

# Life after Critical Illness: A guide for developing and delivering aftercare services for critically ill patients

Consultation Version

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DRAFT

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## Foreword

The world has changed! The advent of COVID-19 means the world may never be the same again. In the UK the acute and critical care communities were at the forefront of caring for this huge flux of critically ill patients and came close to being overwhelmed; amazingly and impressively they prevailed and minimised the loss of life. This influx of critically ill patients has not been witnessed in any of our lifetimes but now it is time to deal with the aftermath.

COVID-19 seemed like a new disease when it first appeared but its course and recovery now appear to be similar to other forms of severe critical illness. In a similar manner to how we quickly identified that we had the knowledge about how to treat COVID-19 in our hospitals and ICUs (although at times not the resources), we also know that we have the knowledge about how to support our patients and their families to recover from the consequences of COVID-19 critical illness (or COVID-19 related severe respiratory failure).

We identified the long-term consequences of critical illness and the myriad of issues faced by patients and families nearly 30 years ago. The UK has led the world in identifying the problems that occur after critical illness and in evaluating methods to improve the outcomes from critical illness. No other country has the clear national guidance, front line services and drive to deal with this problem like the UK has.

That said, there are many challenges still to face! Existing ICU follow up services show incomplete coverage across the UK; there is marked variation in the services supplied; the evidence base does not yet direct us towards the optimal model of care and there is a massive rise in the numbers who need such services due to COVID-19.

This document builds on the clinical practice experience, the evidence base and the existing national guidance available in the UK to give clear and detailed guidance to clinicians in the hospital and community settings, to hospitals, to regional health care providers and to commissioners, on how to develop, deliver and fund these services.

This document is a valuable and timely resource and requires wide spread dissemination and implementation across the UK. What's more, these services need to stay in place even after the decline of COVID-19 as they target a major unmet need related to critical illness and its recovery. Our patients and their families have suffered greatly from the failure to recognise their needs after critical illness both during COVID-19 and before, they deserve an immediate, coordinated response to these challenges so they can make full recoveries and return to their lives.

*Prof. Brian H Cuthbertson*

*Toronto, April 2021*

## 1. INTRODUCTION

Intensive care for critically ill patients has evolved over the decades with outcomes previously heavily focused on patient survival, but now the emphasis has shifted with the recognition that recovery from critical illness affects a patient's quality of life. This was eloquently highlighted in a report by the Kings Fund, in 1989, which concluded 'there is more to life than measuring death'<sup>1</sup>. Rehabilitation is recognised as a key part of recovery from critical illness, managing the impact of impairments or disabilities to restore function and improve independence. **Rehabilitation has to be patient-centred, supporting patients to achieve their individualised goals and maximise recovery of physical, cognitive and psychosocial functions to improve quality of life.**

Intensive care units (ICUs) throughout the United Kingdom (UK) have made continued efforts to develop services for patients recovering from critical illness during hospital admission and after hospital discharge. These efforts are complemented by patient and relative/carer feedback which have driven quality improvements in recovery services and patient experience.

Recovery from critical illness commences within ICU, with the ICU multidisciplinary team (MDT) who expertly assess and plan the recovery during the patients' illness in collaboration with ward-based MDTs on step down. The trajectory of recovery for individual patient is affected by several factors, which include the injury or illness on admission, age, frailty, socio-economic status, ethnicity along with many others. For the majority of patients, the recovery is dynamic and their clinical condition at ICU discharge will improve with co-ordinated input from the whole multidisciplinary team to enable hospital discharge with or without community support.

Since 2010, it has been recognised that there is a complex array of critical illness long-term sequelae affecting the health-related quality of life of both survivors and their families. New disabilities and limitations in activity resulting from critical illness can be grouped within three domains: physical, cognitive and psychosocial<sup>2,3</sup>. Critical illness is also a family crisis impacting the psychosocial wellbeing of family or informal caregivers. Family may experience mental health problems with depression, anxiety and Post Traumatic Stress Disorder and this can be compounded when patients return home, due to the care burden. **The terms post intensive care syndrome (PICS) and post intensive care syndrome-family (PICS-F) are often used to capture the constellation of symptoms and problems that persist following critical illness.**

During the ICU stay, a small minority of patients will develop significant disability and require discharge to a specialist inpatient or community-based rehabilitation service<sup>11</sup>. This can require input from rehabilitation specialists or co-ordinated referrals to established regional centres from the MDT on the ICU or ward.

Some patients are admitted to ICU with specific injuries, illness or after specialist surgery that requires specialist hospital- or community-based rehabilitation e.g. major trauma, head injury, stroke or cardiac surgery and there are established rehabilitation pathways in the community for such conditions.

**However, the majority of ICU patients will be discharged from ICU with their initial recovery coordinated by the ICU MDT.** The ward-based MDT continue this work up to hospital discharge ensuring appropriate onward referrals to community-based rehabilitation or support services to achieve individualised goals. Hospital discharge summaries are relied upon as the sole means of relaying important care information and mark the transition between secondary and primary care.

Outpatient follow-up services for ICU patients were first pioneered at the Whiston and Royal Berkshire hospital some 30 years ago with the specific purpose to improve the quality of care after hospital discharge.

Assessment and rehabilitation during and after ICU is embedded in national standards and guidance, highlighting follow up clinic appointments between 2-3 months after hospital discharge as a key element due to the complexity of PICS and the requirement to ensure the co-ordination of care.

**In 2009, NICE<sup>4</sup> guidance included 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). This guidance achieved only limited traction. In 2015, the Scottish Intensive Care Society Quality Improvement Group published guidance, making critical care rehabilitation one of its Quality Indicators<sup>5</sup>. In 2017, NICE published its Quality Standard (NICE QS 158)<sup>6</sup>, and since then there has been more of a concerted effort for all ICUs nationally to provide rehabilitation and follow up services. In June 2019, the Faculty of Intensive Care (FICM) and Intensive Care Society (ICS) published the Guidelines for the Provision of Intensive Care Services (GPICS) version 2<sup>7</sup> and stated that the ‘Implementation of an intensive care follow-up service allows the provision of vital support following hospital discharge and the most effective management of complications related to critical illness and treatment.’ A recommended standard was published ‘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.’

An array of diverse models of practice has evolved to support recovery from critical illness. It is recognised that local institutional factors have predominantly shaped the composition of these services:

- extent of available resources and funding
- needs of the local case-mix
- professional background of the founding practitioner(s) e.g. nurse, therapist, doctor
- interdependencies with existing pathways and with neighbouring institutions

Across the UK, a lack of prioritisation and clear funding has resulted in inequity of access to post ICU recovery services. Staff shortages include trained occupational therapists and psychologists working within UK ICUs.

Local commissioners and Trust management leads frequently request robust evidence of the cost-effectiveness of such services to justify funding. Cost-effectiveness has been difficult to demonstrate, but this is rarely requested for other specialist outpatient services as the benefits are deemed implicit in these services. Qualitative studies report positive patient feedback on the benefits of post ICU clinics where aftercare is well-co-ordinated, with an opportunity to have contextualisation of the ICU experience along with signposting to community services<sup>8</sup>, and referral onwards to specialist services.

**In the first year after hospital discharge following critical illness, over half of ICU survivors visit an emergency department and a third are readmitted within 30 days of hospital discharge and up to 60% are readmitted within a year.** Furthermore, approximately two-thirds at 3 months, two-fifths at 12 months and one-third at 60 months of previously employed intensive care unit survivors are jobless following hospital discharge<sup>9</sup>. Survivors returning to work often experience job loss, occupation change or detrimental change in employment status<sup>2,10</sup>. Outpatient follow-up services may impact these significant issues after critical illness, but as

yet such outcome metrics have not been evaluated systematically following the intervention of clinic assessments and care-co-ordination.

The question of who should provide recovery services has stimulated debate about whether it should be intensivist led or otherwise<sup>11-13</sup>. 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. Staff benefits include feedback from patients and relative/carers 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.

**General practitioners are often limited by consultation time and the infrequency with which they encounter such complex post ICU patients.** They are best placed to understand the available local community services, but are under enormous strain to manage the various recovery issues experienced by patients. Close collaboration is required between secondary and primary care, but the responsibility for the co-ordination of care should lie with the intensive care and follow-up services in the initial phase after hospital discharge.

The Covid-19 pandemic generated a uniquely large cohort of critically ill patients with the same disease requiring admission to ICU. This grabbed public attention and much effort has been injected into understanding and planning the follow-up of critically ill patients recovering from Covid-19. NHS England and NHS Improvement London have produced guidance on the co-ordination of hospital and community services to support patients that suffered with Covid-19 in hospital and the community<sup>14</sup>. The hope is that the intense focus on the long-term effects of critical illness (Covid and non-Covid) that patients experience will result in wider discussions about rehabilitation with specific focus on national funding of hospital and community services, such as outpatient clinics and community critical illness rehabilitation programmes.

The development of critical illness aftercare services is at the forefront of the Faculty of Intensive Care Medicine's strategy and forms part of the 2017 publication of Critical Futures<sup>15</sup>.

Life After Critical Illness (LACI) was commissioned as workstream 12 of the Faculty of Intensive Care Medicine's Critical Futures Project. In November 2019, the Faculty founded the Life After Critical Illness Working Party (LACIWP) to work across multiple organisations and professions throughout the UK. These organisations reflect the requirement for close collaboration across a spectrum of multidisciplinary organisations when exploring the optimal approach to planning and delivering ICU recovery services.

In addition to UK-wide members of the Faculty, organisations represented on the LACI working party 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
- UK Clinical Pharmacy Association Critical Care Group
- British Dietetic Association

An interim document was published in May 2020 in response to the Covid-19 pandemic<sup>16</sup> focusing on the recovery after Covid-19.

Now, we present an overarching FICM Life After Critical Illness document; whose objectives are outlined below:

- describe UK current practice
- provide an outline of existing inpatient and outpatient recovery service models, with a focus on the latter, incorporating vignettes of good practice
- summarise how existing and evolving models of funding adult critical care will impact provision of critical illness recovery services
- guide recovery clinic business case development for submission to local commissioners or regional funding board (with examples)
- outline future perspectives including innovation and research to improve individual outcomes after critical illness.

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## Patient Vignette

*"Within a few days of being admitted to Royal Berkshire Hospital I was diagnosed with Guillian-Barre Syndrome which caused severe paralysis. I spent four months in hospital, one of which was in Intensive Care and as with many others who have had the same experience I had a very limited memory of my time in the unit. It was fourteen months before I was able to return to work on a full time basis.*

*It wasn't long after my stay in Intensive Care that I began to realise the importance of the support, both psychological and physical, provided by the Rehabilitation after Critical Illness team.*

*Before being discharged to a general ward the reduction in the level of nursing care from one to one to eight or maybe ten to one was explained, triggering a feeling of insecurity in myself and my relatives. This feeling was eased by the knowledge that the RaCI team would be monitoring my progress and would visit if there was any possibility of my condition deteriorating. Support by the team continued after discharge from the hospital with a one to one visit to the Unit, the provision of a diary and access to the follow-up clinic. The importance of the one-to-one visit to the unit and the provision of a diary cannot be over emphasised and was a good starting point on the road to my recovery. These events allowed me to bring everything about my stay into perspective. I was given the opportunity to see the equipment used during my stay in the unit and the reasons for its use were explained in detail thus enabling me to fill in the gaps in my time spent in their care. The visit also enabled me to meet with and thank those dedicated members of staff whose efforts had saved my life and had also provided a high level of support to my family during a very difficult time. The follow-up clinics also provided an opportunity for me and my wife to discuss with the team any problems that had developed since my discharge and any ongoing concerns about my treatment and its possible long term effects on my recovery. I was fortunate in that the team had involved the Community Trust in my rehabilitation care plan as this enabled me to have physiotherapy for a number of months at home.*

*The programme developed by the RaCI went a long way to alleviate the trauma that I and many others develop after a stay in Intensive Care. The support provided by the team was and still is available to me and my relatives 24/7 as There is no statute of limitations on the effect of a stay in Intensive Care.*

*I was fortunate to be involved in the creation of the Reading ICU Support Network that complements the work of the RaCI team. This has made me aware of the ongoing need to support both patients and their relatives/carers for, in some cases, many years after the experience of a stay in Intensive Care. The Network not only allows patients and relatives to share their experiences with their peers but also provides a forum for clinicians to present on related topics and researchers to develop and recruit ex-patients onto their projects."*

**Gordon Sturme**

## 2. OVERVIEW OF CURRENT INPATIENT AND OUTPATIENT PRACTICE

This section sets out the current scope of critical illness recovery practices across the UK, covering both inpatient and outpatient phases, following ICU step down, as depicted in Figure 1 below:

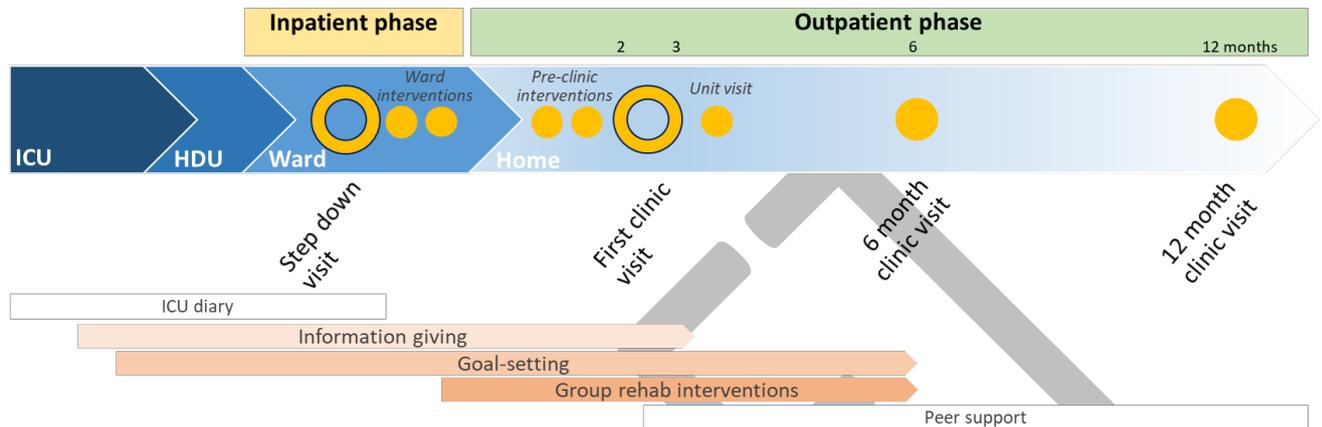


Figure 1. Potential facets of critical illness aftercare spanning the inpatient and outpatient trajectory.

The overall trend across the NHS over the last decade has been a prodigious expansion in critical illness recovery services covering both the inpatient and outpatient phases. This is evidenced by summary findings of the FICM LACIWP survey of UK wide critical illness recovery services that was undertaken in summer 2020. It received an overall response rate of 77%, representing 186 out of 242 UK NHS ICUs. Responses from all devolved nations were as follows: Scotland (n=23/23, 100.0%), Wales (n=12/15, 80.0%), Northern Ireland (n=7/9, 77.8%), England (144/195, 73.8%).

Whereas in the 2013 benchmark study<sup>1</sup> only 27% of UK ICUs provided any form of **outpatient** recovery service, this figure has risen to [redacted] as of 2020. Furthermore [redacted] of sites provide a form of **inpatient** critical illness recovery service following ICU step down (no historical benchmark). A trend towards further expansion is anticipated since [redacted] of responding ICUs reported an intention to expand an existing service and [redacted] to launch a new service, within the next 2-5 years.

In the next paragraphs we present an overview of current formats and staffing models for inpatient and outpatient recovery services with inclusion of relevant LACIWP survey findings.

### 2.1 Inpatient phase - service models

Inpatient recovery services have evolved to address the hospitalised phase of recovery following step down from ICU through to discharge from hospital to home. This phase can range from a few days to several months. UK ICUs report a wide range of inpatient service formats with many ICUs incorporating both face-to-face elements and generic elements to promote recovery (table 1).

Face-to-face ward visits are often the first place for families and patients to reflect on the impact of critical illness outside of the ICU environment in a psychologically safe space. Post-




## 2.2 Outpatient phase - service models

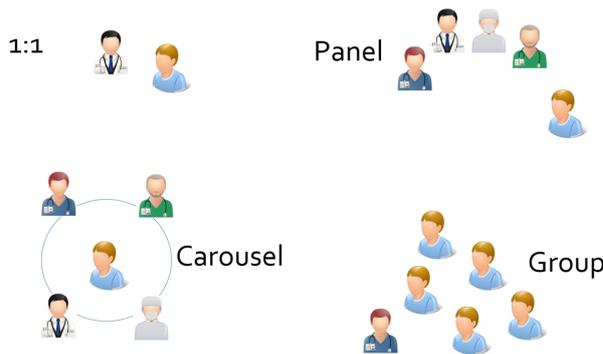
According to the LACIWP survey outpatient consultations were undertaken face-to-face within the hospital in [redacted] of instances prior to the Covid-19 pandemic. These face-to-face clinic consultations would either be uni- ([redacted]), bi- ([redacted]) or multi-professional (3 or more professionals, [redacted]). The latter occurs in either panel mode ([redacted]) or carousel model ([redacted]).

The pandemic accelerated the use of virtual platforms and telephone consultations to reach patients, given lockdown and social distancing restrictions.

The benefits and limitations of each model are outlined below in Table 3, but all are interchangeable.

Table 3. Types of face-to-face outpatient consultation and corresponding options for virtual consultation.

MODEL OF SERVICE	IN-PERSON OPTION	VIRTUAL PLATFORM/TELEPHONE CONSULTATION
1:1 uni-professional	Yes	Yes (1:1 video call or phone call)
Panel MDT	Yes (all MDT members in one room)	Yes (MDT videoconference or phone call with individual patient)
Carousel MDT	Yes (each MDT member in separate room)	Yes (sequential 1:1 video call or phone call)
Group or cohort	Yes (secondary care or community)	Yes (group videoconference or phone call)
Drop-in café	Yes	Yes



### Model benefits and limitations

#### Face-to-face attendances

These offer the following benefits:

- the interpersonal quality of a traditional outpatient professional consultation.
- the opportunity for clinical examination, clinical measurements and same-day investigations if required.
- the opportunity for visiting the critical care unit to environmentally contextualise the ICU experience and meet members of ICU staff.

#### Patient and Family return visit to the Intensive Care Unit

The visit back to the Intensive Care Unit is a valued therapeutic intervention for patients and families, which can take place any time after the first clinic review. For some patients it is revisiting the 'trauma site' and should be conducted when it is psychologically safe to do so. The visit provides an opportunity for patients and their families to go through the notes, see the environment including exposure to sights, sounds and smells and meeting the staff that cared for them. Often it provides a safe psychological space for the patient to gain insight into their critical illness not only from the clinical perspective but also from the families' perspective, thereby providing a dovetailing of experiences. This can be in addition to patient diaries or a standalone intervention.

Limitations:

- Travel
  - cost (although reimbursement is available for those receiving social care benefits).
  - challenges for those with fatigue and disabilities.
- Time
  - impact on work.
  - timing with caring responsibilities.

### Group patient model

This is an alternative to the individual patient consultation which involves several contemporaneous patient participants (an exemplar of this model is InS:PIRE, see Appendix 1). It incorporates the following benefits:

- Shared experience
- Informal peer support
- Co-participation in exercise or activity

Limitations:

- Anxiety of group experience
- Patient confidentiality
- Individualised preference for more personalised approach to care
- Systematic evaluation of an individual with complex issues is more challenging
- Those with sensory disabilities may find it challenging.

### Virtual platform clinics

These are associated with the following recognised benefits:

- Convenient for the patient (no travel, parking or travel costs)
- Home environment can be appreciated
- Multi-person platform enabling translators and other healthcare professionals to join the consultation when required
- Rapport more easily achieved with visual engagement compared to telephone
- Access to family
- Shielding healthcare professional can deliver the service

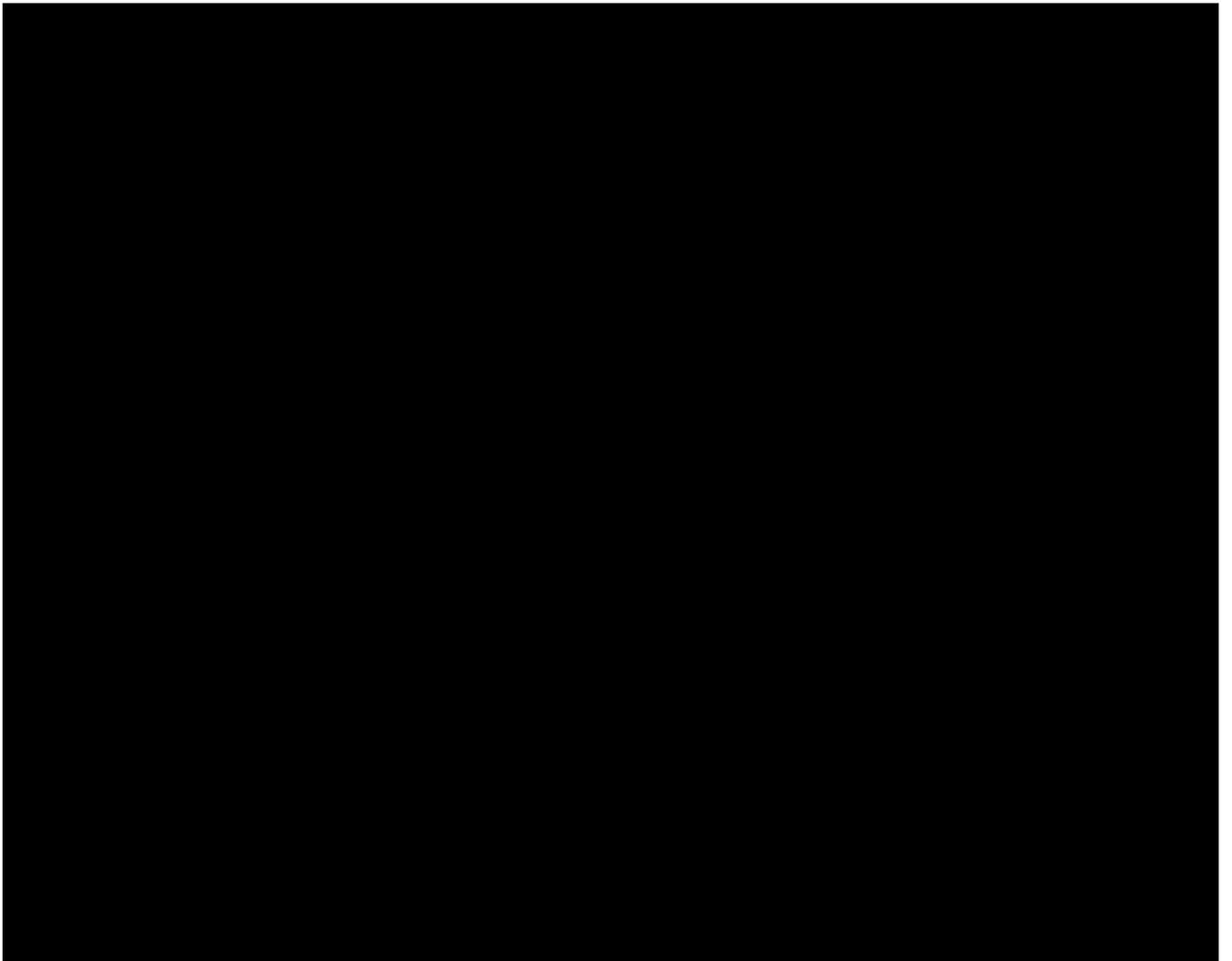
Limitations include:

- Inaccurate patient contact details on medical records – difficult to make contact
- Smart phone or computer not available to all, and/or lack of confidence for use of technology
- Connectivity issues affect quality and duration of consultation
- Inability to undertake direct physical examination
- Blind MOCA required for cognitive assessment and no well validated self-administered cognitive measures
- Inability to visit the ICU and meet members of ICU team
- Lack of access to a private space for consultation.

## 2.3 Outpatient clinic staffing

All outpatient service models can be undertaken by a range of critical care professionals; most commonly ICU nurses, intensivists, physiotherapists, psychologists or a combination with additional MDT members such as dietitian, occupational therapist, pharmacist, speech therapist and liaison or neuro-psychiatrist included if available and according to clinical need. Table 4 and figure 2 show the reported spectrum and combination of MDT professionals delivering the critical care outpatient recovery services.





## 2.4 Relationships with other services

Critical illness recovery services can align themselves with relevant specialty clinics to deliver co-ordinated care that is beneficial for the patient and providers. For example, █ UK ICUs reported active coordination of care with existing respiratory, neurology or trauma clinic. Figure 3 highlights valuable internal and external relationships for critical care recovery services.

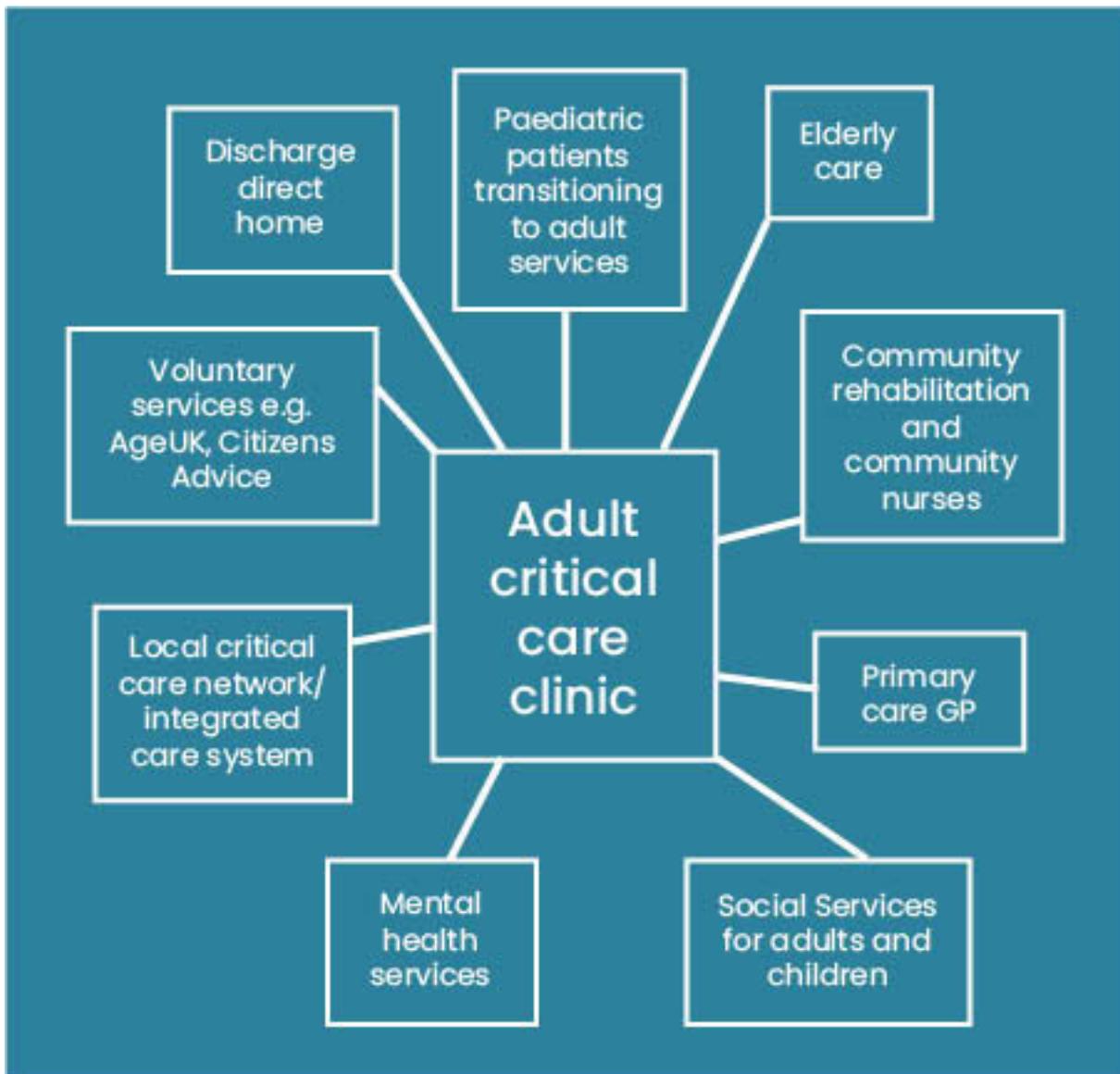


Figure 3. Key partners of a critical illness recovery service within institution and beyond.

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### 3. BEST-PRACTICE PRINCIPLES AND RECOMMENDATIONS FOR THE DELIVERY OF CRITICAL ILLNESS RECOVERY SERVICES: INPATIENT PHASE INCLUDING HOSPITAL DISCHARGE



Figure 4. Inpatient trajectory.

The inpatient phase of recovery is now well established with [REDACTED] UK ICUs reporting provision of a dedicated inpatient critical illness recovery service (there are no historical data to inform rate of adoption). [REDACTED]

[REDACTED] Best-practice principles to support inpatient critical illness recovery services are described here.

#### 3.1 Handover and transfer process ICU to ward

The inpatient phase starts with the handover from ICU to ward.

[REDACTED]

[REDACTED]

The handover of care on transfer from critical care to a general ward is the shared responsibility of the critical care team and the ward team. The formal handover of care should be structured and should include the following as per NICE CG83<sup>1</sup>:

- a summary of the critical care stay, including diagnosis and treatment
- a monitoring and investigation plan
- a plan for ongoing treatment, including medications (see section 3.8) and therapies, psychology sessions if necessary, nutrition plan, infection status and any agreed limitations of treatment
- an agreed individualised structured rehabilitation programme, including physical, psychological, emotional and cognitive needs
- specific communication or language needs.

Furthermore, NICE Quality Standard 158 QS2 states that “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”<sup>2</sup>.

A best practice point would be to undertake at least one rehabilitation session jointly between ward and critical care therapists, either on critical care or ward after stepdown.

To maximise continuity of care it would be best to have the same multi-disciplinary AHP members involved in the patient's entire recovery journey.

The transition from ICU to the ward is often a significant event in the patient journey and can evoke a range of emotions. The first step down visit facilitated by the ICU follow up team can provide an early opportunity for creating a safe space whereby patients and their families can start to make sense of the critical illness experience. It is a time where patients are provided with information and context related to their critical illness and equally a time where the patient and relative experience can be heard. Feedback regarding the quality of the service provision from the service users can identify areas that may need addressing in a timely manner such as quality improvements or mitigating complaints early on.

GPICS V2 Rehabilitation (Chapter 3.6), recommendation 6 states: *"To facilitate the rehabilitation component of the formal handover of care on discharge from critical care to a general ward, weekly multidisciplinary rehabilitation ward rounds should be led by a senior member of the critical care multi-professional team and result in an update to the rehabilitation goals. These should be set in conjunction with the patient and/or carer where appropriate."*<sup>3</sup>

### 3.2 Patient centred goal-setting

Goals should be determined in collaboration with patients and families. Goals should be person-centred and holistic rather than discipline-specific. Goal attainment scaling is a helpful structure for tracking progress against goals<sup>4</sup>.

The goal-setting should be undertaken with a practitioner with appropriate knowledge, skills and expertise in critical illness (and trajectories after critical illness) to support patients and their families/carers in setting achievable and realistic goals. Psychologists may assist with the goal-setting process, and have specific expertise to help engage the patient if goal-setting is challenging due to concurrent psychological distress, cognitive limitations, or early stages of psychological adjustment. Cognitive ability has a substantial impact on the ability for patients to participate in their rehabilitation plan. Cognitive difficulties should therefore be accommodated as much as possible in order for patients to participate in their recovery.

Goal-setting should include medium term goals related to resumption of desired activities or occupations.

All patients should receive a copy of their goals that they and their families can refer to. Goals should be reviewed and updated regularly and prior to discharge. Relevant onward referrals should be completed.

### 3.3 Complex care needs during recovery from critical illness

The severity and duration of critical illness, pre-ICU co-morbidities, clinical and social frailty influence an individual's complex needs during the recovery phase. 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 Medicine advocate early involvement of a consultant in Rehabilitation Medicine 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 using a Rehabilitation Prescription to capture met and unmet needs for rehabilitation following discharge from Major Trauma Centres.

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. 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. Re-referral for re-ablement therapy that arguably terminated prematurely is often required. For some, significant impairments can persist for months, years or sometimes a lifetime.

Where goal attainment is unrealistic the likelihood of returning to pre-morbid functioning should be discussed with patients, their families and carers. It is essential to be open and honest regarding trajectories of recovery following critical illness. In this situation, we should support patients, their families, and carers, to adapt goals to something that is achievable, whilst maintaining as much of the original goal(s) as possible.

Some patients may require ongoing psychological support or therapy due to the psychological impact of critical care, e.g. anxiety, depression and intrusive memories, or to help in adjusting to disabilities or other life changes. Psychological support should have begun in the ICU, continue through the ward stay and continue post-hospital discharge.

### 3.4 Assessment and screening tools

Patients recovering from critical illness require a collaborative MDT approach to achieve bespoke inpatient rehabilitation, goal setting and discharge planning. Suitability of a generic post ICU screening tool for this diverse cohort has not been demonstrated. There have been International modified Delphi studies that have sought to identify the optimal core outcome sets for research studies<sup>5-7</sup>. However, each of these core outcome measures needs also to be assessed in terms of their clinical applicability to identify patient need and help inform planned interventions and onward referrals rather than just act as a part of a data collection tool. Furthermore, for any individual metric, serial rather than isolated measurements are more useful enabling the evaluation of change or lack thereof, helping to inform about patient recovery.

The following assessments have clinical value during the inpatient stay to assess physical, cognitive and psychological morbidity (this list is not exhaustive).

- Physical function and response to therapy is frequently assessed using the Chelsea Critical Care physical assessment tool (CPAx) which has a good construct validity noting potential for a ceiling effect for patients without explicit rehabilitation needs or towards the end of a hospital stay. Alternative physical assessment tools include the Short Physical Performance Battery and the Physical Function in Critical Care (PaciFIC) scale.
- Cognitive assessment, this requires an evaluation of delirium with the often-used confusion assessment method for ICU (CAM-ICU) score validated within ICU and the 4AT delirium score applicable to non-ICU inpatients. If delirium screening is negative, then the abbreviated mental test score (AMTS) or Montreal Cognitive assessment (MOCA) can be utilised to screen for cognitive impairment. Occupational therapy is important for ensuring a *functional* and clinical evaluation is undertaken with planning of interventions and follow-up. This may include referrals to neuropsychiatry, old age psychiatry, memory clinics or GP assessment once home.

- Psychological distress is highly prevalent and the Intensive Care Psychological Assessment (IPAT) tool is validated to detect this distress and alert staff to the need for psychological support. It is not validated for predicting post-traumatic stress disorder, which requires follow-up assessment once the patient has returned home.

In the UK, there is wide disparity in relation to the availability of allied health professionals within critical care units. For example only 6% of services previously reported an occupational therapist within the critical illness recovery team, although GPICS2 section 2.9 recommendation 4 states that:

“the critical care team should include a senior occupational therapist with sufficient experience to contribute to and develop rehabilitation programmes that address the complex functional, cognitive and psychosocial needs of the patient cohort”<sup>3</sup>.

The examples of screening tools above can be used to identify care needs and gather valuable data regarding the gap between GPICS recommendations on workforce and the available workforce within a given critical care unit. This will be helpful for writing business cases to recruit healthcare professionals e.g. occupational therapists and psychologists.

### Inpatient screening tools

During the initial wave of the Covid-19 pandemic, it was clear this new virus would be associated with uncertain outcomes across the spectrum of the disease, but the outcomes of those that became critically ill would be one of the most uncertain. Since April 2020, the Intensive Care Society linked up with members of the British Society of Rehabilitation Medicine to develop an ICU rehabilitation assessment tool. It was founded on a tool, utilised in major trauma rehabilitation centres since 2010 to formulate a specialist ‘rehabilitation prescription’<sup>8,9</sup>. The rehab prescription was developed specifically for patients with more complex rehabilitation needs after trauma to help determine whether rehabilitation was required in a Level 1 or 2 specialist rehabilitation centre. The distinction between the two levels of rehabilitation care services is outlined below.

Level 1: are high cost / low volume services, which provide for patients with highly complex rehabilitation needs that are beyond the scope of their local and district specialist services.

Level 2: are services planned over a district-level populations of 350-500K and are led or supported by a consultant trained and accredited in Rehabilitation medicine (RM), working both in hospital and the community setting.

It is recognised that the large majority of trauma patients will progress satisfactorily along the pathway to recovery with only the support of their local (Level 3) rehabilitation services. These level 3 services are led by non-specialist rehabilitation teams who provide general multi-professional rehabilitation.

The Post-ICU Presentation Screen (PICUPS)<sup>10</sup> tool is a 14-item checklist to support triage and handover of patients stepping down from ICU into the acute wards, and onwards into rehabilitation. The PICUPS Plus provides an additional 10 optional items to be utilised on an individualised basis depending on presentation and aims to identify issues that will impact progress during recovery and influence the development of the Rehabilitation Prescription.

A recent publication outlining the development of a preliminary clinical evaluation tool concluded ‘PICUPS’ is *potentially* useful as a tool for identifying rehabilitation needs as patients step down from ICU and acute hospital care<sup>11</sup>.

## Readmission risk screening

Within 3 months of hospital discharge, 25% of critical illness survivors experience an unplanned hospital readmission with half having a complex set of pre-existing health and psycho-social needs: multi-morbidity, polypharmacy, significant psychological problems, mobility issues, problems with specialist equipment and fragile social support.

In Scotland, a research screening tool was introduced at the Royal Infirmary in Edinburgh to identify those patients at highest risk of readmission. The tool was called 'Supporting Community Recovery and Reducing Readmission Risk following critical illness' (SCARF). The SCARF tool can be used to identify patients with complex health and social care issues. These patients are at the highest risk of hospital readmission. See *Appendix 3, for full details.*

## SCARF Tool

Risk-factors screened for in SCARF-tool	Meaning
'Comorbidity'	Patient had 4 or more different morbidities before this admission to ICU
'Live alone'	Patient lived by themselves before this admission to ICU
'Polypharmacy'	Patient was taking 4 or more prescribed medications before this admission to ICU
'Pre-existing mental-health problems'	Patient had a history of any mental health problem before this admission to ICU
'Pre-existing mobility problems'	Patient had a history of any morbidity problems before this admission to ICU

Individuals identified as high risk of readmission are put on the SCARF pathway, which involves rapid information transfer from hospital to GPs, health and social care partnership teams and community pharmacies. A key feature of the project is establishing close links with community based teams with the goal of ensuring rapid information transfer from hospital to community to enable health and social care staff to anticipate the needs of these vulnerable complex patients prior to their discharge home.

The aim is to achieve a 20% reduction in the 90-day and 6-month hospital re-admission rates for those at highest risk of re-admission following critical illness in Lothian, Scotland.

### 3.5 Education of ward staff

Many patients and families report how difficult the step down from ICU into the ward is. They sometimes feel that ward staff lack understanding of their ordeal. We suggest units consider a programme of education for ward staff in relation to:

- symptoms and sequelae of PICS-F
- understanding of what people experience when in ICU
- assessment and management of delirium and cognitive impairments
- factors that influence nutritional intake e.g. poor appetite, taste changes, poor appetite
- management of nutritional issues e.g. provision of extra snacks, importance of nutritional supplements, need for ongoing enteral nutrition in some cases
- awareness and psychological care for distress including anxiety, low mood, panic, intrusive memories, nightmares, flashbacks and cognitive issues

- risk of medication-related errors, changes in route or dose, communication of drug allergies and highlight prioritisation for structured review/reconciliation by pharmacist
- support for discharge home – e.g. fatigue management, pain, physical re-ablement, sleep, work/activity resumption and access to benefits
- contacting the critical illness recovery team.

### 3.6 Communication with GP

#### At ICU admission

Where possible a notification should be sent to the patient's GP on admission to critical care however this is not currently supported by most health systems.

#### At ICU discharge

A discharge letter from the critical care team to the GP may help facilitate discharge planning later and support accurate communication/support with family.

It is important to ensure the discharge summary provides the GP with a succinct overall picture of what the patient has been through and what his/her needs will be and let them know an appointment will be made to attend the clinic<sup>7</sup>.

#### At hospital discharge

GPs are reliant on the quality of received information in discharge summaries to understand the patient's ICU experience, the possible basis for their physical, psychological, cognitive and functional impairments, reasons for treatment decisions and an explanation of medication changes made and plan for ongoing treatment and review according to clinical progress. This information needs to be routinely included in hospital discharge letters.

#### Supporting GPs

GPs are often unaware of events which occurred in the ICU and/or may lack the time, experience, and resources to diagnose and treat post critical illness problems<sup>22</sup>. Support for GPs to become better informed about the problems ICU patients suffer after discharge is encouraged through the use of educational resources and closer primary/secondary care liaison. Use of portals such as Consultant Connect and signposting of referral pathways back into critical illness recovery services is helpful. In the SCARF pathway (see Appendix 3), an email is sent to the GP at ICU discharge forewarning likely need for extra support and then again at hospital discharge when the community pharmacy and local hubs are also copied in and additional information relevant to ongoing recovery is provided in addition to the ward discharge letter.

### 3.7 Information given during the inpatient phase

NICE CG83<sup>1</sup> (2009) highlights the importance of evidence based, tailored information that is repeated at key time points, delivered to the patient and family in a culturally acceptable format, in different languages and accessible to those with additional needs such as physical, sensory or learning disabilities.

- Information about the rehabilitation care pathway.
- Differences between critical care and ward-based care; including the differences in the environment, and staffing and monitoring levels.
- Transfer of clinical responsibility to a different medical team (including information about the formal structured handover of care recommended in NICE clinical guideline 50).
- If applicable, emphasise the information about possible short-term and/or long-term physical and non-physical problems that may require rehabilitation.
- Emphasise the potential short and long term nutritional issues that may be experienced.

- Relevant information about medicines should be shared with patients, and their family members or carers, where appropriate. If applicable, information about sleeping problems, nightmares and hallucinations and the readjustment to ward-based care<sup>12</sup>.
- Where possible provide a lay summary about the individual patient's ICU stay.

Some hospitals develop their own paper-based written information (for example, booklets, pamphlets and leaflets) to supplement verbal information but not all meet recommendations for accessibility. Use of commercially designed information paper-based resources, for example those produced by ICU Steps,<sup>13</sup> offer an opportunity to provide standardised patient centred information, but cannot provide tailored information.

Digital platforms for information sharing within critical care settings may offer advantages. Information provided through mobile applications (Apps) and websites (for example, <http://www.criticalcarerecovery.com/>; <https://covid19.criticalcarerecovery.com/>) offers an easy way to keep information up to date and can be tailored to individual needs. However, despite the potential benefits, there remains a lack of evidence to support the implementation of digital platforms into critical care settings or to determine the impact of their use.

Data suggest that personalised information can help patients better understand their illness experience, increase their satisfaction with care and reduce anxiety<sup>14,15</sup>.

Furthermore, the information needs of patients and their family members are not the same, with family members needing information focused on their own health needs as well as about how they can support their loved one<sup>16,17</sup>.

There remains uncertainty how best to deliver personalised information to optimise recovery or impact health outcomes including unintended negative effects; this results in variations in practice across the UK. Where appropriate, asking patients and families for feedback on the material they are provided with can be a useful step.

### 3.8 Preparation for hospital discharge

NICE Quality Standard 158 QS3<sup>2</sup> states that "*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*". This should incorporate:

- Discharge arrangements
- Information about physical recovery, based on the goals set during inpatient care if applicable
- Information about psychological recovery and adjustment
- If applicable, information about diet and any other ongoing nutritional interventions e.g. oral nutritional supplements
- How to manage activities of daily living including self-care and reengaging with everyday life
- If applicable, information about driving, returning to work, housing and benefits.
- Information about local statutory and non-statutory support services, such as support groups
- General guidance, especially for the family and/or carer, on what to expect and how to support the patient at home. This should take into account both the patient's needs and the family's/carer's needs
- Give the patient their own copy of the critical care discharge summary in a format in which they can understand

- Liaise with primary/community care for reassessment post critical care discharge.
- Ensure information, including documentation, is communicated between hospitals and to other hospital-based or community rehabilitation services and primary care services
- Relevant information about medicines should be shared with patients, and their family members or carers.

Patients should be given the contact details of a relevant ICU healthcare professional(s) on discharge from critical care, and again on discharge from hospital. Signpost psychological support services including ICU peer support groups, IAPT (Improving Access to Psychological Therapies) talking therapy self-referral (in England) or other counselling services, primary and secondary mental health services, crisis numbers, mental health charities and helplines (e.g. Mind).

Attention should be paid to discharge destination. Should the patient be discharged to a relative's home, then a new pharmacy and GP practice may need to become involved.

### Medication considerations prior to discharge

ICU patients can experience significant changes to their medication during an acute ICU and hospital episode<sup>18</sup>. These changes may include discontinuation of clinically important chronic medication (e.g. antipsychotics) and/or continuation of inappropriate medication on ward transfer and hospital discharge<sup>18</sup>; creating problematic polypharmacy burden for the patient<sup>19</sup>. Medicines reconciliation and medication review are key to safe and effective patient care<sup>20</sup>. Medicines reconciliation should be carried out at patient care transitions (e.g. ICU to ward transfer; hospital ward to community discharge) and not just on hospital admission<sup>20</sup>. Medication reviews undertaken in the ICU, ward and community (GP/pharmacy) are important to ensure that high-risk patient receives the right medication<sup>20,21</sup>.

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## 4. BEST-PRACTICE PRINCIPLES AND RECOMMENDATIONS FOR THE DELIVERY OF CRITICAL ILLNESS RECOVERY SERVICES: OUTPATIENT PHASE FOLLOWING HOSPITAL DISCHARGE

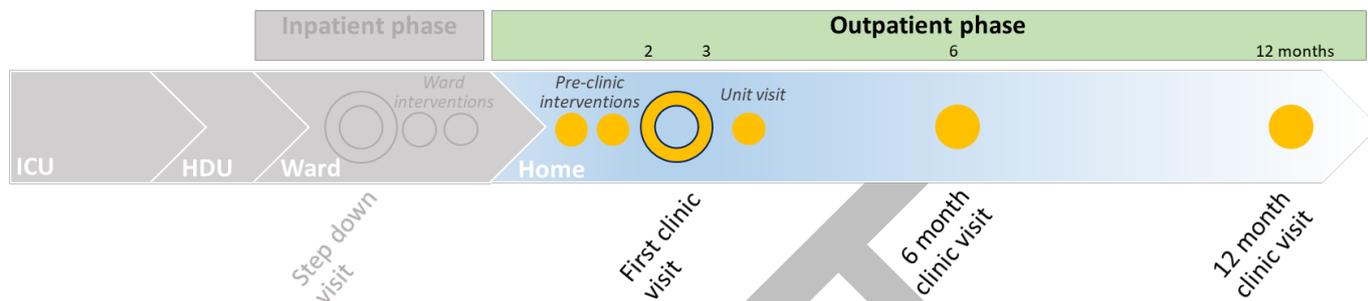


Figure 5. Outpatient trajectory.

The Life After Critical Illness Working Party (LACIWP) sought to define best-practice principles to support critical illness recovery after hospital discharge. Areas where consensus is lacking are also acknowledged.

### 4.1 Selection and booking of patients

#### Inclusion criteria

UK guidance referencing inclusion criteria include the following:

- The NICE Clinical Guideline 83 published in 2009 recommends outpatient review of “patients with rehabilitation needs...”<sup>1</sup>.
- 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...”<sup>2</sup>.
- 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”<sup>3</sup>.
- The Scottish Intensive Care Society Audit Group (SICSAG) Minimum Standards and Quality Indicators for Critical Care in Scotland do not mention any eligibility criteria for follow up<sup>4</sup>.

LACIWP recommends applying a threshold of **duration of mechanical ventilation (>72 hours) and/or length of stay in critical care (>96 hours)** for invitation to outpatient follow up. This composite is felt to capture both acute illness severity as well as intensity of exposure to critical care interventions. It is acknowledged that reliance on a time-based index alone is a crude approach lacking both sensitivity and specificity for the population at high risk of PICS. Other high risk categories may include:

- Out of hospital arrest
- Anaphylaxis
- Maternal critical illness
- Trauma;
- Specific critical care exposures e.g. ECMO or significant ICU delirium;

- Unexpected adverse outcomes/unanticipated complications of planned treatment;
- Intensivist/MDT/ward clinician/AHP discretion;
- Patient or family concern;
- Self-referral, GP referral or other clinician referral.

A newly established service may initially need to impose stricter criteria while embedding new processes. However, to understand sequelae of a novel critical illness e.g. COVID-19, then conversely criteria may need to be loosened

Caution: reliance on CCMDS database which counts length of stay/mechanical ventilation in calendar days rather than hours may result in overestimation of patients meeting the 72h criterion.

It can be very challenging considering whether to include some patients in the offer of a follow up clinic appointment as predicting the likelihood of benefit can be difficult. Each service will have to give careful consideration to the perceived benefits of clinic attendance, especially those who have complex health-social care needs, social isolation, vulnerability or limited means to access healthcare. Critical illness can be a pivotal moment that can result in a change in behaviour with more desire to engage with healthcare professionals. Equally, although the patient may not benefit significantly their relative or carer can benefit enormously. If there is an active decision not to offer a clinic attendance then this should be highlighted in the discharge summary to allow the GP to review the decision and refer into the service if deemed necessary.

Some patients' multidisciplinary needs may already be adequately met within their existing holistic specialist services (examples include transplant, cystic fibrosis, dialysis, stroke neurorehabilitation, cardiac rehab, sickle cell disease, rehabilitation medicine).

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

### **Clinic booking process**

Local circumstances will dictate an automated or manual process for booking appointments. The advantage of selection based on length-of-stay criterion alone is automation and simplicity. Manual triage of unit discharge summary data or telephone screening calls is more labour intensive, however offers the possibility to target resources to those deemed in greatest need, and may therefore influence non-attendance rates.

We recommend linking the appointment booking process with the point of critical care discharge or their home discharge date depending on unit informatics. Active manual tracking of patients after discharge from critical care is burdensome but can help refine the patient cohort attending clinic.

Consider patients' individual needs:

Virtual:

- digital literacy
- access to smart devices
- language (use of interpreters and phone translation)
- deafness, hearing or visual impairments etc

Face-to-face:

- clinic accessibility
- transport
- financial support for travel cost if eligible (e.g. on income support)
- provision of supplemental oxygen

### Primary care referral options.

#### Electronic referrals (e-RS):

The mechanisms for making referrals from primary care to secondary care services involves the use of NHS England's e-Referral service (e-RS), or national equivalent. This is available to GPs to be able to make electronic referrals into specialist secondary care clinics. Scotland uses SCI Gateway which is a single national system that integrates some aspects of primary care IT systems (e.g. Vision, EMIS) and secondary care IT systems (e.g. Intersystems TrakCare). SCI-Store enables sharing of laboratory information, clinic letters, referrals, and discharge letters. SCI-Gateway enables GPs to make protocol based referrals which includes extracted clinical and demographic information from their systems. There is no national or local option designated for post ICU clinics, but discussion with your local e-RS team (every NHS England Trust has one,) can enable the development of a pathway for GPs to refer into your service via e-RS. This can then be shared with local GPs via their intranet and email distribution lists.

Within e-RS there is an advice and guidance (A&G) service, which enables electronic referrals to be sent by GPs to request A&G. This can be helpful to GPs and establish contact with primary care to strengthen and develop working relationships to ensure optimal patient care and outcomes. Standard operating procedures are required to ensure the process to convert A&G to a referral are robust.

There is a plan to ask the e-RS clinical reference group to allow 'Post-ICU recovery' clinic to be an option within the national system for outpatient Post ICU clinic services to more accessible to GPs.

#### Consultant connect:

This service requires a specialist from the outpatient service to be available for telephone advice to GPs 9-5pm Monday to Friday. It enables GPs to call 'Consultant Connect' during patient appointments to get instant treatment advice from a specialist to check whether a referral is necessary.

Close collaboration with other local hospitals is encouraged to enable referral into services where psychology, occupational therapy or neuropsychiatry are available; a hub and spoke model.

Pre-clinic phone-calls or automated short message service (SMS) texts can reduce did not attend (DNA) rates. Many patients struggle with cognition and will require these reminders.

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 and an offer to provide feedback for their reasons for not attending. GPs should also be notified. We should be aware that it is often the most vulnerable who may not attend.

There is potential to consider routine GP (or specialist practice nurse) follow up appointments for all patients who have been in ICU to accompany the ICU- GP discharge letter. This will ensure those who don't meet the requirements for ICU follow up do not fall through the net and that the GP practice are aware of their needs.

Critical Illness Recovery Services inevitably carry a DNA 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 DNA rate accordingly once steady state is reached.

During the critical illness episode the patients' own contact details are rarely entered in the clinical record and next of kin (NOK) details predominate. We recommend that unit staff routinely reconfirm patients' own phone and email and/or the address they will be discharged to. This facilitates right-person-first-time communication with the recovery services and other appointments. Information governance should ratify that NOK can provide these details on the patient's behalf.

### Who should attend?

Where the service model allows, we recommend that relevant next of kin, family, and/or caregivers are invited to accompany the patient to the virtual or face-to-face appointment, especially if emotionally impacted by the experience. They may need their own designated period of time during the consultation to address their own psychological or social needs.

Studies ("SCARF") have shown that individuals with complex health-social care needs are at particularly high risk of rapid hospital readmission following an ICU stay. Characteristic features associated with this group include pre-existing problems associated with mobility or mental health, multiple co-morbidities, polypharmacy and social isolation. Often these patients have few new physical needs and thus do not trigger attendance criteria for a follow up clinic.

## 4.2 Timing of intervention

### Initial outpatient review

UK guidance relevant to timing of the initial outpatient review:

- NICE CG83 recommends a review "2–3 months after their discharge from critical care".<sup>1</sup>
- QS158 concurs with "2 to 3 months after discharge from critical care".<sup>2</sup>
- 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"<sup>3</sup>.
- SICSAG's Minimum Standards and Quality Indicators for Critical Care in Scotland state that outcomes should be reviewed consistently at follow-up appointments but does not specify timeframe<sup>4</sup>.
- People with COVID-19 cared for in an ICU/HDU setting to be seen 4-6 weeks post-discharge (NHS 2021)

Measurement from time of hospital discharge rather than critical care discharge is more likely to ensure consistency and comparability of outcome data between patients and between services. However a subset patients may spend many weeks hospitalised following their critical care step down. These are likely to be at high risk for PICS and should be offered support at 2-3 months after ICU discharge, even if they are still an inpatient prior to hospital discharge. It should be noted that some patients may require help prior to the 2-3 appointment. 5% of patients needing intensive care will require specialist rehabilitation medicine input and this can be initiated prior to hospital discharge.

Tertiary centres will need to factor in repatriations of patients to local or regional institutions. This comes with the uncertainty of knowing eventual hospital discharge date. This can be overcome by ensuring good communication with the hospital the patient is repatriated to, or

telephone call to patient/NOK to confirm discharge home and offering an appointment 4 months from repatriation allowing 4-6 weeks of inpatient stay locally.

Occasionally the patient may have died during this time period so preparation to manage this sensitively through all communications needs consideration.

### **Subsequent outpatient reviews**

Following the initial outpatient review a minimum of one subsequent appointment should be provided if there are multiple action points/interventions from initial consultation to be completed and followed-up or where:

- Complex care coordination is required following critical illness
- Onward referrals and recommendations were made that need follow-up and review
- 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
- significantly delayed occupational recovery domains such as return to work, driving, travel, can be addressed
- Advanced care planning can be considered supporting the patient, family and GP

### **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 and established impairments can be viewed as chronic and they should have been appropriately referred for specialist input or can be managed by the GP. 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.

Primary care and Community services have a very significant part to play in supporting both patient and family across the recovery trajectory. This highlights a requirement to improve links and ensure effective information sharing between primary care and secondary/tertiary care. This should commence prior to hospital discharge, with provision for ongoing contact agreed at a local level. Providers of an outpatient service must ensure this good practice is adhered to and must maintain effective working with local GPs.

## **4.3 Operational considerations**

Consideration should be given to the following aspects of service delivery.

### **Venue/number of consultation rooms**

Requirements will depend on service model (e.g. virtual/F2F; 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, oxygen delivery, medical escalation pathway, privacy for psychology consultations). Proximity to relevant services (radiology, phlebotomy, parking) and to ICU for visits should be factored in. The environment preferably should not evoke strong memories of critical illness.

Privacy, videoconferencing equipment and connectivity will dictate the best environment for virtual clinics.

### **Scheduling frequency of outpatient service**

No recommendation - This will be determined by local factors including MDT work patterns, service model, venue availability and volume of work.

### **Equipment**

Consider:

- Videoconferencing or telephone equipment if virtual and appropriate support to enable access (if required)
- IT access to electronic health record and tablets for electronic questionnaires.
- Physiological measurement (spirometry, dynamometry, stopwatch, BP manometer and peripheral saturations probe, weighing scales)
- Accessibility (e.g. chairs, wheelchairs, hearing loss, visual impairment, need for oxygen)
- Clinical (phlebotomy, local anaesthetic and wound packs)
- Stationery (request forms, feedback questionnaires, prescription forms)
- PPE.

### **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. Use integrated primary/secondary care clinical portals where regionally applicable (e.g. in Wales) to share discharge letters. GPs must have a reliable and formal process for referring patients to the service e.g. via ERS.

### **Conduct of the clinic**

Preparatory work to review patient records, ascertain timeline of critical care events and to share this information between relevant professionals will enhance quality of care given in clinic.

Pharmacy colleagues should be engaged with accessing the most up-to-date medication and allergy records.

Where the service model permits:

- a pre-clinic team meeting: discuss all patients, identifying potential key recovery needs and individual challenges
- a post-clinic debrief: share findings, address discrepancies and agree interventions collaboratively with MDT.

Convening the team can also serve as an educational, supportive and iterative service improvement exercise. However, the number and type of trainees invited to observe the clinic requires careful consideration to ensure this does not impact on the patient experience or their willingness to engage. Patient information or clinic attendance letter should explicitly

highlight that students may be present during a consultation, but the patient has the right to request they leave.

#### 4.4 Governance

##### Management and leadership

Services should have a designated lead clinician. Services should be incorporated within the critical care service management structure. Activity, governance and finances should be regularly reported to the department management team. Provision should be made for risks, incidents and complaints to fall under the wider critical care unit governance umbrella. Compliments from patients and families should be shared through the patient experience channel. All external peer reviews and formal quality assessments of the critical care service (e.g. CQC, GIRFT) should include the Critical Illness Recovery Services.

##### 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. Patient and family experience evaluation and feedback processes should be built into the service. There can also be a link to service improvement and research questions, which could be fed back to the local R&D/improvement teams and/or academic partners to support the development of collaborative projects, which could be completed by trainees as part of higher level degrees.

##### Risk assessment

Standard operating procedures should be developed to safeguard risks. Examples include:

- Local Clinical governance processes
- Managing non-attendance and barriers to attendance
- Ensuring accessibility of service for all patients including hard-to-reach patients
- Escalation of patients (and loved ones) presenting with heightened suicidality, psychiatric risk and psychological morbidity
- Nutrition risk pathway
- Conduct of visits back to critical care unit (effect on emotional safety of patients)
- Return of critical care diaries (effect on emotional safety of patients)
- Information governance including consent to circulate patient outcomes to the unit staff, use of photos, etc.
- Process for observers, trainees and volunteers
- Digital privacy and security when using virtual consultations

#### 4.5 Key critical care metrics

Routine collection of ICU metrics is important when establishing a clinic, as it will enable providers to describe the case mix and quantify the need for the service. In order to provide data the following metrics are very useful for presenting at departmental meetings and for feedback:

- Length of stay
- Readmission
- APACHE2 and SOFA score
- Days mechanically ventilated
- Reintubations
- Tracheostomy Y/N
- Grade of kidney injury
- Days of renal replacement therapy

- Advanced cardiovascular support (multiple inotropes, IABP, other mechanical)
- ECMO Y/N
- Surgeries and procedures
- Infection status
- Delirium Y/N/duration
- Nutritional support
- Comorbidities and mental health background

#### 4.6 Outcome measures

There is currently a lack of consensus as to the most appropriate outcome measures to use in clinical practice. Core outcome measures for research<sup>5</sup> involving survivors of critical illness have been agreed based on consensus between clinicians, researchers, and patient representatives, and are presented in Table 5<sup>6</sup>. Furthermore, core outcomes are under development in relation to trials of physical rehabilitation in critical illness<sup>7</sup>. Clinicians may consider whether these outcome measures are appropriate for use in their local practice. As an example, the following psychology questionnaires are commonly used in the UK PHQ 9, GAD 7 and TSQ. It is recognised that it is good practice to use PHQ-9 as it includes a question about risk to self.

Table 5. Core outcomes and measurement instruments for research involving survivors of critical illness<sup>6</sup>

Outcome	Outcome measure
Health-related quality of life	EQ-5D (3L or 5L version) SF-36 v2
Mental health	HADS IES-R
Pain	EQ-5D Pain question
Cognition	MOCA-Blind

#### 4.7 Training in outpatient recovery services

Access to training in critical care rehabilitation has been piecemeal, relying on availability of local services. Nonetheless out-patient recovery clinics and programmes offer an invaluable opportunity for healthcare professionals to truly comprehend the physical and psychological impact of a prolonged period of critical illness on our patients and this dialogue can be a key part in service improvement. This teaching experience would be beneficial for medical students and postgraduate trainees from multiple specialties, not just those training in critical care medicine. The importance of this topic is recognised both within the content of the ICM training curriculum and the FFICM examination. It is hoped that in the near future, this could become a core part of the ICM curriculum for all ICM trainees.

Expansion of these services offers the further potential to develop networking opportunities, regional education days and sharing of ideas, as well as providing the impetus for quality improvement projects and patient feedback for revalidation purposes.

#### 4.8 Public and patient involvement and engagement (PPIE)

PPIE is important in research and all aspects of patient care and helps to inform healthcare providers about what is needed to ensure the highest standards of care are achieved. The FICM LACIWP mandated PPIE 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. PPIE should be encouraged for any Critical Illness Recovery Service development. Some patients wish to contribute to their local intensive care service, having survived critical illness; they have made many valuable contributions<sup>8-10</sup>.

#### 4.9 Peer support

Peer support groups, either stand-alone or incorporated into post ICU programmes, are important for patients AND their families. Examples of such programmes include:

- ICU Steps groups
- Institution affiliated peer support groups, either coffee groups or formal group gathering
- Institute condition specific peer support groups, either coffee groups or formal group gathering
- Virtual videoconference-based support groups
- Social media based groups

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. However, not all patients who wish to utilise peer support have the digital literacy or equipment to access a digital platform. This should be carefully considered when setting up these types of services. The safety of participants, necessity for a moderator, and information governance issues need to be considered with such an approach.

The LACI survey indicated that peer support services for patients and families were available in nearly half of responding institutions (n=85/176, 48.3%) predominantly as community or hospital-based support group meetings (n=57, 67.1%). Other formats included peer support groups based within ICU follow-up clinics (n=11, 12.9%) or within ICU (n=5, 5.9%), psychologist-led outpatient groups (n=4, 4.7%), or affiliation with ICU charity-led support groups (n=3, 3.5%).

Providers should consider establishing and developing support groups considering to the needs and preferences of their patients and the service available within their centre.

#### 4.10 Service launch and promotion

New outpatient services need to be promoted within the Trust and externally with local GP and community services. Most GP practices have local intranet networks and email distribution lists and engaging with the teams that edit and distribute new information and content can be most helpful.

##### **Within Hospital/Trust:**

There needs to be sharing of information about the service with the directorate to engage all members of staff regarding the follow-up and recovery services. This can be achieved by having posters, leaflets, digital onscreen advertising in ICU waiting areas with sign posting to other well established support groups e.g. ICU Steps.

Clinic newsletters to ICU staff are highly valuable in providing morale boosting updates on the patient's recovery as well as educational opportunities reflecting patient feedback on care within ICU. Patient feedback will often provide an opportunity to highlight specific members of the ICU team that they recall being particularly important part of their recovery journey. Any newsletter that includes information regarding patient progress requires consent to be gained during clinic and documented. The inclusion of a patient photo can be helpful

for staff to make a connection with the patients. Additionally, a discussion with local information governance teams to ensure they are satisfied with the content within a newsletter is encouraged.

Pre-Covid, in person ICU visits were valued by patients and staff, but this is currently not possible as many clinics are virtual and visiting regulation prohibit it.

There are always opportunities to reach beyond the ICU directorate with presentations at grand rounds, use of email distributions list and Trust intranet sites to promote new services or significant changes to existing services.

### Within community healthcare and GP networks:

It is important to engage with GP federations, Primary Care Networks (PCNs) and clinical commissioning groups to understand how to promote a new service, whether this can be achieved via email distribution lists, webinars or GP educational sessions. Some Trusts in London have primary care liaison managers, but most do not, so this puts the onus on those delivering the service to reach out to community healthcare teams.

Some Trust may have an e-newsletters that is distributed to local community healthcare providers e.g. "Connect", the monthly e-newsletter from Guy's and St Thomas' that shares news, service updates, training and events, for GPs and primary care colleagues. Connect is distributed to over 2500 emails in primary care with the large majority being in south east London.

### SECTION 4 REFERENCES:

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- 8 Patient and Family Member Experiences in Critical Care Research and Quality Improvement Projects [https://www.nursingcenter.com/journalarticle?Article\\_ID=5639482&Journal\\_ID=54027&Issue\\_ID=5639174](https://www.nursingcenter.com/journalarticle?Article_ID=5639482&Journal_ID=54027&Issue_ID=5639174)
- 9 The nature and extent of service user involvement in critical care research and quality improvement: A scoping review of the literature <https://doi.org/10.1111/ijcs.12406>
- 10 Involving patients and families in critical care research and quality improvement <https://doi.org/10.1111/nicc.12418>

## 5. FUNDING AND COMMISSIONING CRITICAL ILLNESS RECOVERY SERVICES: ENGLAND, SCOTLAND, WALES AND NORTHERN IRELAND

### 5.1 Commissioning justification

*“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.” (National Institute for Clinical excellence (NICE) Clinical guideline (CG) 83)<sup>1</sup>.*

There are national guidelines, both NICE clinical guideline 83<sup>1</sup> and Intensive care Quality Standard 158<sup>2</sup> that provide the justification for commissioning critical illness recovery services, which are further endorsed by section 3.7 of the Guidelines for the Provision of Intensive Care Services (GPICS) version 2, published in June 2019<sup>3</sup>.

Inconsistent commissioning of critical illness recovery services perpetuates inequity of care between networks, hospitals, and even between patients in adjacent ICU beds whose eligibility for rehabilitation can perversely differ based on admission reason, for instance between stroke or trauma and non-trauma ICU patients.

FICM recently conducted a UK wide survey for critical illness recovery services with 183/242 responses relating specifically to outpatient services/clinics. Of the 130 reported outpatient services, [REDACTED] were funded from existing critical care funds (run “at risk”), and the remainder were unfunded.

There is also an example of case law, where a successful challenge was raised against a CCG that chose to not follow NICE guidance<sup>4,5</sup>. Such case law highlights the responsibility commissioners have to fully consider any business case, which aims to fulfil the clinical guidance laid out by NICE. It may well be helpful to cite such case law when submitting a business case for a critical illness recovery service to local commissioners.

Overall, there is a paucity of quantitative data to support recovery services such as outpatient clinics that holistically evaluate patients after critical illness<sup>6</sup>. Furthermore, it has not been possible to demonstrate the cost-effectiveness of these clinics. However, these clinics' primary aim is the co-ordination of complex patient care needs and to date metrics such as the reduction in healthcare utilisation and time taken to return to work for both patient and carer have not been assessed. Future studies are required to evaluate the impact such clinics have on these outcomes rather than mortality alone.

In this section, we will cover:

- a brief explanation of the general principles of commissioning with specific attention to each of the four nations of the UK
- changes to payment systems for both critical care and outpatients services pre- and post-COVID pandemic
- key elements needed for business case development
- contract obligation for clinicians running outpatient services.

#### **ENGLAND:**

**There are 4100 adult critical care beds in England.**

#### **Pre-COVID general commissioning principles:**

NHS England defines *commissioning* as “the process of purchasing and monitoring health services to get the best health outcomes”<sup>7</sup>. NHS England is responsible for commissioning specialist services and general practice and the clinical commissioning groups (CCGs),

which comprise groups of general practices (GPs) come together in each local area to commission the remaining healthcare services to meet the needs of their patients and population<sup>8</sup>.

### Critical care services commissioning

There are six national programmes of care (NPoCs) that oversee the commissioning of specialised and highly specialised services in NHS England. One of the six NPoCs is Trauma and within this there are seven clinical reference groups (CRG) and the fifth CRG is responsible for adult critical care services<sup>9</sup>. The scope of the CRG is to advise NHS England regarding the funding of adult Critical care and extracorporeal membrane oxygenation (ECMO) services. NHS England commissions approximately 60% of the total adult critical care activity in England and clinical commissioning groups the remainder.

### Commissioning Outpatient services

The approach to agreeing tariffs for outpatient services was detailed in the NHS England and NHS Improvement paper on the National Tariff Payment System (NTPS) published in March 2019<sup>10</sup>. This paper highlights some key factors that determine a tariff for an outpatient service:

- a uni- or multi-professional clinic
- a patient consultation is a new or follow-up patient visit. (To incentivise a change in the delivery of outpatient follow-up activity and to encourage a move to more efficient delivery models freeing up consultant capacity, first attendances tended to be over-reimbursed and corresponding follow-up attendances under-reimbursed).
- Multidisciplinary clinics with a carousel format with a patient seen by different clinical professionals on a one-to-one basis can be sequentially individually charged consultations or a 'one-stop-shop' tariff, reflecting the total cost to the trust for delivering this mode of care.

Most clinics and services rely in internal funding for staff and a basic clinic tariff is applied to the new and follow-up patients seen.

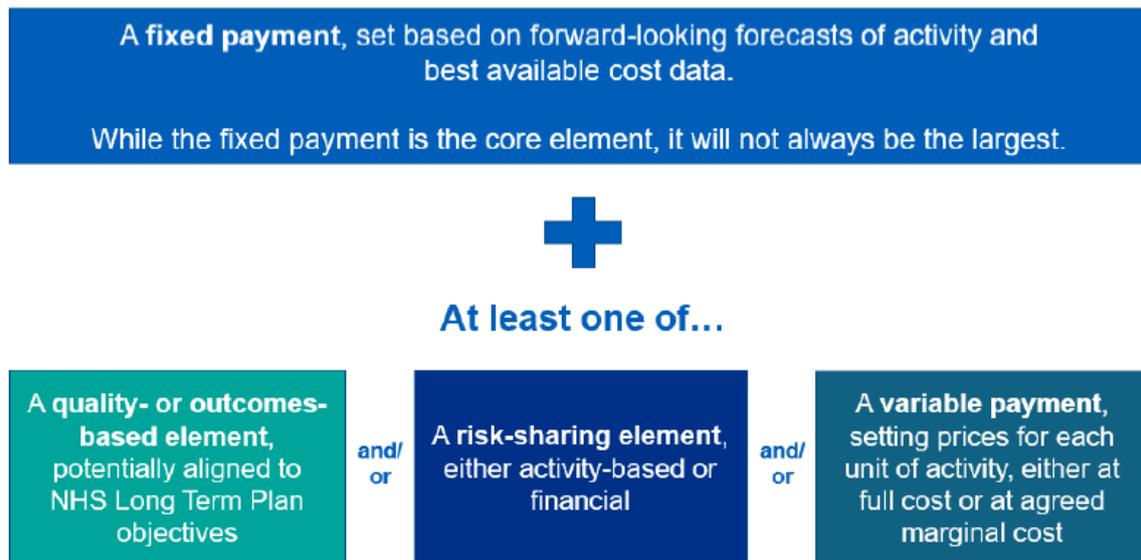
An example of a 'one-stop-shop' tariff is the one agreed with local commissioners for the multidisciplinary critical illness recovery clinic at Guy's and St Thomas'. The full business case (FBC) was submitted to support a multi-professional model see Appendix 2. The NICE shared learning accessed at <https://www.nice.org.uk/sharedlearning/development-of-a-multidisciplinary-post-critical-care-clinic-at-guy-s-st-thomas-nhs-foundation-trust> provides additional information regarding this model<sup>11</sup>.

It is also worth highlighting the publication of the The NHS *Long Term Plan* in January 2019<sup>12</sup>, which made a number of commitments regarding the approach to the future delivery of NHS services:

- the introduction of integrated care systems (ICSs), which were intended to bring about major changes in how health and care services are planned, paid for and delivered. ICSs are partnerships that bring together providers and commissioners of NHS services across a geographical area with local authorities and other local partners, to collectively plan and integrate care to meet the needs of their population. The NHS long-term plan set out an expectation that systems would streamline commissioning arrangements so that there is 'typically' a single CCG for each ICS.
- there was focus on payment processes with planned "reforms to the payment system to move funding away from activity-based payments and ensure a majority of funding is population-based" and "move to a **blended** payment model, beginning with emergency care, with a single set of financial incentives aligned to the commitments in the Long Term Plan."

In 2019/20, blended payments were introduced to the National Tariff Payment System (NTPS) for emergency care and adult mental health services. For 2020/21, there were proposals to introduce blended payments for maternity services and **outpatient attendances**, while piloting the approach for **adult critical care**<sup>12</sup>.

Figure 6. Blended payment model



In critical care, the piloting plan of a blended payment model, presented an opportunity to explore whether support for incorporating a quality or outcomes-based element for critical care blended payments could be envisaged. The key driver behind this was to provide individual critical care units the necessary funding through the blended payment for critical illness recovery services to be sustainably delivered in England with the aim of improving equity of access and the potential to set minimum standards for such services.

However, just as this proposal was being raised the Covid pandemic intervened leading to sweeping emergency funding interventions by the government, from which we are only just emerging, but which continue to affect critical care services funding.

#### **COVID-19 pandemic: The impact on funding critical care and outpatient services**

NHS providers and commissioners spent an additional £5.6bn between April and July 2020, £5.1bn more than the agreed pre-Covid budget. Most of this was in response to coronavirus and the need to maintain physical distance between patients and enhance infection-control measures. Important changes were introduced to ensure the funding was distributed to Trusts to deliver the NHS response to the Covid pandemic.

These changes brought in by NHS England and NHS Improvement ensured "the cash flow for NHS and non-NHS suppliers of goods and services was not a barrier to service provision". Instead of local commissioning groups agreeing expected levels of activity with NHS trusts, and some parts of the payments being contingent on the achievement of certain levels of activity and quality, NHS England told commissioners to pay local trusts a fixed amount and allowed them to claim back any extra costs associated with responding to coronavirus. This also removed the possibility of perverse 'penalties' (losing money) if acute trusts had not

undertaken elective operations after NHS England and NHS Improvement had told trusts to postpone most non-urgent care from 15 April.

A temporary scheme to allow NHS trusts to claim reimbursement for any additional costs necessary to respond to Covid-19 lasted until October 2020. Additionally, funding for virtual clinics was aligned with 'face-to-face' clinic tariffs to promote this method of delivering outpatient services, which was required to help maintain social distancing.

These funding structures enabled critical care services to respond to the first surge in the pandemic and also plan the follow-up services for patients managed in hospital and critical care. In May 2020, FICM published provisional guidance on recovery and rehabilitation following the pandemic<sup>13</sup>.

In August 2020, UCL Partners in conjunction with NHS England and NHS Improvement London set out evidence-based core standards for an Integrated Care System with regard to COVID-19 rehabilitation services<sup>14</sup>, which included critical illness rehabilitation. These guidelines highlighted the need for post-Covid clinics delivered by respiratory physicians to be integrated with existing critical illness recovery clinics that had allied health professionals e.g. occupational therapy and psychology.

The Covid-19 pandemic and tariff presented an opportunity to develop critical illness recovery services, where none existed, to ensure critically ill Covid-19 patients were followed up. Several Trusts were able to develop new services and work collaboratively with respiratory post-Covid clinics to address the holistic needs of Covid patients that were admitted to critical care<sup>8</sup>.

However, in some Trusts the impact of Covid had far reaching effects on the workforce and resources with existing critical illness recovery services that were unable to continue their established follow-up services as shown in Table 6.

Table 6. Themes characterising future plans for service development in next 2-5 years

Theme	
[REDACTED]	[REDACTED]

As of June 2021, it was announced under the Post Covid plan 2021-2022 that £70 million was committed along with the £24 million already spent on Post Covid clinics, £30 million allocated for the rollout of enhanced services to general practice and £50 million committed to post covid research for England. This highlighted the recognition of the impact of Covid on patients, particularly those in critical care, but was to be utilised to manage patients

affected by Covid who were in the community, hospitalised and/or managed in critical care.

Covid will likely impact future funding of the NHS, but the media coverage of the severe Covid patients that required critical care and the surge in critical care beds during the first surge has raised the general public's and CCGs' awareness of the impact of Covid and critical illness on patients and carers. The government has responded with money and new strategies to help deliver support for those affected by Covid. Critical care services must utilise this raised awareness to develop and submit business plans to deliver new critical illness recovery services where able. Commissioners may be more receptive to the obvious need to provide holistic assessments and co-ordinated aftercare for critical care patients affected by Covid and non-Covid diseases. The emphasis has to be on the equity of access for such services across England. It could be sensible to consider post covid clinics adapting to post-critical care clinics in the medium to long term plan to use the skilled staff and networks developed in the creation of post covid services, while maintaining the sustainability of excellent multidisciplinary care.

Meanwhile, there is an opportunity to reopen the discussion with NHS England via the adult critical care CRG regarding the future blended tariff payment model for adult critical care services. If support for the quality or outcomes-based element could be agreed then this could potentially improve the equity of access and reduce the effect of health inequalities on outcomes after Covid and non-Covid critical illness.

There is significant funding constraint and variation in the availability of critical illness recovery services in the devolved nations of Scotland, Wales and Northern Ireland.

### **NORTHERN IRELAND (NI): Ferguson**

#### **There are 108 critical care beds in NI.**

In Northern Ireland, the National Health Service (NHS) is referred to as the Health and Social Care (HSC). Just like the NHS is it free at the point of delivery, but in Northern Ireland HSC also provides social care services like home care services, family and children's services, day care services and social work services as well as policy and legislation for hospitals.

There is one Health and Social Care Board (HSCB) that is responsible for assessing the health and social care needs of Northern Ireland, commissioning services to meet those needs and monitoring the performance of services. Its role is broadly equivalent to Clinical Commissioning Groups (CCGs) in England, and Health Boards in Scotland and Wales, but as well as commissioning health services it is also responsible for social services. Care services (including Critical Care) are managed by the Specialist Services Commissioning Team in Northern Ireland. There are no tariff arrangements for outpatients in Northern Ireland.

The HSCB has five Local Commissioning Groups (LCGs) and each LCG covers the same geographical area as their respective Health and Social Care (HSC) Trust. The Board is also directly responsible for managing contracts for the family health services provided by GPs, dentists, opticians and community pharmacists. These are all services not provided by Health and Social Care Trusts. While the Board commissions services, it is the Trusts that actually provide these services 'on the ground'.

Integrated Care Partnerships (ICPs) operate in smaller regions than the HSC Trusts, linking up services including pharmacy, ambulance services, social work and nursing care. They are multidisciplinary teams that should ensure that each patient has to deal with fewer health professionals, and that their care happens near to their home in convenient locations.

**Pre-COVID:**

Two critical care units in NI offered follow up services, with staffing having evolved around local perceived requirements, however with partial internal funding arrangements (not regionally commissioned). The provision of post-critical care follow up was ultimately devolved to specialty input, without consistency in terms of availability of this service regionally.

**Post COVID:**

The NI Department of Health Strategic Clinical Advisory Cell (SCAC) has commenced work to ensure that all patients receive appropriate follow-up after COVID-19, and this includes those who have been in critical care. There has been active involvement in post-COVID-19 follow-up in some but not all of our units. Where there is no dedicated post-COVID-19 critical care involvement, follow-up is via respiratory teams using BTS guidance.

SCAC is aware of Network concerns around the inequity of limiting follow-up to COVID-19 patients and it is hoped that the Critical Care Network Northern Ireland can work with SCAC to move forward on follow-up services for all critically ill patients who would benefit.

DRAFT

**SCOTLAND: Caroline Ferguson and Elizabeth Wilson**

There are 585 critical care beds in Scotland with a plan to reach 700.

In Scotland, health services are devolved to the Scottish Government. The Scottish NHS consists of 14 regional Health Boards, covering all of Scotland. They take the role roughly equivalent to Clinical Commissioning Groups in England, in that they plan and deliver health services based on the needs of the local community. Health Boards have responsibility for the protection and the improvement of their population's health and for the delivery of frontline healthcare services.

Within Scotland there are 24 geographically disparate Intensive Care Units which annually provide specialist care for over 45,000 severely ill or injured patients. These units comprise a heterogeneous mix, ranging from large university affiliated speciality & tertiary referral centres to small remote district general units. Nonetheless the rehabilitation needs of these patients remain the same.

In 2015, the Scottish Intensive Care Society (SICS) Quality Improvement Group produced a document entitled "Minimum Standards and Quality Indicators for Critical Care in Scotland". This outlined key quality indicators which are now reported on annually, in the Scottish Intensive Care Society Audit Group (SICSAG) Report.

One such quality indicator addressed the need for critical care rehabilitation, stating "All patients, on discharge from critical care, should have an assessment of their rehabilitation needs, with quantified outcomes, using a tool that can track progression from the Acute Sector into Primary Care to facilitate care needs in the community"<sup>15</sup>. It went on to specify "Rehabilitation should be communicated verbally to the daily ward round for each patient receiving input. This should be ideally given by a Therapist of suitable seniority who understands the complexity of rehabilitation needs of critically ill patients and is able to explain and amend treatment goals/plans as discussed at the time of the ward round. Outcome measure should be consistent throughout the patient's pathway and able to facilitate care needs assessments. These outcomes should be reviewed consistently at follow-up appointments and discussed with the patient and primary carer". This document aligns itself with other UK recommendations and standards, including NICE guidelines and Guidelines for the Provision of Intensive Care Services, which highlight the essential need for both inpatient and out-patient follow up in this patient cohort.

**Pre-COVID:**

There was wide variation within Scotland, in terms of access to resources and the types of critical care rehabilitation and follow up services available. The majority of hospitals offered some form of designated ICU patient follow up, in either the inpatient or outpatient domain, but very few were able to provide dedicated support throughout the entire patient journey and at key interfaces:

- At discharge from critical care to downstream general wards
- At hospital discharge into the community
- Bridging community services with specialist secondary care reviews.

There were numerous reasons why this has not been achievable, despite enthusiasm from the critical care community as a whole, but undoubtedly the most important of these is insufficient financial resources.

Funding of specialist services within NHS Scotland is quite different from other parts of the UK. There is no formal commissioning process or National Tariff Payment Scheme. Instead Health Boards are allocated funding from a central budget, based on population. Critical care bed

numbers are commissioned on local assessment of need and benchmarking, but other service developments are typically funded by presentation of business cases to individual Health Boards or hospitals, for consideration at a local level. Supporting evidence of outcome benefit and cost effectiveness of interventions strongly support a business case. These can be difficult to quantify for rehabilitation follow up services, especially when competing with other services all seeking support from the same funding stream. There is thus the potential for wide variation and inequality of service provision between regions.

Many of these ICU follow up services originated as research projects, funded from sources such as The Health Foundation, and Healthcare Improvement Scotland. Positive patient/carer feedback provided through satisfaction questionnaires and supplemented by letters of support, have provided the necessary impetus to enable many of these pilot projects to secure funding directly from NHS Health Boards and allow these services to continue long term.

- NHS Grampian and NHS Tayside, there exist traditional out-patient follow up clinics (PRaCTICaL study)<sup>16</sup>
- NHS Fife, NHS Lanarkshire, NHS Ayrshire and Arran and most sites in NHS Greater Glasgow and Clyde provide a 5 week out-patient multi-disciplinary recovery programme for patients and carers (InS:PIRE).

#### **Post-COVID:**

The impact of the COVID pandemic on critical care services has been immense. One positive outcome has been the increased public profile of our specialty. In Scotland we have also been testament to many examples of other specialties and AHPs supporting the recovery of ICU patients where input was needed, including psychiatrists evaluating the psychological status of our patients and expertise offered from rehabilitation medicine specialists. In July 2020 the First Minister for Scotland acknowledged the difficulties facing patients who had survived a critical care admission with a diagnosis of COVID and the need for robust support and follow up services, referencing the InS:PIRE model of multi-disciplinary ICU follow up.

A unique opportunity is available for Scotland and indeed the whole of the ICU community, to apply the principles of "Getting It Right First Time" and push for development of a National ICU follow up programme, utilising models that have been shown to be most effective. In the interim, Health Boards which hitherto had no outpatient follow up service, have rapidly developed innovative new resources e.g. Critical Care Recovery Hubs (Case example C Page 60) to meet the patient demand associated with the pandemic. It has been proposed by the Scottish Intensive Care Society that in time networking between regions will develop.

#### **WALES: Jack Parry-Jones**

There are currently 176 critical care beds in Wales.

Following discussion with the Welsh Critical Care and Trauma Network there are currently no Health Board has imminent agreed plans to implement an increase the number of critical care beds. There are plans however to use available critical care beds with greater efficiency by creating or expanding Health Board's Post-Operative Care Units, and by increasing Long Term invasive Ventilation (LTiV) and weaning beds in a regional service (10 beds). Both PACU beds and LTiV beds will free up acute critical care beds. A detailed analysis of Welsh Government plans for critical care can be found here.

Six of the seven Health Boards in Wales have critical care services: Aneurin Bevan University Health Board (ABUHB), Betsi Cadwaladr University Health Board (BCUHB), Cardiff and Vale University Health Board (CVUHB), Cwm Taf Morgannwg University Health Board (CTMUHB),

Hywel Dda University Hospital Health Board (HDUHB), and Swansea Bay University Health Board (SBUHB). A request was made through the Welsh Critical Care and Trauma Network (WCCTN) for a report by each Health Board on its current provision of critical care follow up and rehabilitation services, and their future plans. At the time of writing, five of the six have responded. Some of these responses are very well advanced and complete. If consolidated, these could form the basis for a Welsh response to the need for a sustainable critical care rehabilitation and follow up service for all survivors of critical illness in Wales. The Critical Care "Getting it Right First Time" (GiRFT) team have recently demonstrated the large disparity in critical care service provision across England. Critical Care Follow Up services in Wales currently fall under the same umbrella of some areas of excellence, and some areas of no provision. Overall, the critical care follow up services are disparate, not commissioned and their need not fully recognised within Health Board's plans. Covid-19 may paradoxically have helped with the recognition of patient and family need for these services. In May 2021 the WCCTN initiated a Follow Up and rehabilitation group to better understand the constraints to implementing better follow up services across all Welsh Health Boards.

No Health Board has a fully commissioned follow up service but five of the six Health Boards do have some critical care follow up provision. All of these services are funded out of existing critical care service directorates, or anaesthesia/critical care directorates. The true costs are therefore not fully recognised, and expanding them to meet standards is proving difficult. Commissioning in the Welsh National Health Service is different to the English NHS. There are no tariff arrangements for outpatients. Two Health Boards, BCUHB and SBUHB have detailed costs for the provision of a follow up service across their sites. The respective costs are estimated at £170,000 to £217,000/annum. Staffing costs form almost 100% of the total cost.

The follow up service SBUHB has been in existence the longest in Wales and has a proven track record, particularly around therapies provision. Both SBUHB and BCUHB have innovative plans based on using "Rehabilitation Technicians (band 4) or an "Acute Intervention Team" to provide the initial point of contact with patients post discharge to the ward. During the latter part of 2020, SBUHB put a significant investment of circa £300k into strengthening AHP support on critical care. This allowed the piloting of a mental health liaison role with a psychiatry nurse resident on the ICU 4 days/wk leading to rapid assessments, early discharges and rapid access to appropriate longer-term treatment. A multidisciplinary tracheostomy team initiates input during the ICU stay and then continues to follow up and manage tracheostomy issues on the ward after discharge. CVUHB also utilises a tracheostomy team which has reduced the time taken to de-cannulation and discharge home. Those Health Boards with existing follow up services have excellent patient and family feedback:

CVUHB has been in the vanguard (in the UK) of directly employing a psychologist for critical care patients and critical care staff. The provision is very well advanced and embedded within the unit service culture. This has helped incentivise others to follow suit (ABUHB, CTMUHB, and BCUHB). CVUHB has however struggled to get follow up services in place. SARS CoV 2 has actually helped make the wider hospital aware of the need for both mental and physical follow up post any critical illness, not just Covid.

CTMUHB has some follow up but it is not universal across the Health Board which has expanded its geographical area.

HDUHB does not currently have a critical care follow up service, but have provided detailed reasons as to why they need these services. These include:

- A risk that the patient's further needs may not be identified after the patient has been discharged
- A failure to meet standards e.g. as defined by GPICS V2, NICE Clinical Guidelines 83 etc
- A limited capacity to best enhance the benefits of critical care interventions
- A reduction in efficacy of follow up by using non-specialist staff i.e.
- using staff with limited awareness of issues relevant to critical care

- An increased total hospital length of stay
- An increasing time away from home does not reflect “kind” care
- An increased risk of hospital re-admission- compromising safety/ sustainability
- An increased pressure on wider unscheduled and primary care system
- An increased cost across primary and secondary care.

HDUHB does recognise the need for significant investment in therapies (AHPs).

In summary, the Welsh Health Boards's critical care services have in the main responded fully to the LACI initiative. The existing follow up services already have some real areas of excellence, but these are not universal across Wales. Those that do have excellent services in some areas e.g. physiotherapy in SBUHB, tracheostomy care in CVUHB and SBUHB, psychology in-put in CVUHB, and costings and service planning in SBUHB and BCUHB, could really help develop the National service planning, framework and delivery of Follow up services by sharing lessons learnt with those Health Boards who are just starting their journey with these services.

How these services are going to be commissioned (staffing in particular) with sustainable delivery across Wales is a key area of focus in the medium term. The input of the Life After Critical Illness team is much appreciated in leading the development and promoting the need for these services for patients and their relatives in Wales.

## 5.2 Business planning services

Until a national tariff can be incorporated to critical care services or agreed for critical illness recovery services, business planning and development of business cases to present to local commissioners will continue to be required in England.

The process of developing a business case for an outpatient service requires collaboration between clinicians and directorate managers.

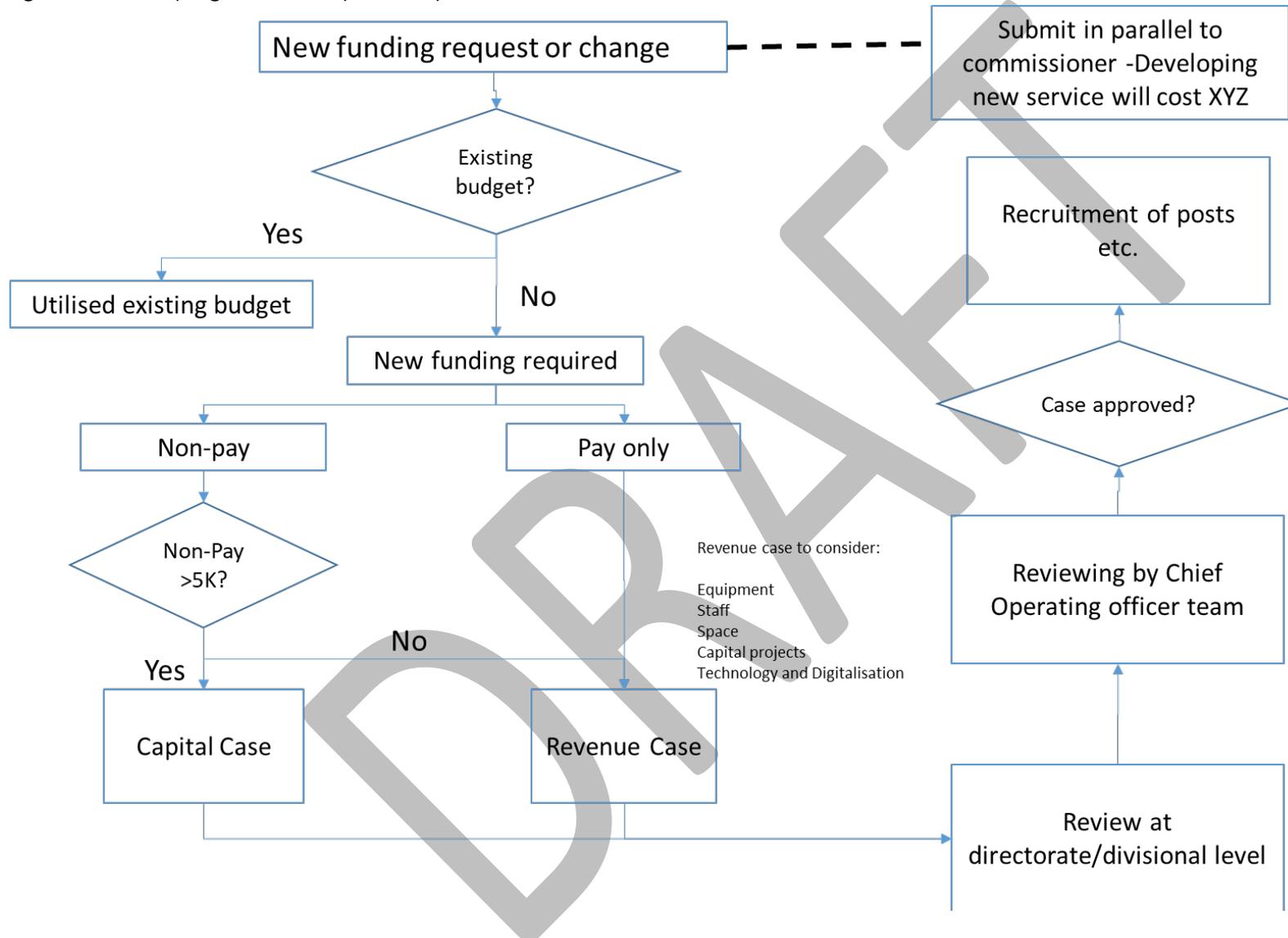
Most business cases are generated during business planning. Questions that should be asked before you write a business case are:

- What is it that your business case is trying to achieve and what are the alternative ways of achieving its objectives?
- How does your proposal meet the Trust's strategic objectives? This will need to be clearly evidenced in your business case.
- Can the resources required be found from within existing budgets?

Can you transform your services or workforce without additional resources?

The key steps in formulating a business case are summarised in figure 7.

Figure 7. Developing a business (revenue) case



The business case will need to be completed on a standard Trust template (Appendix 2) and cover the following main headings:

**Executive summary** – a summary of the entire proposal

**Background** – set the epidemiological background to post intensive care syndrome, how it affects the national and local population and how much it costs the NHS.

**Current service provision** – explain the current provision of services.

**Proposal for the service** – outline the proposed service with financial, workforce, venue and equipment. The management team will be responsible for producing this evidence.

**Drivers for the new service** – link how the proposed service will impact national/local objectives and improve patient care and quality of life and benefit the organisation. Highlight the clinical risk associated with the service not being commissioned. Emphasise the strategic fit with own organisation's mission statement and core values. Relate to national guidance and medical college/faculty recommendations including the key paragraph for commissioners in QS158.

**Deliverable outcome/activity to date** – project the number and type of patients the service will see.

**Patient/carer feedback/GP** – provide case studies, patient feedback and if possible GP feedback of any pilot clinic that may have been established. In addition, feedback from patients and families on the impact/experience of not having co-ordinated care and support after discharge.

## References

## Appendices

### Financial appraisal

This requires managers to determine the tariff per patient or block payment required to deliver the clinic. This will be more complex if the clinic model is multi-professional, whereas, for single professional models there will be existing tariffs within the Trust that can be mirrored in any proposal.

The financial appraisal will require a detailed breakdown of the expenditure for running the service and should encompass the following: **Workforce** may include any or all of the following depending on the chosen clinic model:

<b>Critical Care directorate</b>
Consultant (s)
Nurse (s)
Administration
Pharmacist (s)
Dietician
<b>Therapies directorate</b>
Occupational therapist (s)
Physiotherapist (s)
<b>Psychology directorate</b>
Psychologist

A multidisciplinary clinic model affects how the tariff is utilised and requires critical care managers to liaise with other directorates e.g. therapies directorate to establish back payments for their services, which are required within the clinic.

### Estate

Frequency of the clinic and the number of clinic rooms, will need careful consideration along with the outpatient model utilised as this will affect the estate required i.e. single vs multi-professional and whether the clinic is conducted in a carousel format with patients seeing clinicians individually or as a group of multi-professionals in one room.

There will also need to be some proposed activity projections.

Examples of successful business cases can be viewed in Appendix 2.

## 5.3 Outpatient service: Principles of delivery

In 2018, The Royal College of Physicians published a document entitled, "Outpatients: The Future, adding value through sustainability"<sup>17</sup>, which is highly relevant for planning the development of an outpatient service, states that current outpatient models are outdated and need to be more focused on value and sustainability, with *value* as an organising principle for commissioning services. For sustainability there needs to be consideration of social and environmental factors as well as financial ones. These are useful guiding principles when considering how to deliver and formulate a business case, Figure 8.

Figure 8. The Royal College of Physicians approach to quality<sup>18</sup>



It is, also, important to consider the principles for good outpatient care and consider how these will be addressed in the business case.

Figure 9. Principles for good outpatient care<sup>17</sup>.

- 1 Demand for an outpatient service should be met by the available capacity. Capacity should take into consideration fluctuations in demand and staff availability throughout the year.
- 2 Interventions to reduce new patient demand should be targeted at all referral sources. They must not deter necessary referrals or damage professional working relationships.
- 3 Generic referrals should be pooled to minimise waiting times for appointments. Local consultants should review an agreed mix of generic and sub-specialty referrals according to demand.
- 4 All outpatient care pathways should aim to minimise disruption to patients' and carers' lives.
- 5 Clinic templates should allow for timing flexibility depending on case complexity and the needs of the patient. They should allow a realistic timeframe to conclude business and avoid frequent unsatisfactory visits.
- 6 Patients should be directly involved in selecting a date and time for an appointment. That can happen either in person, via telephone or electronically.
- 7 All clinical information should be available to both the clinician and patient prior to consultation. That includes notes, test results and decision aids.
- 8 Patients should be fully informed of what to expect from the service prior to appointments. That includes the aim of the appointment and expected waiting times.
- 9 Alternatives to face-to-face consultations should be made available to patients and included in reporting of clinical activity.
- 10 Patients should be supported and encouraged to be co-owners of their health and care decisions with self-management and shared decision-making.
- 11 Patients and community staff should be able to communicate with secondary care providers in a variety of ways, and know how long a response will take. This aids self-management, and provides a point of contact for clarification or advice regarding minor ailments.
- 12 Access to follow-up appointments should be flexible. Patient-initiated appointments should be offered, replacing the need for routine 'check in' appointments.
- 13 All care pathways should optimise their staff skillmix. Allied medical professionals and specialist nurses should be an integral part of service design.
- 14 Letters summarising a clinical encounter should be primarily addressed to the patient, with the community healthcare team receiving a copy.
- 15 All outpatient services should offer a supportive environment for training.
- 16 All outpatient-related services should promote wellbeing for staff and patients.

## Contracts

A Primary Care Foundation and NHS Alliance report indicated that 27% of GP appointments could potentially be avoided with changes to how the system works, attributing 4.5% of these to how primary care and secondary care work together, equating to an estimated 15 million appointments nationwide<sup>18</sup>.

The British Medical Association (BMA), working with NHS England and other organisations, agreed changes to the NHS Standard Contract for 2017-19, under which clinical commissioning groups (CCGs) commission health services from providers.

There are a number of new requirements which clinicians and managers across the NHS need to be aware of, and which are summarised below<sup>19</sup>. These are key for any provider of an outpatient clinic service to ensure good practice for patient care and working relationship with local GPs.

## Key national requirements

### Managing DNAs and re-referrals

Providers should no longer ask GPs to re-refer DNA appointments.

### Managing onward referrals

Clinicians working for the provider should make an onward outpatient referral, without needing to refer back to the GP, **where it is directly related to the condition for which the original referral was made, or the patient has an immediate need for investigation or treatment.**

### Communicating with patients and responding to patient queries

Providers should put in place and publicise arrangements for handling patient queries; providers should communicate the results of investigations and tests to patients directly.

### Discharge summaries

Discharge summaries must be sent to the GP within 24 hours after every discharge from inpatient, day case or A&E care.

### Clinic letters following outpatient attendance

Clinic letters should be sent to GPs within 10 days (7 days from April 2018) where there is information the GP needs to act on in relation to the patients' ongoing care; clinic letters should be sent electronically using standardised clinical headings (by October 2018).

### Medication

Providers to issue medication following discharge from hospital for a minimum period of seven days (unless a shorter period is clinically appropriate) and following a clinic attendance where a patient has an immediate clinical need, for a locally agreed period of time. More information on prescribing is available [here](#).

### Out-patients

Where a patient has an immediate clinical need for medication as a result of attending an outpatient clinic, the secondary care provider must supply medication sufficient to last at least until the point at which the outpatient clinic's letter can reasonably be expected to have reached the patient's GP, and when the GP can therefore accept responsibility for subsequent prescribing. Consideration should be given to providing a minimum of 7 days' supply to allow patients sufficient time to contact staff at their general practice (or shorter if medicines are not required for that length of time)<sup>20</sup>.

### Shared care protocols

Shared care protocols may be agreed locally, but hospitals must only initiate the care under the protocol where the individual GP has confirmed willingness to accept clinical responsibility for the particular patient in question.

### Fit notes

At a suitable point in time (on discharge from hospital or at clinic), clinicians must issue fit notes to patients where appropriate, the provider organisation must enable this, and the notes must cover an appropriate period of time<sup>21</sup>.

### Onward referrals

In April 2016, changes to the NHS standard contract between CCGs and providers allowed for onward referral of patients by the secondary care clinicians rather than always requiring referral back to the originating GP. This important change was welcomed by the Medical Royal Colleges and the British Medical Association who recognised the advantage in terms of convenience for both patients and clinicians.

The Academy of Medical Royal Colleges produced guidelines to inform and guide clinicians locally regarding onward referrals and this has been endorsed by the BMA and NHS England<sup>22</sup>.

This guidance states that where a patient has been referred to one service within a provider by the GP or has presented to the emergency department, the provider clinician is allowed to make an onward outpatient referral to any other service, without the need for referral back to the GP, where:

*Either*

the onward referral is directly related to the original presenting emergency

*Or*

the patient has an immediate need for investigation or treatment e.g. suspected cancer

### **Exception**

The contract does NOT permit a secondary care clinician to refer onwards where the patient's condition is non-urgent and where the referral made is not directly related to the condition.

This guidance is helpful for clinician delivering outpatient services for patients after critical illness and enables swift and appropriate referrals co-ordinating patient care in an efficient process.

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## 6. Future perspectives

This is a period of diverse expansion and discovery in the field of critical illness recovery. The ability to keep people alive for longer and after more severe illness brings questions about the quality of life after critical illness to the fore. The acknowledgement of physical, psychological and cognitive problems that can occur after critical illness, and the impact that these have on return to a normal life, has increased significantly in recent years. This has been mirrored by the development of services to assess and support the needs of patients and their families (see survey results), but these services are not yet universal impeding equity of access across the UK. The COVID-19 pandemic has heightened awareness, both to healthcare professionals and the wider public, of the many issues that patients and their families face during recovery after a critical illness. The planned permanent increases in critical care capacity over the next few years must be accompanied by a corresponding matched increase in provision for survivors or critical illness.

Describing the 'Post Intensive Care Syndrome' (PICS) has undoubtedly helped to further focus research and clinical practice efforts in this area by identifying common and consistent themes. The expectations and reality of life after critical illness for individual patients, however, can vary immensely. As in many other areas of healthcare, the challenge that we must meet is to provide structured and equitable care, regardless of geographical region, reason for ICU admission, or patient demographics, whilst at the same time being flexible enough to be responsive to the needs of individuals. We must foster innovative approaches which respond to the needs of local populations and specific conditions.

Including post ICU recovery services in national guidance (e.g. NICE CG83, GPICS) has not translated to the widespread provision of services that was intended. Patients, healthcare professionals and commissioners need now to enable these services to be funded centrally and incorporated in to the adult critical care specification. Post ICU recovery services must no longer be seen as an optional add-on, as it is essential to delivering high quality critical care.

Deciding what outcomes are meaningful to both patients and healthcare organisations, and how these can be measured, remains a challenge. Measuring physical, psychological, cognitive and social impacts of critical illness is desirable to demonstrate improvement or change within an organisation. Developing multi-centre or national post ICU data registries will allow outcomes to be shared between organisations. Any proposed measures should also take into account the patient and families' experience of their illness and care. Involving patients in service development, such as experienced-based co-design<sup>1-5</sup>, may have a role in order to define outcomes that matter to patients, and not just to healthcare systems.

Technologies to support post ICU services have developed in recent months, none more so than video consultation. Whilst for many this will widen access to support and avoid the need to travel, we must be mindful to retain the personal and individual care that we pride ourselves on delivering during the acute phase of illness, and which we know that patients and their families value during their recovery after leaving hospital. It is important that technological innovations, which may suit many patients, do not result in health inequalities. App-based technologies (e.g. for assessment and reporting) are helpful to support, rather than replace, direct and personal interactions with patients and families. Individual follow-up services will need to retain a range of options for their patients.

Future NHS reforms may lead to improved coordination of critical care follow up services across networks and with other specialist/secondary care teams which could both break down 'silo' working and improve experience and outcomes for patients. We are only just learning how to also integrate critical care follow-up with primary care and community services (more information on INSPIRE and SCARF can be found in Appendix 1)

which can present a significant challenge when the patient's local area is far from the secondary/tertiary care centre where the acute critical care was delivered.

Recognising that health and wellbeing are determined mainly by social, economic and environmental factors will become ever more important as we support patients' recovery. Initiatives such as social prescribing<sup>6</sup> may be beneficial to survivors of critical illness. Approaches which include peer support, both in-person and online, are gaining traction. Closer working with relevant third sector organisations is also likely to be helpful in supporting patients. Whilst there is still a large unmet need, highlighted by the recent pandemic, and patients value the input of the critical care teams who cared for them, we must take care not to 'over-medicalise', but to provide the best conditions for optimal recovery, and inspire confidence as patients transition towards independence.

We must also look after the needs of our critical care staff. The first year of the COVID-19 pandemic has drawn further attention to staff psychological distress and burnout as a serious concern. Involvement in supporting patients' recovery following discharge from hospital after critical illness is often cited as a positive experience for critical care staff. The sense of fulfilment that comes from meeting a patient or family who you have worked so hard to look after acutely, stays with you long afterwards. Including more staff in post-ICU activities may well bring organisational benefits through staff recruitment and retention, as well as benefits to individual staff through enhanced wellbeing and joy at work. As follow-up after critical illness becomes recognised as a subspecialty interest, with specific required competencies, accreditation will need to be defined and developed.

We need to use data from critical care follow-up services, and the experiences of patients and staff, to drive changes in acute care that in turn prevent or mitigate some of the longer-term physical, psychological and cognitive issues faced by patients. Patients must be offered the opportunity to participate in research wherever possible. The ongoing relationship between critical care teams and patients and their families through critical care follow-up services is likely to be helpful both in promoting Patient Public Involvement for research planning, and in collecting outcome data.

Improving patient experience, improving the health of populations, and reducing the per-capita cost of healthcare (the triple aims of healthcare) along with so-called triple integration (removing boundaries between mental and physical health, primary and specialist care, and health and social care) remain key areas of focus for the NHS. Nowhere is there a better paradigm than during recovery after critical illness.

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## APPENDIX 1: CASE STUDIES

### Case example A

#### ***Intensive Care Syndrome: Promoting Independence and Return to Employment InS:PIRE***

The Service Model:

Our ICU follow up service is a multi-professional group rehabilitation course that occurs over a 5 week period. We aim to see patients and their relatives at least 6 weeks post discharge from hospital.

Key Interventions:

#### **Personalised appointments with:**

- A doctor and nurse. In this session patients receive a lay summary of their hospitalisation. Personal goals for both the patient and caregiver are set and the input which InS:PIRE can support are also discussed.
- A physiotherapist. A full MSK assessment is undertaken and any pain issues explored. The physiotherapist can then refer the patient to ongoing services in the community if appropriate.
- A pharmacist provides a full medicine reconciliation exercise and discusses any ongoing medicine/drug issues.

If requested patients and relative can access appointments with:

- The Citizens Advice Bureau who come to help individuals with benefits advice, disability badges, housing and other social issues.
- An OT, who is a vocational rehabilitation expert, can help patients get back to work in a structured fashion.

#### **Group sessions:**

- Clinical Psychology- highlighting common feelings and fears after ICU and what to do when things become problematic. Patients and caregivers are separated for these sessions.
- Representatives from our local brain injury clinic attend and address memory and sleep issues.
- Mindfulness
- There are educational talks on sleep hygiene, nutrition, pacing and pain.
- There is also the opportunity to refer on to our dietetic team as well as addictions, urology (to address sexual dysfunction issues) and the Speech and Language Service.

#### **Peer Support**

As the clinic runs, we have informal peer support for patients and caregivers while they wait for their appointment slot. This is provided by hospital volunteers and patient and caregivers further along the recovery trajectory. These volunteers speak with current service users and provide refreshments from a small kitchen area. This support has received overwhelming positive feedback from patients and indeed the volunteers involved.

Funding:

The team initially received funding from The Health Foundation to test this model in one site in Scotland (2014). After an initial successful evaluation, InS:PIRE was spread to 4 other health boards in Scotland, demonstrating that the model works in different settings. Since that grant

funding has ceased, 3 of the health boards in Scotland have secured ongoing funding and hopefully the 4<sup>th</sup> will follow suit soon.

Since the onset of the pandemic we have had to alter the format of the clinic to a virtual setting using either telephone or videoconferencing using NHS Attend Anywhere software. This has been very successful and all the InS:PIRE sites have altered their format in different ways.

Advantages: Only way to see patients during lockdown but we have had good uptake to the clinic.

Disadvantages: Many patients don't want to use digital software so many of the consultations occur by telephone, which makes it harder to assess patients.

Less access to carers and family members who we know face significant challenges when their relative comes home.

More difficult to provide peer support if patients have digital poverty.

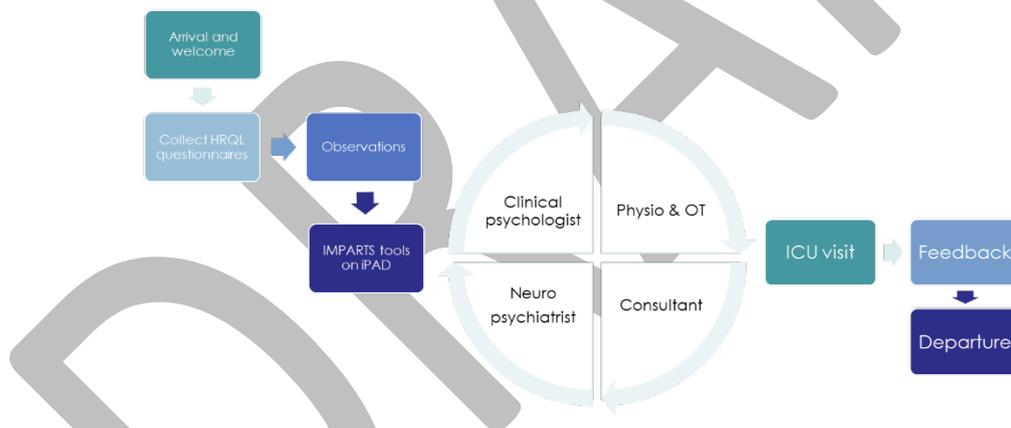
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## Case example B

### *Transitioning to virtual: the GSTT Critical Illness Recovery Clinic*

The Service Model:

A commissioned multi-disciplinary face-to-face carousel clinic which sees patients and their relatives 6-10 weeks post discharge from hospital. The clinic recently transitioned to a virtual MDT carousel format.



Key Interventions:

#### **Before clinic**

- medicine reconciliation and review by ICU pharmacist
- online patient reported outcome measures (mood, PTSD, sleep, sexual)
- ICU diary return
- Nutrition self-screening (PG-SGA) if attending virtual clinic
- Pre-clinic debrief to review patient ICU timeline, co-morbidities and drug history

#### **Within clinic**

Sequential appointments with:

- Doctor and / or nurse. Provide timeline and explanation of events in hospital. Medical assessment, systems review, consolidation of nutrition screening. Visit back to ICU.

- Physio & OT. Functional assessment, cognitive assessment MOCA, exercise advice, liaison with community services, return to work assessment, driving resumption, welfare benefits.
- Psychologist. Assess/brief intervention.
- Neuropsychiatry. Risk, cognition, medicines optimisation.

### Post clinic

Team debrief to co-ordinate interventions for identified recovery issues  
Information provision.

Specialist medical and surgical referrals and referrals to dietitian, speciality/community services e.g. OT/CMHT/psychology.

Follow up appointment typically 3 months.

Funding:

CCG commissioned service for any patient >72h mechanically ventilated.

## Case example C

### **“Growing Rehabilitation And Intensive Care Recovery In Lothian - GRAIL Quest”.**

Lothian Critical Care Recovery Service (LCCRS) incorporating **SCARF**

Over the past decade we have undertaken robust research into critical care rehabilitation at the Royal Infirmary, Edinburgh. Consequently our service has evolved over time. Initial focus was on optimising in hospital post-ICU rehabilitation. Concordant with this, we identified a group of patients with complex health and social care issues through the SCARF project.

**Supporting Community Recovery And Reducing Readmission Risk Following Critical Illness (SCARF):** A quality improvement project supported by the iHUB Scottish Improvement Fund (March 2018-June 2019), which comprises:

- A simple screening tool (assessing multi-morbidity, poly-pharmacy, mobility, fragile social support and psychological issues) to categorize ICU patients as 'SCARF positive' or 'SCARF negative' (see page 21). SCARF positive patients have a high prevalence of social deprivation and mental illness and make up 25% of all ICU survivors.
- A nurse visit to all patients (plus their carer) at ICU discharge, during ward stay and prior to hospital discharge.
- Direct referral and communication with GPs, pharmacists and Health-Social care hubs, during the post-ICU hospital stay.
- A nurse-led telephone based consultation at 2 and 8 weeks post-hospital discharge.

Evaluation with patients/carers and health care professionals has been extremely positive with process control methodology suggesting a downward trend in all hospital readmissions following ICU discharge over the intervention period (around 4% absolute; 15% relative reduction).

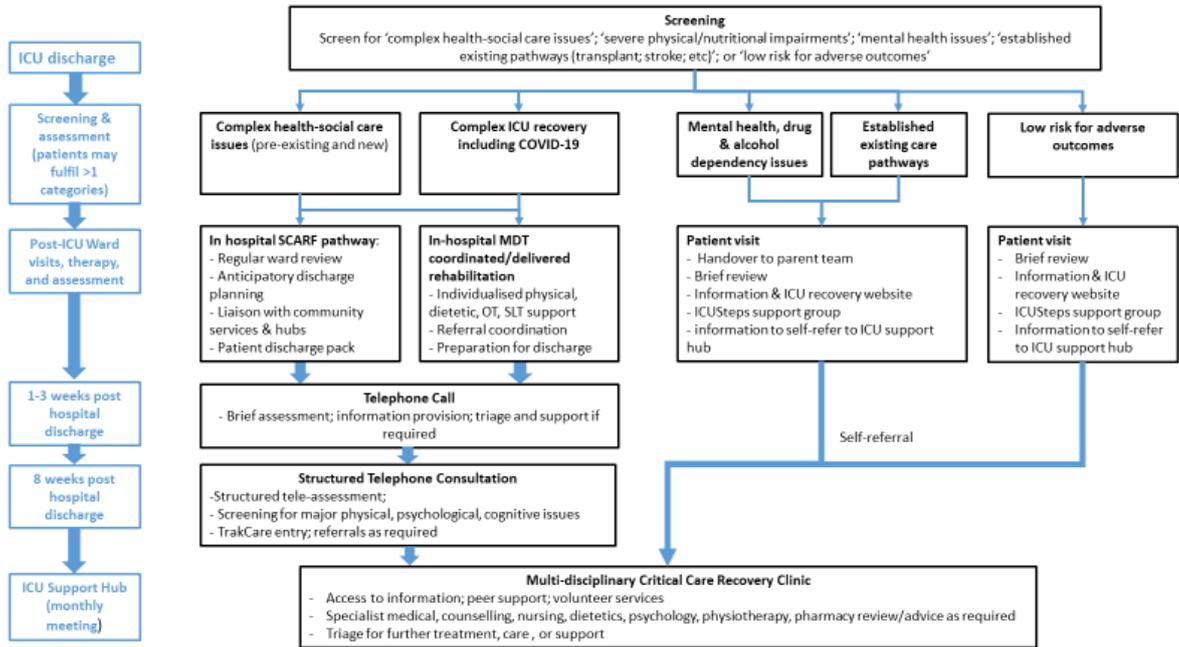
For those assessed as having complex physical, mobility and nutritional impairments the above service was supplemented by a Band 4 Generic Rehabilitation Assistant (GRA) dedicated to supporting the rehabilitation needs of these patients between ICU discharge and hospital discharge. They also coordinated a volunteer programme on a weekly basis, which patients/families found valuable. These patients were reviewed weekly on a hospital round by a consultant intensivist and the GRA.

### The Service Model

From June 2020, through temporary service re-provision and short-term funding acquired

during the COVID-19 pandemic, we have successfully established “the holy grail”: an integrated post ICU recovery service across Lothian Health Board. Key features of the **GRAIL** service are:

- Service leadership by a senior AHP with expertise in post ICU care
- Triage at ICU discharge by a dedicated team to identify an appropriate rehabilitation pathway:
  - Complex physical, mobility and nutritional needs
  - Complex health and social care needs (SCARF)
  - Patients with existing rehabilitation pathways
- A weekly MDT meeting including: consultant intensivist, critical care recovery (LCCRS) nurses, physiotherapist, dietitian, speech & language therapist, occupational therapist, psychiatrist/psychologist, GRA and consultant in rehabilitation medicine.
- Delivery of daily rehabilitation and goal setting for patients with major physical/nutritional requirements, provided by the same specialist AHPs on the MDT, with assistance from the GRA.
- Coordinated information provision for patients, family support, anticipatory discharge planning and early liaison with primary care and health-social care services by LCCRS nurses.
- Medical support from consultant intensivists with expertise in ICU rehabilitation, incorporating ward review, provision of a lay summary and medicine reconciliation for the most complex patients.
- Further discharge planning and integration with a range of health and social care hubs, third sector organisations and referral to additional support services, just prior to hospital discharge.
- Use of a digital platform, “Tailored Talks” to issue personalized information, support and advice for patients recovering from critical illness and their carers/families. Resources provided for reliable digital websites and links to local ICU Steps group.
- A multi-disciplinary follow up support hub (clinic). To enable optimal utilization of limited resources and ensure patient review by appropriate members of the critical care recovery MDT, prior telephone triage is undertaken by the LCCRS nurses. In attendance at the hub are a critical care consultant, LCCRS nurse, psychiatrist, physiotherapist, dietitian, occupational therapist and speech and language therapist. There is thus an opportunity to address any unforeseen needs for those requiring additional assessment. Most clinics have been face to face, but we offer a telephone or Near Me video consulting service for the small number of patients who prefer this.



The main strength of this service is that it delivers a comprehensive, co-ordinated rehabilitation pathway for ICU survivors, which commences in the intensive care unit and extends beyond hospital discharge into the community, before linking back into secondary care through a follow up hub. It ensures continuity of care by the same multi-disciplinary staff throughout the entire patient journey and at key transition points.

Over the past year we developed a business plan to enable the long term provision of this service and in April 2021 we were delighted to learn this had been successful. It also includes the additional support from pharmacy and the Citizen's advice bureau. We intend to invite volunteers from ICU Steps to the follow up hub to provide peer support once pandemic restrictions allow.

## APPENDIX 2: EXAMPLE BUSINESS CASE

### 2014/15 Acute Service Development Proposal

PLEASE NOTE - Evidence of QIPP savings/cost Neutrality will be a strong deciding factor, and proposals that do not demonstrate this may not be considered.

Title of Proposal	Development of a Multidisciplinary Post-Critical Care Clinic
<p><b>1. Description of Proposal</b></p>	<p>It is proposed to offer dedicated outpatient Post-Critical Care Clinic at 2-3 months after discharge to all survivors who stayed in ICU for <math>\geq 7</math> days and were ventilated during their stay.</p> <p>The provision of a follow-up service for post-Critical Care patients is recommended by NICE Guidelines and by Core Standards for ICUs.</p> <p>Survivors of critical illness frequently experience impairment of cognition, mental health and physical function known as post-intensive care syndrome (PICS).</p> <p>For each problem there are a range of well-recognised features:</p> <ul style="list-style-type: none"> <li>• cognitive problems (e.g. poor attention span, memory problems)</li> <li>• psychiatric problems (e.g. post-traumatic stress, anxiety, depression) – evidence shows that the prevalence of depression among post-critical care patients is 17-43% and the prevalence of PTSD is 21-35%</li> <li>• neuromuscular problems (e.g. intensive care unit acquired weakness, joint pain/stiffness, exercise intolerance) – evidence shows that all muscle biopsies taken at 6-24 months after ICU discharge are abnormal</li> <li>• chronic pain and discomfort (e.g. at chest drain sites)</li> <li>• sensory changes (e.g. hearing loss, sight problems, change in taste/smell)</li> <li>•</li> </ul> <p>These problems present as a complex combination leading to:</p> <ul style="list-style-type: none"> <li>• reduced quality of life</li> <li>• reduced physical functioning</li> <li>• delay in or inability to return to work</li> </ul> <p>Some patients develop problems specific to procedures or conditions in Critical Care (e.g. scarring and tracheal stenosis after tracheostomy).</p> <p>Risk factors for developing these problems are not yet fully understood, but include factors during the ICU stay (e.g. sedation, use of inotropes/vasopressors, glycaemic control,</p>

mechanical ventilation, peri-operative factors, diuresis), and factors prior to ICU stay (e.g. co-morbidities, socioeconomic status).

Many patients have complex medical and surgical conditions that require several specialists delivering care during and after their stay in hospital. The delivery of well coordinated care after discharge can be difficult with the responsibility landing primarily with the patient's general practitioner.

The mental health of family members may also be adversely affected and this is termed PICS-family (PICS-family).

There is an evolving literature on interventions during the Critical Care stay that may reduce longer-term complications. These include minimising use of neuromuscular blockade and steroids to reduce incidence of ICU-acquired weakness, targeted sedation, minimising the use of benzodiazepines for sedation, recognition and early treatment of delirium and the use of ICU diaries. Early physical rehabilitation is also a crucial component of care during critical illness.

The University Health Network (Toronto) highlights the importance of providing support to family and carers of patients, as they are a key risk modifier of the outcome.

To provide as much benefit as possible to the patients from this follow-up service, it will be important to engage families and carers in the evaluation process. Feedback from families and carers collected shows a clear desire for a post critical care clinic service, therefore we can be confident that families/carers will engage with this and help to reach the best possible outcome for patients.

A post-Critical Care clinic was developed and piloted. The service model includes a multi-disciplinary team including:

- Critical Care Consultant
- Critical Care Nurse
- Physiotherapist
- Occupational Therapist
- Psychologist
- Dietician
- Pharmacist

The clinic appointment letter is sent to the patient along with two quality of life questionnaires the SF-36 and EQ-5D. A food diary is also sent to the patient to complete during the week before clinic attendance.

On arrival to the clinic the patient completes an iPad-based questionnaire to evaluate anxiety, depression and PTSD symptoms. The Integrating Mental and Physical healthcare: research, Training and Services (IMPARTS) team helped to

	<p>develop and provided the iPad to deliver the mental health questionnaire evaluation.</p> <p>All patients asked about their memories of ICU, which in combination with the questionnaire responses highlights those suffering with anxiety, depression and PTSD. Patients are asked if they received their ICU diaries and if not they are retrieved and given to the patient.</p> <p>A psychologist then conducts a qualitative telephone interview following the clinic visit. Those identified as having severe depression, anxiety and PTSD are referred to liaison psychiatry.</p> <p>Cognition is evaluated using the Montreal Cognitive assessment (MOCA).</p> <p>A thorough functional assessment including history, examination and review of organ dysfunction encountered during the ICU stay along with ongoing symptomatology is reviewed.</p> <p>A physiotherapist completes a thorough physical assessment including completion of the functional independence measure and functional assessment a global measure of disability.</p> <p>A food diary is completed in the week before the clinic attendance and this review by the dietician to decide whether a formal review of nutrition is required.</p> <p>A critical care nurse is present in the clinic to complete baseline observations including heart rate, blood pressure, oxygen saturations, weight and height. They also escort patients and relatives to the ICU to see where they were cared for during their illness.</p> <p>A clinic letter is created by the MDT and sent to the GP with recommendations regarding the chronic medical and surgical conditions identified. There are suggestions regarding the adjustment of medications, surveillance of chronic conditions and recommendations regarding referral to local specialist medical or surgical services. Mental health and cognitive issues when identified are reported along with suggestion regarding their management included. Advice is also offered to patients regarding driving restrictions and these recommendations are also included. Local rehabilitation services are contacted by the physiotherapist to ensure inclusion into these programmes were available to the patient. Nutritional advice when given is also included.</p>
<p><b>2. Please identify if the proposal is one of the following:</b></p> <ul style="list-style-type: none"> <li>• An activity recording change</li> </ul>	<p>This is a new service development. This pilot has so far been successful and well-received, but is unsustainable in its current form without funding. PICS is poorly assessed or not at all within the existing framework of care after discharge from hospital – for example, community counselling services are available, but they often have little understanding of</p>

<ul style="list-style-type: none"> <li>• <b>A new Service Development or Significant Service Reconfiguration</b></li> <li>• <b>Other - please describe</b></li> </ul>	<p>post-critical syndrome. The co-ordination and implementation of treatment/specialist follow-up of complex surgical and medical problems is difficult with unrecognised mental health and cognitive impairment.</p> <p>It is expected that by proactively supporting patients after their stay in Critical Care, it will be possible in some circumstances to avoid missed follow-up appointments with specialist services, identify important co-morbidities that need regular review and highlight unrecognised mental health issues. This will hopefully reduce readmissions to hospital, attendances at local GP practices and assist in some patients returning to work earlier. We have already identified a number of patients that have not been given follow-up appointments locally or missed them for one reason or another. Not only is this of clear benefit to the patient, but is also a more efficient and more effective way of providing care.</p>
<p><b>3. Stakeholder support – identify key internal and external stakeholders demonstrating that they have been consulted and support the proposal (e.g. clinical/GP/Specialist commissioning support for any service developments)</b></p>	<p>Feedback from families of patients who have stayed in Critical Care has consistently expressed desire for a follow up model. This feedback has been collected through questionnaires, interviews, and workshops since December 2011, and has been used in the development of this proposal.</p> <p>Since the commencement of the pilot, feedback has been collected from those patients who have attended the clinic and this has been immensely positive. Patients stated in the feedback questionnaire:</p> <p>'Someone was actually listening to me and how I was feeling. I think the clinic is a good idea and much needed. After leaving hospital it would have been nice to have someone coordinate between the different departments etc'.</p> <p>'The appointment really helped me , as I had no memory of being in ICU. The consultant and physio really explained what I had been through and helped with further referrals. Up till then I did not feel that I understood my condition and was not offered any follow-up appointment from my local medical team'</p> <p>We involved a local GP who attended the clinic and had the following comment regarding the service.</p> <p><i>'I attended the follow-up clinic for ICU patients. I have the following comments to make from a GP perspective. These patients have complex medical care needs and to try to address their issues within the time constraints of a 10 minute consultation and the limited experience we have dealing with such patients does the patients a great disservice.</i></p> <p><i>In the clinic, patients had a 60 minute appointment with a multidisciplinary team approach whereby both their physical and psychological issues were addressed.</i></p>

*During the clinic I managed to talk to several patients after their consultations and they all expressed very high satisfaction rates with the follow-up clinic and patients were very pleased to have the opportunity to discuss many of their post ICU medical concerns. I believe that this clinic provides a holistic approach to address an area of medical care that I feel at present is rather poorly served. I have no hesitation in strongly recommending the service from a primary care perspective'.*

There has been strong clinical support for this proposal and good engagement with the pilot from across the multidisciplinary team in Critical Care.

Throughout the process of developing this proposal, advice has also been taken from other organisations with established Critical Care follow-up clinics – e.g. Royal Berkshire NHS Foundation Trust, Royal Brompton & Harefield NHS Foundation Trust, and University Health Network (Toronto). Advice has also been sought from the local Network, which has expressed a keen interest in the pilot.

**4. Strategic Fit – identify key relevant external and internal strategic drivers (e.g. KHP, NSF's, IOG's, strategic priorities , KPI's etc) and how the bid supports their delivery.**

**Core Standards for ICUs (2013):**

2.1.6: Patients discharged from ICU should have access to an ICU follow-up clinic. Following a period of critical illness, patients should be offered the support of a specialised critical care follow-up. Critically ill patients have been shown to have complex physical and psychological problems that can last for a long time. These patients benefit from the multi-modal approach that an ICU follow-up clinic can deliver. The clinic does not necessarily have to be provided by the hospital that the patient was treated in. It could be delivered on a regional basis.

**The Critical Care service has been collecting family experience data since December 2011:**

In a setting where patients are critically ill and unable to express themselves, family members often act as surrogates for the patients. The family account is important to patients helping to inform them of what happened during their illness. ICU diaries are completed for all ICU patients that have care in ICU for more than 72 hours and are given to patients at discharge. The feedback from patients is that they are helpful in supplementing family accounts. ICU diaries have been reported to reduce the incidence of PTSD. The pilot clinic has highlighted that many patients find the diary very helpful, but there are patients who prefer not to relive their experiences by reading the diary so chose not to.

Family members provide physical, emotional and socio-economic support during a patient's convalescence and rehabilitation. This affects them and they can suffer PICS-family. Families can provide a continuous observation of how the intensive care service is being delivered and an insight into where improvements could be made. Family satisfaction is regarded as a quality indicator in Intensive

Care. A number of key service changes were proposed in feedback from family questionnaires, family interviews and a workshop attended by patients and families. Chief amongst these was the provision of Post Critical Care clinic.

**Rehabilitation after critical illness (NICE Clinical Guideline 83, 2009):**

1.1.23 Review patients with rehabilitation needs 2–3 months after their discharge from Critical Care. Carry out a functional reassessment of their health and social care needs, using the dimensions in recommendation 1.1.20. If appropriate, also enquire about sexual dysfunction.

1.1.24 The functional reassessment should be face to face in the community or in hospital, performed by an appropriately-skilled healthcare professional(s) who is familiar with the patient's critical care problems and rehabilitation care pathway.

1.1.25 Based on the functional reassessment:

- Refer the patient to the appropriate rehabilitation or specialist services if:
  - the patient appears to be recovering at a slower rate than anticipated, according to their rehabilitation goals, or
  - the patient has developed unanticipated physical and/or non-physical morbidity that was not previously identified.
- Give support if the patient is not recovering as quickly as they anticipated.
- If anxiety or depression is suspected, follow the stepped care models recommended in 'Anxiety' (NICE clinical guideline 22) and 'Depression' (NICE clinical guideline 23).
- If PTSD is suspected or the patient has significant symptoms of PTS, refer to 'Post-traumatic stress disorder (PTSD)' (NICE clinical guideline 26).

The expectation, already confirmed by experiences of the pilot, is that the provision of a comprehensive functional physical and psychological assessment of patients following their Critical Care stay will identify issues that can be addressed earlier and avert the need readmission or repeat appointment with the GP. This is in line with the Trust's aims of reducing acute activity and admissions and reducing burdens on the broader health economy.

**5. Proposed Implementation Plan - timetable, compliance with procurement rules, etc.**

In 2015, a pilot Post Critical Care clinic was commenced seeing patients whose ICU length of stay was >7 days. A total of 24 patients, 2-6 patients per clinic per month have been assessed. The service has evolved during this time and will continue to develop. Currently, patients are identified retrospectively from the database of ICU admission. This database has identified that between August 2014 and 2015 approximately 338/1581 i.e. 20% of patients per year survive Critical Care with a length of stay of 7 days or more. Based on the experience of the pilot study, it can be expected that on average 28 patients per month would meet the criteria for consideration of a post critical care clinic appointment. However, only approximately 20-40% of these would be

	<p>suitable to attend the clinic. The other 60% of patients that would not be suitable would comprise those with active palliative care, unable to travel the long distance and those that do not feel it would be beneficial. This equates to approximately 68-135 patients attending the post critical care clinic per year: 4-5 clinic appointments of one hour every other week.</p> <p>Over the next year, there will be further development of this pilot service with the identification and evaluation of the patient prior to ICU and hospital discharge. This will improve the evaluation of the changes in the functional status of the patients over time (hospital discharge to attendance at the post critical care clinic between 2-3 months following discharge).</p> <p>The model of the clinic described in detail earlier will need to develop. It is planned that input from occupational therapy and psychology services will be increased if funding is secured.</p> <p>The current evaluation process of the service will continue to include questionnaires to evaluate: quality of life (SF-36, EQ-5D) and patient feedback regarding the different elements of the clinic process (getting to the clinic, doctor consultation, physiotherapy consultation, usefulness and timeliness of the clinic).</p> <p>The quality of life questionnaire, EQ-5D will be sent repeatedly at 3, 9 and 12 months to enable a cost-effectiveness analysis to be undertaken using a comparator group from previous studies.</p>
<p><b>6. Risk Assessment - Describe any risks should the proposal not receive commissioning support (including clinical risk, risk of loss of activity / income, loss of reputation – and risk to business continuity)</b></p>	<p>Clinical risk to patients - many of the problems relating to a patient's stay in Critical Care are not recognised, understood or dealt with in the 'traditional' outpatient clinic (e.g. surgical), or by GPs.</p> <p>Patients have not been given appropriate specialty outpatient appointments, because clinical information is lost between discharge from ICU and hospital or they have failed to attend and no further appointment requested. In some cases, patients have not received an outpatient follow-up appointment e.g. (pilot clinic case) a woman who underwent a lung resection for a carcinoid tumour did not receive a follow-up appointment. She did not enquire why this was not the case, because she was suffering with unrecognised cognitive impairment. A man who suffered an MI underwent PCI and developed AKI requiring dialysis did not receive follow-up with local cardiology services on discharge following the recovery of his kidney function.</p> <p>Several medical conditions require a patient to notify the DVLA e.g. seizures or cardiac arrest. The post critical care clinic provides another opportunity to provide patients with advice regarding driving, using the DVLA guidance on medical conditions.</p>

	<p>There is a significant risk of not identifying patients with PICS, which left untreated, will lead to multiple attendances to GP surgery, emergency department or even readmission to hospital. This is clearly not beneficial for the patient, the organisation or primary care services and could be prevented by pre-emptive identification of problems.</p> <p>Loss of reputation/status as a world class Critical Care service – other organisations are providing a Critical Care follow-up service and we are not meeting the standards in this area.</p>																																				
<p><b>7. Financial Appraisal - Outline the financial impact for commissioners</b></p>	<p>We are proposing a locally agreed tariff for this clinic which is costed as per the below model on a per patient basis</p> <p>The cost of running this service to the Trust is £594 per appointment. This is based on 1 clinic per month, with each clinic consisting of 5 appointments, and the following staffing costs:</p> <table border="1" data-bbox="592 880 1390 1285"> <thead> <tr> <th>Staff</th> <th>Time per clinic (hrs)</th> <th>Cost per clinic (£)</th> <th>Cost per patient (£)</th> </tr> </thead> <tbody> <tr> <td>Consultant</td> <td>8</td> <td>1844</td> <td>369</td> </tr> <tr> <td>Psychologist</td> <td>3</td> <td>411</td> <td>82.2</td> </tr> <tr> <td>Dietician</td> <td>2</td> <td>236</td> <td>47.2</td> </tr> <tr> <td>Occupational Therapist</td> <td>2</td> <td>236</td> <td>47.2</td> </tr> <tr> <td>Pharmacist</td> <td>1</td> <td>118</td> <td>23.6</td> </tr> <tr> <td>Physiotherapist</td> <td>3</td> <td>361</td> <td>72.2</td> </tr> <tr> <td>Admin Support</td> <td>2</td> <td>26</td> <td>5.2</td> </tr> <tr> <td><b>TOTAL</b></td> <td></td> <td><b>3232</b></td> <td><b>646.6</b></td> </tr> </tbody> </table> <p>Based on the above costings the total potential financial impact directly to commissioners will be in the range of £43,969 (n= 68) to £87, 291 (n= 135).</p>	Staff	Time per clinic (hrs)	Cost per clinic (£)	Cost per patient (£)	Consultant	8	1844	369	Psychologist	3	411	82.2	Dietician	2	236	47.2	Occupational Therapist	2	236	47.2	Pharmacist	1	118	23.6	Physiotherapist	3	361	72.2	Admin Support	2	26	5.2	<b>TOTAL</b>		<b>3232</b>	<b>646.6</b>
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<p><b>8. What are the annual activity projections, and proposed Contract Currency?</b></p>	<p>In April 2015, a pilot Post Critical Care clinic was commenced seeing patients whose ICU length of stay was &gt;7 days. A total of twenty-four patients, 2-6 patients per clinic per month have been assessed. The service has evolved during this time and will continue to develop. Currently, patients are identified retrospectively from the database of ICU admission. This database has identified that between August 2014 and August 2015 approximately 338/1581 i.e. 20% of patients per year survive Critical Care with a length of stay of 7 days or more. Based on the experience of the pilot study, it can be expected that on average 28 patients per month would meet the criteria for consideration of a post critical care clinic appointment. However, only approximately 20-40% of these would be suitable to attend the clinic. The other 60-80% of patients that would not be suitable would comprise those with active palliative care, unable to travel the long distance, those that</p>																																				

do not feel it would be beneficial or they are in local rehabilitation centres. This equates to approximately 68-135 patients attending the post critical care clinic per year: 4-5 clinic appointments of one hour every other week.

**9.What are the activity projections by CCG?**

Southwark	20%
Lambeth	17%
Lewisham	8%
Bexley	5%
Bromley	4%
Greenwich	5%
Other London CCGs	15%
Other CCGs	27%
<b>Total for GSTT</b>	<b>100%</b>

DRAFT

## APPENDIX 3: RELATED RESEARCH STUDIES

### SCARF - Supporting Community Recovery and Reducing Readmission Risk Following Critical Illness

The SCARF project operational since March 2018 has delivered very promising initial results in supporting community recovery and reducing unplanned hospital readmissions for an identified high-risk cohort of patients surviving a critical illness with complex health and social care needs.

People who receive care in an intensive care unit (ICU) following a critical illness often leave hospital with complex health and social care needs. This places them at high risk of poor outcomes, and also unplanned hospital readmissions. There is a growing international recognition in the critical care community around the need to better support this particular cohort's health and psycho-social care needs, and provide personalised care and support. If we could improve patient outcomes and/or decrease readmissions through a structured intervention this is likely to be both clinically and cost-effective.

The complexity of many ICU survivors includes both physical and psychologic problems, but also social issues such as employment problems, financial and family stresses, and social isolation. Effective management requires personalised support for all of these concurrently, and is ideally anticipatory rather than reactive. If possible it should start from ICU discharge, and involve the ward based hospital stay, the key transition home, and community support. A challenge for many ICU patients is the diverse pathways and service transitions that occur, often based around parent specialty rather than the individual needs of patients.

If the required support from health and social care services is not available or accessed quickly enough, recovery can be negatively affected and this likely contributed to high hospital readmissions. Family members and carers of ICU survivors may also require support from health and social care services and third sector groups given the stressfulness of their own experience.

SCARF, a quality improvement project (funded by Healthcare Improvement Scotland) used an adaptive, iterative process, allowing the SCARF project team to make decisions in a responsive way as the project progressed. The project used a screening tool, newly developed through previous research conducted by the University of Edinburgh's Critical Care Research Group (ECCRG), to identify those at highest risk of readmission. This screening checklist included multimorbidity; polypharmacy; frequent previous hospitalisations; mental health issues; fragile social circumstances; and impaired activities of daily living. Using this during ICU or at discharge identified around 25% of all ICU survivors have complex health and social needs. Importantly, these individuals had a 45% risk of readmission during the first 3 months after going home. The SCARF intervention starts at ICU discharge, and the SCARF pathway involves rapid information transfer from hospital to GPs, community pharmacists, health and social care partnership teams during the pre-hospital discharge period. In addition, information about recovery is provided to patients and families, and connections with peer support groups and relevant third sector organisations. The pathway is delivered by a multidisciplinary team, but coordinated by dedicated ICU trained 'SCARF' nurse practitioners who also call patients around 2 and 8 weeks after discharge to further support and address holistic needs.

Preliminary data indicate the approach provides valued support from a patient, carer, and provider perspective. We have also seen a progressive decrease in unscheduled readmissions in this group over the project, which is now embedded in clinical service.

Ongoing development has included the development and build of a digital support platform (with a commercial partner) that allowed multiple clinicians within the MDT to create and provide 'tailored talks' to patients and carers at the 'right time' in recovery.

These are 'bite sized' self-management and information resources on a wide range of issues faced by survivors, which can be viewed on multiple devices and provided remotely. These are being integrated into the clinical pathway, and are provided as required by different members of the MDT (including all AHP groups, psychology/psychiatry etc). It is hoped these resources may be made available to other NHS providers through a licensing arrangement with the commercial partner.

### **Rehabilitation after COVID-19 critical illness; a qualitative study exploring people's experiences and recovery needs (Funded by Burdett Nursing Trust)**

Suzanne Bench, PhD, RGN; Nicky McGuinness, MSC, RMN; Alison James, MSC, RN; Gaby Parker, DClinPsy; Matthew Hodson, PhD, RN; Helen Cherry, patient rep; Hilary Floyd, MD; Nicola Thomas, PDoc, RGN.

The aim of this qualitative study is to understand the experiences of people diagnosed with severe COVID-19 and their perspectives on the health and social care support required to optimise community-based rehabilitation and recovery. Worldwide, 26-32% of people hospitalised with COVID -19 required an admission to an intensive care unit (ICU) in 2020. We have little understanding of the impact of critical illness relating to COVID on people's lives and wellbeing after hospital discharge.

Data collection took place September 2020 to April 2021. We interviewed 20 adults discharged from ICU to one of two community organisations in England: Central London Community Healthcare NHS Trust (CLCH) in London and the NHS Seacole centre in Surrey, via a secure virtual platform (such as Microsoft teams, Zoom) or by telephone. Anonymised and verbatim-transcribed interview data were uploaded into NVIVO and are currently undergoing a standard process of inductive thematic analysis.

### **ORRCI: On the Road to Recovery after Critical Illness**

The purpose of this interventional cohort study is to increase understanding of driving impairments after critical illness and establish a knowledge base for informing safe and timely 'driving resumption' after critical illness in the UK. Recovering critically ill adult patients (n=80) who previously held a driving licence and intend to resume driving will undergo a comprehensive driving assessment at the 2 month time-point following hospital discharge. Participants are followed up for 12 months to determine the prevalence of driving-related impairments and determine their driving status as well as enablers and barriers associated with driving outcome.

### **Digitally Enhanced Intensive Care Survivor Recovery Pathway**

This digital service innovation project is exploring the use of an e-care platform to provide remote care and support recovery from critical illness. The platform will deliver individualised patient care throughout the trajectory of critical care step down to acute wards to discharge home and 12 months beyond. It will incorporate remote secure video communication, virtual rehabilitation activity, information giving, goal setting, family inclusion and self-reported outcome measures. A cohort of 200 patients in SE London comprising both Covid and non-Covid ICU survivors who each required ventilation for more than 72 hours will use either the platform on their own device, or be issued with a configured tablet if they do not have a smart device or have been admitted without their device. Acceptability, feasibility and cost effectiveness of the intervention will be assessed.