – sick day rules, diabetes management
- Tracheostomy related injury / granulation / tracheal stenosis
- Glottic injury and dysphonia

Gastro-intestinal

- Hyperglycaemic cumulative effect
- Diabetes mellitus and new insulin therapy
- Swallow impairment
- Nutritional / weight loss assessment

Neurological-peripheral and central nervous systems

- Heightened risk of ICU acquired weakness given deep sedation, NM blockade, prolonged recumbency
- Neuropraxias, neuropathies, paraesthesiae due to prolonged recumbency
- Strokes/SAH
- Anosmia/ageusia
- Extreme fatigue

Renal / Kidney

- Acute kidney injury recovery and risk of progressive /established chronic kidney disease or end-stage kidney disease with requirement for haemodialysis

Skin and soft tissue

- Prone position-related issues including shoulder girdle pain, pressure sores, facial injury, eye (globe/corneal/retinal) injury
- ECMO specific issues – sutures/groin sites

Infection

- Infection status – continued viral shedding & risk of recurrence
- Vaccination / Antibody testing

Sexual health

- Erectile dysfunction and impotence
- Contraception

Medical imaging

- Catch up of any medical imaging that was postponed during the acute admission due to infection control reasons.
- Follow up imaging e.g. CXR, brain MRI, review of incidental findings on axial imaging

RISK FACTOR/UNDERLYING CONDITION MANAGEMENT

- Hypertension – recognition and management
- Effect of ACEI/AR2B
- Diabetes
- Obstructive Sleep Apnea screening
- Weight management
- Risk of reinfection/rehospitalisation – vaccinations, rescue packs etc
- Smoking cessation, life style interventions
- Polypharmacy and medicines management including cessation of inadvertently continued psychoactives, anticoagulants, opioids

COGNITIVE

- Memory/concentration/attention/executive function linked to severe illness, repeated hypoxic episodes and neurotropism of coronavirus
- Brain fog
- Sleep dysfunction
- Heightened risk of delirium due to exceptional environmental factors (overcrowding/PPE/large numbers of staff/noise) and pharmacological factors (prolonged sedation possibly with longer acting agents if supply limitation)
- Stroke/ICH/SAH risk (profound hypoxaemia/ECMO)
- Slowed speed of information processing

PSYCHOLOGICAL

- Emotional stressors sudden isolation, PPE, crisis mentality, bed-space proximity, heightened attention/coverage, incomplete knowledge of illness. Witnessing traumatic incidents of other hospital patients, including death
- Survivor guilt
- Risk of complicated grief if bereaved of other family members while in hospital
- Fear of catching the virus again, of passing it on to others
- Impact of no visiting policy; lack of shared experience with family
- Lack of ICU diary, poor understanding of ICU events
- Inability to do visits back to the ICU
- COVID SARS was associated with a variety of psychological manifestations
- Exacerbation of existing low mood and depression and anxiety
- Post traumatic stress from delirium
- Psychological adjustments to long term physical and cognitive symptoms

FAMILY

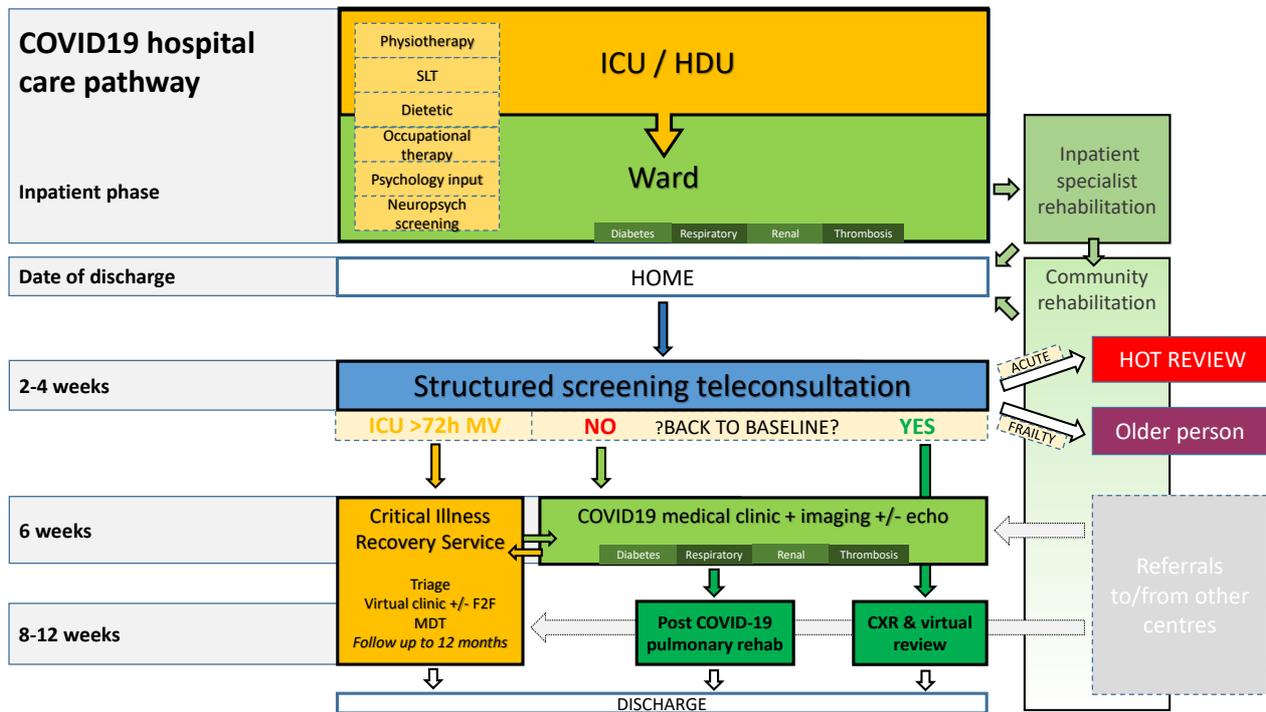
- Prolonged isolation from loved one, inability to visualise care environment, limited understanding of care given, unable to participate in care
- Backdrop of social distancing, fear of transmission and lockdown mental state.
- Likely repeated delivery of potential poor prognosis over the phone leading to psychological distress
- Adjustment and impact of new virtual visiting solutions
- Complicated grief if bereaved and separated from patient

SOCIAL

- Clinical and social frailty pre-ICU e.g. ability to access shops and pharmacy
- Driving return
- Return to work with potential for changed work role/expectations due to social restrictions or furloughing, expectation to batch annual leave and lack of familiarity with government help scheme.
- Financial impact
- Family/childcare
- School
- Impact of lockdown/social distancing on usual support networks and social scaffold
- Smoking cessation

The design of Critical Illness Recovery Services for COVID-19 patients requires a collaborative approach between inpatient services e.g. critical care / acute and respiratory medicine (BTS guidance)²³, therapies and neurorehabilitation teams where available. An example of an integrated COVID-19 hospital care pathway is shown in Figure 2.

Figure 2: EXAMPLE COVID-19 HOSPITAL CARE PATHWAY



At present, it is unclear what proportion of patients will require specialist, bed-based or home-based community rehabilitation. There is a vital piece of work to be undertaken to understand the potential requirement for such rehabilitation services. This will require close collaboration with rehabilitation specialists and community therapy teams to co-ordinate this effort. This first pandemic surge has slowed. The lower acuity, short-ICU stay, COVID-19 patients are now home, but the remaining prolonged ICU-stay COVID-19 patients remain in level 3 or 2 ICU areas, they have a tracheostomy or remain intubated and many of a range of other on-going needs including renal / liver replacement, ICU acquired weakness and other neurological issues. This group will undoubtedly pose the greatest rehabilitation challenge, should they survive. Their rehabilitation may not be able to be completed in a hospital environment if the pressure on inpatient bed capacity rises due to the combination of a second COVID-19 pandemic surge when lockdown restrictions are eased, additional significant increases in non-COVID clinical activity and the recommencement of elective surgery.

Unfortunately, a proportion will never recover, and will require ongoing support and neuropalliative care in nursing home settings

4 REQUIREMENTS FOR THE FUTURE

The Coronavirus pandemic has tragically forced an intense focus on the management of critical illness not only within ICU, but now, as we pass the first peak surge in intensive care admissions, towards the recovery and aftercare of these patients. The proportion of critically ill patients requiring complex rehabilitation afterwards is likely to be in the order of 30% rather than 5% as was initially predicted.

The impact on all ICUs within critical care networks has been immense and has required close network collaboration to manage the pandemic surge in admissions which needs to continue in the aftermath and planning of follow-up. Follow-up services configured with the potential to run a 'hub and spoke' network of referrals between uni- or multi-professional outpatient services and larger MDT outpatient services may be important to consider, as may the establishment of new services where they previously were lacking. Initially when clinics are beginning from scratch, we would propose the option of grouping together with a unit with an established follow-up service so that all aspects of rehabilitation can be accessible to patients in that hospital group. Where new services may be commissioned between this provisional guidance and the fuller guidance due later in the year, we would recommend that providers commission along the lines set out in the models described; or liaise with other hospitals in their Network or region to work together on an interim solution to identify and treat patients in need of physical, psychological, cognitive and social/family issues in the aftermath of critical illness.

Pre-existing high hospital readmission, reinfection and mortality rates after critical illness are key drivers for ensuring that recovery, rehabilitation and follow-up process are well co-ordinated between secondary/tertiary and primary/community care. This may be challenging given where we are starting from, but it does provide an exciting opportunity to form stronger links with all major stakeholders e.g. general practice, community services, rehabilitation medicine, peer support services and regional critical care networks to ensure individuals receive the best possible rehabilitation services now and for the future.

All of this work will require the collection of exposure and outcome data to inform future care models and pathways for this group of patients and families. Patient-centred occupational goals and outcomes may require adapting for social distancing, self-isolation, altered work patterns, health seeking behavioural change and travel restrictions. Family and carers may not be able to contribute to care or support attainment of goals as before.

The pandemic provides an opportunity for financial transformation. Critical illness aftercare is a predictable unit of activity that needs to be forecast into the intensive care tariff for all eligible patients. A robust, sustainable commissioning model which takes into account risk factors for adverse outcomes and which incentivises high quality recovery services should be prioritised.

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APPENDIX 1: BEST-PRACTICE PRINCIPLES AND RECOMMENDATIONS FOR THE DELIVERY OF CRITICAL ILLNESS RECOVERY SERVICES FOLLOWING HOSPITAL DISCHARGE

The Life After Critical Illness Working Party sought to define best-practice principles applicable across the breadth of service delivery irrespective of the precise model in place. Areas where consensus is lacking are also acknowledged.

1 Selection and booking of patients

Prediction of those critically ill patients most likely to benefit from Critical Illness Recovery Services is under-researched.

Excerpts of relevant UK guidance:

- The NICE Clinical Guideline 83 published in 2009 recommends outpatient review of “patients with rehabilitation needs...”.
- The Quality Standard 158 published 2017 stipulates that “adults who stayed in critical care for more than 4 days and were at risk of morbidity have a review...”.
- The relevant standard 3.7.1 in Guidelines for the Provision of Intensive Care Services version 2 (GPICS2) published 2019 dictates that selection of patients should be “based on length of stay (more than three days) or at increased risk e.g. maternal patients or anaphylaxis”.

1.1 Inclusion

Duration of mechanical ventilation (>72 hours) and/or length of stay in critical care (>72 or >96 hours) are the principal criteria for patient inclusion. This index is felt to capture a composite of both acute illness severity as well as intensity of exposure to critical care interventions. However, a newly established service may need to increase this length of stay threshold to reduce the potential number of new patients per clinic to allow new processes to bed in. Conversely a pandemic may drive relaxation of thresholds in order to calibrate understanding of the novel critical illness sequelae.

Reliance on a time-based index alone is a crude approach lacking both sensitivity and specificity for the population at high risk of PICS. Postulated additional selection criteria may include:

- High-risk categories such as: out of hospital arrest, anaphylaxis, maternal critical illness, pandemic;
- Specific critical care exposures e.g. ECMO or significant critical care delirium;
- Patients experiencing unexpected adverse outcomes/unanticipated complications of planned treatment;
- Intensivist/MDT discretion;
- Patient or family concern;
- Self-referral, GP referral or other clinician referral.

1.2 *Exclusion*

Consideration should be given to deselecting patients deemed unlikely to benefit from the service e.g.:

- degenerative condition deemed unlikely to recover function;
- progressive malignant disease;
- burdensome ongoing treatment e.g. chemoradiotherapy;
- severe cognitive impairment or brain injury;
- current debilitating drug or alcohol misuse;
- palliative therapy goals
- long-term physical and psychiatric disabilities requiring residential care

Services with limited capacity should consider not inviting patients whose multidisciplinary needs are already adequately met within existing services (examples include transplant, dialysis, stroke neurorehabilitation, sickle cell disease).

Patients exceeding 12 months since their critical illness at the point of referral should be considered on a case by case basis.

1.3 *Booking process*

Local circumstances will dictate an automated or manual process for booking appointments which may have changed during Covid-19. The advantage of selection based on length-of-stay criterion alone is automation and simplicity. Manual triage of unit discharges is more labour intensive, however offers the possibility to target resources to those deemed in greatest need, and therefore influence non-attendance rate.

We recommend linking the appointment booking process with the point of critical care discharge. This option minimises loss to follow up. Alternatively, patients may be booked later in their pathway at the point of or beyond their home discharge date. Whilst this eliminates variation in residual length of stay in hospital and enables a potentially more refined cohort, it is nevertheless more administratively burdensome necessitating active manual tracking of patient progress after discharge from critical care.

Irrespective of the outpatient booking process chosen, we recommend pre-clinic phone-calls or automated short message service (SMS) texts to maximise attendance. Many patients struggle with cognition and require these reminders. Consider patients' bespoke needs regarding accessibility, transport, financial support for travel cost if eligible (receiving department for works and pensions benefits e.g. Universal Credit, ESA or PIP), language (use of interpreters and phone translation), provision of supplemental oxygen. Calling may assist with understanding barriers to attendance. A personal approach is advocated.

We recommend that those patients who decline attendance or are doubtful about attending should be sent an interest/information letter with the option to rebook.

Critical Illness Recovery Services inevitably carry a non-attendance rate which cannot be eliminated but can be minimised and audited. There are digital options to aid this audit process and often they

will be used by other clinic services in the Trust e.g. [DrDoctor](#). We recommend that the bookings model be adjusted for the local non-attendance rate accordingly once steady state is reached.

During the critical illness episode patients' own contact details are rarely entered in the clinical record and next of kin details predominate. We recommend that unit staff routinely reconfirm patients' own phone and email prior to critical care discharge where possible. This facilitates right-person-first-time communication with the recovery services.

1.4 *Who should be seen?*

Where the service model allows, we recommend that relevant next of kin, family, and/or caregivers are invited to accompany the patient to the appointment, especially if emotionally impacted by the experience.

2 **Timing of intervention**

2.1 *Initial outpatient review*

Excerpts of relevant UK guidance:

- NICE CG83 recommends a review "2–3 months after their discharge from critical care".
- QS158 concurs with "2 to 3 months after discharge from critical care".
- GPICS states "patients discharged from the critical care unit must have access to an intensive care follow-up programme which can include review of clinical notes, patient questionnaires to assess recovery and an outpatient clinic appointment two to three months' post hospital discharge if required for specific patients".

Note the inconsistent definition of time-zero as either critical care discharge or hospital discharge.

We recommend targeting an interval of 2-3 months from time of hospital discharge where the service model allows. This is most likely to ensure consistency of time-point along the recovery trajectory that patients are reviewed and will ensure comparable outcome data between patients and for benchmarking between services.

2.2 *Subsequent outpatient reviews*

Subsequent appointments at 6 and 12 month time-points should be provided if relevant to the service model, to ensure that:

- Where complex care coordination is required following critical illness, it is being accomplished;
- Onward referrals and recommendations are being implemented;
- Critical care related medications e.g. anticoagulants, antipsychotics, analgesics are ceased/continued appropriately;
- Those with slower recovery trajectories or illness chronicity can benefit from time-appropriate assessments/interventions;

- Sequential measures of relevant outcomes e.g. cognitive function, physical measures, quality of life can be done;
- Where significantly delayed, occupational recovery domains such as return to work, driving, travel, can be addressed;
- Advanced care planning can be considered;
- Practitioners' expertise is enhanced through exposure to the full spectrum of recovery trajectories after critical illness.

2.3 *Discharge from outpatient services*

The shape of a given patient's trajectory of recovery is nearly always apparent by the one-year time-point. Impairments arising beyond one year are less reliably attributable to the initial critical illness. We recommend that continuing to invite individuals beyond the first year after hospital discharge, or for more than three attendances, should be considered only in exceptional circumstances and for clearly defined purposes.

3 **Operational considerations**

Consideration should be given to the following domains.

3.1 *Venue/number of consultation rooms*

Requirements will depend on service model (e.g. cohort or individual) and number of professionals involved. If in-person visits are being done consultation spaces should conform to typical outpatient requirements (sinks, examination couches, soundproofing, resuscitation equipment, medical escalation pathway). Proximity to relevant services (radiology, phlebotomy, parking) and to ICU for visits should be factored in. Environment preferably should not evoke strong memories of critical illness. Privacy and connectivity will dictate the best environment for virtual clinics.

3.2 *Frequency of service*

This is dependent on local factors including service model, anticipated activity, staff availability and venue capacity.

3.3 *Equipment, such as, but not limited to*

- Physiological measurement (spirometry, dynamometry, stopwatch, BP manometer and peripheral saturations probe)
- IT equipment (tablets for electronic questionnaires, laptops for electronic record)
- Accessibility (chairs, wheelchairs)
- Clinical (phlebotomy, local anaesthetic and wound packs)
- Stationery (request forms, feedback questionnaires, prescription forms)

3.4 *Administrative support*

The majority of service models will necessitate administrative support to accomplish booking, confirmation calls, venue liaison, sending out completed clinic letters and coordinating *ad hoc* enquiries. Clinic letters should be sent to the patient and GP within 7 days of the consultation, based on “NHS Standard Contract Technical guidance 2018/19” and copied to all relevant specialist clinicians.

3.5 *Conduct of the clinic*

The consensus is that investing preparatory work to review patient records, ascertain timeline of critical care events and a mechanism for sharing this information between professionals delivering the clinic will enhance care given on the day. Pharmacy colleagues should be engaged with accessing the most up-to-date medication and allergy records. Where the service model permits we recommend a pre-clinic team meeting to briefly discuss all patients, identifying key recovery needs and individual nuances/challenges. We also recommend a post-clinic debrief to share findings, address discrepancies and agree interventions. Convening the team also serves as an educational, supportive and iterative service improvement exercise.

4 Direction and governance

4.1 *Management and leadership*

Services should have a designated lead clinician. Services should be incorporated within the management structure of the critical care service. Activity, governance and finances should be regularly reported to the department management team. Provision should be made for incidents and complaints to fall under the wider critical care unit governance umbrella. All peer reviews and formal quality assessments applicable to the critical care service should encompass the Critical Illness Recovery Services.

4.2 *Developing audit, service evaluation and feedback*

We recommend embedding audit and service evaluation at the outset. This should encompass activity, attendance, non-attendance, duration of consultation, outcome measures, referrals made and interventions done. Patient experience evaluation and feedback processes should be built into the service.

4.3 *Governance and risk*

Standard operating procedures should be developed to safeguard risk elements of the service, examples include:

- Local Clinical governance processes
- Managing non-attendance
- Ensuring accessibility of service for all patients (and adapting it to specific needs)

- Escalation of patients (and loved ones) presenting with heightened psychiatric risk and psychological morbidity
- Nutritional risk pathway
- Conduct of visits back to critical care unit
- Return of critical care diaries
- Information governance including consent to circulate patient outcomes to the unit staff, use of photos, etc.
- Rostering and staffing
- Process for observers, trainees and volunteers

4.4 *Public and patient involvement (PPI)*

PPI is important in research and all aspects of patient care and helps to inform healthcare providers ensuring the highest standards of care are achieved. The FICM LACIWP mandated PPI involvement to enable these views and experiences to help shape the clinical considerations of the recovery pathway. There are two patient representatives on the working party who form an important part of the group. PPI should be encouraged for any Critical Illness Recovery Service development.

4.5 *Peer support*

- Peer support groups are important for patients AND their families and friends and examples of such programmes include:
 - ICUsteps groups
 - Institution affiliated peer support groups, either coffee groups or formal group gathering
 - Social media based groups; face-to-face or virtual
 - Death Cafes

Peer support sessions are an ideal forum for patients/families/staff to discuss their experiences, given the relatively homogenous nature of many of the clinical and non-clinical issues. It is also a relatively efficient way of addressing the needs of some patients and families. Although group sessions are practically more difficult to organise during a pandemic, this will become easier in time. There is a great potential for virtual peer support meetings. The safety of participants, necessity for a moderator, and information governance issues need to be considered with such an approach.

Further reading:

SCCM Thrive International Peer Support Collaborative. Models of Peer Support to Remediate Post-Intensive Care Syndrome. https://www.sccm.org/getattachment/Education-Center/Annual-Congress/Congress-Media-Room/Models_of_Peer_Support_to_Remediate_Post_Intensive-34.pdf?lang=en-US