

**USING PATIENTS', RELATIVES' AND CLINICIANS'
EXPERIENCES TO IMPROVE FOLLOW UP SERVICES AND
RECOVERY AFTER CRITICAL CARE: AN EXPERIENCE-BASED
CO-DESIGN STUDY**

by

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Type of Award Doctor of Philosophy (PhD)

School Health and Wellbeing

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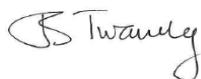
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PREFACE

My interest in the outcomes for patients and their families following an episode of critical illness evolved progressively, growing out of a career in critical care nursing. As a nurse working in the critical care setting, my initial enthusiasm was to care for the sickest patients in the hospital with the purpose of learning new technical skills and helping patients to survive. My interests were in the best way to deliver care and treatment and my first research study explored the impact of the experience of staff on how patients weaned from mechanical ventilation. Over several years in that setting both my clinical and research interests expanded, and I conducted a qualitative research study for my MSc exploring how family members responded to the patient's critical illness. I came to understand the challenges patients and families faced in the hospital setting and this stimulated a curiosity about the wider impact that critical illness had on patients and their families.

My awareness of the wider and longer-term outcomes for patients and families following critical illness were heightened when I changed career to become a critical care research nurse. Through delivering multicentre clinical research trials in the critical care setting it was necessary to follow up patients recruited into trials over several months or sometimes years. Through meeting with patients and their families to collect outcome data for studies, I realised that the outcome of critical illness is much more multifaceted than the measures of 'survival' and 'quality of life' indicated. Patients appeared to face many and varied challenges after discharge from critical illness, often relying on their families and their own resourcefulness to guide their recoveries. Following up patients to record outcomes for research trials also created the opportunity for me to work in a more interactive way with the critical care outreach and critical care follow up teams. I learned more about the delivery of services to help patients and families after critical illness. At the time of beginning this thesis, the experiences of patients during recovery from critical illness were not widely known and amongst those healthcare professionals who delivered follow up services, some were beginning to question the impact of their service upon patients. These circumstances formed the inspiration for this thesis.

ABSTRACT

Background

Following an episode of critical illness, two thirds of critical care unit (CrCU) survivors experience significant problems with physical functioning, mental health, social issues and returning to work. There is limited understanding and evidence to guide how services can effectively support patients and families during a prolonged recovery. This study aimed to identify and prioritise service improvements for patients who have survived an episode of critical illness.

Methodology and Methods

Using Experience-based Co-design (EBCD) methodology this study explored the experiences of former CrCU patients, their family members and the staff who delivered CrCU follow up services at a large teaching hospital in the Northwest of England. Filmed interviews with 10 former CrCU patients and audio recorded interviews with 9 staff members were conducted and a 30 minute film of patients' experiences was developed which illustrated the major touchpoints (key events and experiences) of the recovery journey. A patient feedback event was held for patients to rate the touchpoints and capture the emotions and keywords evoked by each touchpoint to identify the positive and negative experiences of the recovery journey. Following this, a joint patient and staff event for patients, families and staff, was held and the patient film was used to trigger emotive aspects of the patient recovery journey. This triggered collaborative discussion between patients, families and staff which focused on identifying priorities for service improvement.

Findings

Four priorities for service improvement were identified; improving the CrCU experience for patients; addressing patients' emotional and psychological needs; positioning patients at the centre of services; and, developing a supportive framework to promote the recovery process.

Contribution to current knowledge

The EBCD methodology enabled the whole patient journey from critical illness through recovery to be captured. The focus on improving patient experiences and the development of collaborative partnerships between patients, families and staff has determined which elements matter most to patients during their recovery. Using this approach progressed care delivery, bringing what patients felt was important into the centre of service co-design and created the potential to improve outcomes.

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some epic sulks and hysterics and still making me laugh every single day. This achievement is ours. I couldn't have done it without you.

GLOSSARY OF TERMS

ABCDEF	A care bundle that is designed to optimise recovery after critical illness. The bundle includes: Assess , prevent, and manage pain; Both spontaneous awakening trials (SAT) and spontaneous breathing trials (SBT); Choice of analgesia and sedation; assess, prevent, and manage Delirium ; Early mobility and exercise; and, Family engagement and empowerment.
Acute Respiratory Distress Syndrome (ARDS)	A type of respiratory failure characterized by rapid onset of widespread inflammation in the lungs.
Advanced Respiratory Support	Invasive mechanical ventilatory support.
AHP	The Allied Health Professions (AHPs) comprise of 14 distinct occupations including: art therapists, dietitians, dramatherapists, music therapists, occupational therapists, operating department practitioners, orthoptists, osteopaths, paramedics, physiotherapists, podiatrists, prosthetists and orthotists, diagnostic and therapeutic radiographers, and speech and language therapists.
Basic Respiratory Support	Indicated by one or more of the following: More than 50% oxygen delivered by face mask. Close observation due to the potential for acute deterioration to the point of needing advanced respiratory support. Physiotherapy or suction to clear secretions at least every two hours. Patients recently extubated after a prolonged period of intubation and mechanical ventilation. Continuous Positive Airway Pressure (CPAP) or non-invasive ventilation (support for respiratory failure delivered through a clear plastic hood or mask) Patients who are intubated to protect the airway but needing no ventilator support and who are otherwise stable.
Case-mix	The type or mix of patients treated by a hospital or unit.

Critical Care Discharge Co-ordinator	Nurse who facilitates safe discharge of critical care patients to a ward setting.
Critical Care Outreach	A nurse-led service that supports ward nurses and doctors who are caring for acutely ill in-patients, assesses acutely ill / deteriorating patients on wards, and advises the patient's team on monitoring, investigations and management plans. Reviews patients post CrCU to reduce readmissions.
Critical Care Psychologist	A clinical psychologist who supervises the psychological and cognitive assessment of all patients, both in the CrCU, and after transfer to other wards. Provides or supervises psychological support to patients and occasionally relatives who are highly stressed or traumatised.
Critical Care Services	Incorporates specialist wards such as High Dependency Units (HDUs) and Intensive Care Units (ICUs) for purposes of NHS England Service Specification commissioning standards.
Critical Care Unit (CrCU)	A unit combining HDU beds and ICU beds.
Critical Illness	A life-threatening condition in which patients need to be admitted to a specialist area for close observation and specialist care.
Delirium	A change in a person's mental state or consciousness, which is often shown as confusion, difficulties with understanding and memory, or personality changes. It is also known as an 'acute confusional state'.
Endotracheal tube	A flexible plastic tube that is placed through the mouth into the trachea (windpipe) to help a patient breathe. The endotracheal tube is then connected to a ventilator, which delivers oxygen to the lungs. The process of inserting the tube is called endotracheal intubation.
Experience-based Co-design (EBCD)	An approach that enables staff, families and patients (or other service users) to co-design services and/or care pathways, together in partnership.
FICM	The Faculty of Intensive Care Medicine ,the professional body responsible for the training, assessment, practice and continuing professional development of Intensive

	Care Medicine doctors and practitioners in the UK.
GPICS	Guidelines for Provision of Intensive Care Services published by the Faculty of Intensive Care Medicine and the Intensive Care Society.
High Dependency Unit (HDU)	A department of a hospital for patients who are seriously ill or require close observation but do not require intensive care. Also known as a Level 2 area.
ICNARC	Intensive Care National Audit and Research Centre.
Intensive Care Society (ICS)	Intensive Care society; the largest multi-professional critical care membership organisation in the UK.
Intensive Care Unit (ICU)	A special department of a hospital or health care facility that provides intensive treatment. Also known as an intensive therapy unit, intensive treatment unit (ITU) or a Level 3 area.
Multiple Organ Dysfunction Syndrome (MODS)	Altered organ function in an acutely ill patient requiring medical intervention to achieve homeostasis. Also known as multiple organ failure (MOF), total organ failure (TOF) or multisystem organ failure (MSOF).
NHS England Monthly Sitrep Report	A monthly publication of data collected on urgent operations cancelled and critical care capacity as a snapshot report. This is reported on the last Thursday of the month.
National Institute for Health and Care Excellence (NICE)	The National Institute for Health and Care Excellence is a UK-based public body of the Department of Health which publishes guidelines for the use of health technologies, clinical practice, health promotion and social care.
Organisational development	The process by which organisations achieve change and effectiveness by the development of their strategies, structures and processes.
Patient Feedback Event	A facilitated meeting that invites patients who have already been interviewed as part of the project to develop their collective feedback about the service.
Post-intensive Care Syndrome (PICS)	Post-intensive care syndrome is a collective term for the common complications following critical illness which includes cognitive, psychiatric and/or physical problems.

Primary Care	Includes general practice, community pharmacy, dental, and optometry (eye health) services.
Renal Replacement Therapy (RRT)	A therapy that replaces the normal blood-filtering function of the kidneys. It is used in acute and chronic kidney failure. This is also known as haemodialysis or haemofiltration.
SCCM	The Society of Critical Care Medicine is the largest non-profit medical organization dedicated to promoting excellence and consistency in the practice of critical care. SCCM has members in more than 100 countries.
Secondary Care	Healthcare provided by hospitals and specialists.
Sepsis	A potentially life-threatening condition caused by the body's response to an infection.
Sitrep	Situation report a monthly report on urgent operations cancelled and critical care capacity in the UK.
Staff Feedback Event	A facilitated meeting for staff who are members of the service team and EBCD facilitator/s to talk about their views of the services they provide.
Stepdown	Beds that may be used to provide a higher level of care for patients deteriorating on a ward ("step-up"), a lower level of care for patients transitioning out of intensive care ("stepdown") or a lateral transfer of care from a recovery room for postoperative patients.
Survivorship	The health and life of a person post-treatment until the end of life. It covers the physical, psychosocial, and economic issues beyond the diagnosis and treatment phases. Family members, friends, and caregivers are also considered part of the survivorship experience.
Tertiary care	Healthcare provided in specialist centres.
Touchpoints	A touchpoint is all of the communication, human and physical interactions that customers experience during their relationship lifecycle with the healthcare service organization.
Tracheostomy	An opening created at the front of the neck so a tube can

be inserted into the windpipe.

Trigger film	A narrative film showing service users' experience of a service.
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ABBREVIATIONS

AHP	Allied Health Professionals
ARDS	Adult Respiratory Distress syndrome
CrCU	Critical Care Unit
EBCD	Experience-Based Co-Design
FICM	Faculty of Intensive Care Medicine
ICNARC	Intensive Care National Audit and Research Centre
ICS	Intensive Care Society
ICU	Intensive Care Unit
PICS	Post-Intensive Care Syndrome
PTSD	Post-traumatic Stress Disorder
SCCM	Society of Critical Care Medicine

1 INTRODUCTION

The Critical Care Unit (CrCU) admits the most critically ill patients in the hospital setting, delivering complex treatments and supportive care in the scenario of life-threatening illness and organ failure. 14% of patients admitted to CrCU will die on the unit and 20% of patients discharged from hospital will die within one year (Szakmany et al., 2019). The consequences of survivorship following critical illness are of global concern (Iwashyna, 2010). Patients, their families and healthcare professionals often expect patients to recover quickly and carry on with their lives where they left off (National Institute for Health and Care Excellence [NICE], 2009). However, two thirds of CrCU survivors experience extensive physical disability, disturbing mental health problems, cognitive impairment and social exclusion following critical illness (Desai, Law, & Needham, 2011; Granja, Amaro, Dias, & Costa-Pereira, 2012; Griffiths, Barber, Cuthbertson, & Young, 2006; Griffiths & Jones, 2007; Oeyen, Vandijck, Benoit, Annemans, & Decruyenaere, 2010). During recovery, survivors often need ongoing care and many never return to their pre-illness health status, previous workload or level of income (Griffiths et al., 2013). In recent years, the improving survival rates of patients with debilitating co-morbidities are creating a burden of prolonged recoveries, which is associated with increasing health and social care usage and costs (Geense et al., 2019).

A wide range of primary and secondary care services may be involved in a patient's care following critical illness. The nature of services available varies on a local and regional basis and it can be difficult for patients to identify what kind of support is available, where it is offered, and the processes for accessing this support (Prinjha, Field, & Rowan, 2009). This complexity of service delivery across multiple physical boundaries and professional specialisms is an obstacle to continuity of care delivery and a holistic approach that meets patients' diverse recovery needs. What characterises a successful outcome following critical illness varies between individual patients, and also between families and the staff involved in their recoveries. The challenge lies in delivering timely care across multiple settings, responsive to each individual's physical and psychosocial needs and goals.

This thesis used the Experience-based co-design (EBCD) methodology to aid the improvement of services for patients recovering from critical illness. This introductory chapter describes the background to the study, which was undertaken in a large

teaching hospital in the Northwest of England. The EBCD methodology introduced the concept of using patients' and family members' experiences as the central tenet in the redesign of services (Bate & Robert, 2006). This thesis makes a novel contribution by expanding the evidence which informs the design and delivery of services for recovering patients. Specifically, it explores patient, family and healthcare professional experiences, and uses these as the foundation for discussion and collaboration between patients, family members and staff to determine priorities for service improvement.

This chapter will:

1. Provide an overview of critical care provision
2. Describe the CrCU
3. Describe the prevalence and impact of post CrCU morbidity
4. Describe the care and services that have been developed to support patients and their families during recovery

The unit that is the subject of this study is called CrCU and is a combination of ICU and HDU. To avoid the confusion of using multiple terminologies, the term CrCU has been adopted throughout this thesis and is used in place of ICU or ITU whenever those terms appear in the literature.

1.1 Critical Care Provision

1.1.1 Global context

Little statistical evidence is available to estimate the global burden of critical illness. A worldwide snap shot incorporating data from 730 participating centres over 84 countries looked at CrCU admissions over a 10 day period. 10,069 patients were admitted but only represent a small proportion of the overall worldwide admissions (Sakr et al., 2018).

In 2000, it was estimated that 4.4 million people were admitted to CrCU in the United States (US) each year (Young & Birkmeyer, 2000). By 2011 this was estimated at over 4.6 million people (Barrett, Smith, Elixhauser, Honigman, & Pines, 2014). CrCU bed availability varies between countries. Bed availability in the US is between 20 and 31.7 beds per 100 000 people compared with the United Kingdom (UK), which has 3.5 to 7.4 beds per 100 000 (Prin & Wunsch, 2012). Worldwide, it has been estimated that just over a third of patients are admitted due to surgical causes following elective or emergency operations, with another 7% as a result of trauma, and the rest due to

medical problems such as pneumonia or sepsis (Sakr et al., 2018). Global mortality from a critical illness was estimated as 22.4% in 2018, but with significant variations between regions, especially those with lower wealth and resources. Areas of economic deprivation can be associated with significantly reduced numbers of beds and more limitations on the types of support that can be provided (Sakr et al., 2018). Ironically, this can result in high unit survival rates because only those felt to have the best chances of survival are admitted to these limited resources.

1.1.2 United Kingdom context

In the UK, a situation report (Sitrep) is published by NHS England to report on the number of operations cancelled and the availability of CrCU beds. In August 2019 there were 4,084 adult critical care beds available with 3,241 occupied, giving an occupancy rate of 79.4% (NHS England, 2019). 97% of CrCUs currently provide operational and quality data to the Intensive Care National Audit and Research Centre (ICNARC), a national quality audit organisation (ICNARC, 2018). In the last published annual summary as of 31st March 2018 the NHS had 196 adult general CrCUs. Of these, 12 were combined general and neurosciences; eight were specialist neurosciences; 14 were specialist cardiothoracic; and, one was a specialist liver unit (ICNARC, 2018).

The case mix of patients varies significantly from unit to unit depending on the other local or specialised services that are available at each hospital, such as coronary care and respiratory care. The average age of a CrCU patient is 60.7 years with 55% being male and 45% female; 75.5 % of patients live without assistance prior to admission (ICNARC, 2018). Around 40% are surgical patients with half of these being planned and half urgent or emergency surgical admissions. The remaining 60% are medical (non-surgical) admissions (ICNARC, 2018).

The mean length of stay in critical care is almost five days. Once the decision has been made that the patient is ready to be transferred to a general ward (described clinically as ready for *step down*) around 36% of patients will be moved to that ward within four hours, another 45% within the next 20 hours. Patients spend a mean of 15 days in the wider hospital setting until discharge. This figure has decreased consistently over the last five years, without a corresponding decrease in CrCU duration, meaning that patients are now discharged on average two to three days earlier from hospital (ICNARC, 2018).

1.2 The Intensive Care/Critical Care Unit

1.2.1 Origins

“Intensive care” arose as a speciality in response to the polio epidemics of the 1950s (Adhikari, Fowler, Bhagwanjee, & Rubenfeld, 2010). The paralysis caused by the disease required the use of artificial ventilators to support the breathing of paralysed patients. CrCUs in the UK developed in different parts of the country based on the varying needs of patients within the individual hospitals, such as respiratory problems associated with tetanus outbreaks or complications following cardiac and thoracic surgery (Reynolds & Tansey, 2011). As technology and medicines have developed, the remit has broadened to provide support for a number of other organ systems, most commonly cardiovascular and renal (Reynolds & Tansey, 2011).

Anaesthetists were the main pioneers of *intensive care medicine*, taking skills learned in operating theatres and in the ‘shock tents’ where injured soldiers were treated in military conflicts and transferring these skills to the treatment of critically ill patients (Rodriguez, 2001). Initially, patients were cared for on ordinary wards or in side rooms. Later, patients were brought together to make it easier to educate and support nurses, though early CrCUs often had to make do with any space that was available in the hospital. Units became increasingly standardised as new areas were built following publication of guidance by the Department of Health (DoH). Modern-day CrCUs have to take into account the significant development in the amount and types of possible interventions that can be used to support patients and also building designs intended to reduce healthcare associated infections. Whilst guidance directs the design and infrastructure requirements for new builds, many CrCUs are left with the legacy of the original accommodation restraints.

1.2.2 Modern-day

The second edition of the Guidelines for the Provision of Intensive Care Services (GPICS 2) (GPICS 2, 2019) guides the level of care each patient requires, based on the number of organs that need supporting, as shown in Table 1.1. For example, if a patient is receiving mechanical ventilation for respiratory failure and renal replacement therapy due to renal failure, this means two organ systems are being supported.

Level 0	Patients whose needs can be met through normal ward care in an acute hospital.
Level 1	Patients at risk of their condition deteriorating, or those recently relocated from higher levels of care, whose needs can be met on an acute ward with additional

	advice and support from the critical care team.
Level 2	Patients requiring more detailed observation or intervention including support for a single failing organ system or post-operative care or those 'stepping down' from level 3 care.
Level 3	Patients requiring advanced respiratory support alone, or basic respiratory support together with support of at least two organ systems. This level includes all complex patients requiring support for multi-organ failure.

Table 1.1 GPICS levels of care

The GPICS 2 guidance directs the degree of nursing care and complexity of interventions required for the patient admitted into that bed. A *level 3* bed is required for all patients requiring support for multi-organ failure. This is also termed an Intensive Care bed. The mandated nursing level is one nurse per patient. The nursing support required for a *level 2* bed is one nurse for every two patients. This is also known as a High Dependency bed. Nursing levels are maintained 24 hours per day.

CrCUs have traditionally been classed as general or specialised. General CrCUs admit patients from any clinical area, whereas specialised units admit patients belonging to a specific clinical speciality (e.g. neurosurgical, cardiothoracic). Patients are admitted under a particular speciality, such as surgery or medicine (known as the *parent* speciality). However, on CrCU, specialised critical care consultants are responsible for providing treatment for patients. They are supported by a number of junior and senior doctors on training pathways.

The environment and technology have changed significantly over the last 60 years (Young & Sykes, 1990). The technology of mechanical ventilators has developed considerably from their origins as '*bellows*' which required patients to be heavily sedated and paralysed in order to allow the ventilator to take over all breathing functions (Young & Sykes, 1990). High levels of sedation and analgesia increase the risk of developing ICU-delirium, a serious condition characterised by confused thinking and reduced awareness of the environment which can increase mortality and morbidity in CrCU and during recovery (Page & Katawala, 2011). Highly sophisticated modern ventilators are designed to work with the patients' breathing efforts in a much more comfortable way (Young & Sykes, 1990). This requires little or sometimes no sedation with the consequence that patients are more aware of their surroundings, although they still may only be partially conscious of events (Moreira & Neto, 2016).

Mechanical ventilation is usually delivered via an endotracheal tube (ETT) or a tracheostomy tube. Once a tube is inserted into the patient's airway it prevents them from automatically clearing airway secretions, thus requiring endotracheal suctioning to maintain airway patency. The ETT also prevents patients from eating and drinking and they are typically fed through a nasogastric tube that passes through a nostril and into the stomach. The ability to verbally communicate is also significantly impaired with an ETT. Less invasive forms of respiratory support have been developed which are delivered by a range of masks, hoods and nasal cannulae. These systems can be delivered without sedation and do not affect the patient's ability to eat or drink. Patients can often be attached to a wide range of equipment, as shown in Figure 1.1.



Figure 1-1 Equipment used in CrCU

Such machinery, infusions and monitors severely restrains patients' movements, limits their view, restricts their immediate proximity to family and separates them from other patients. The functioning of such equipment also generates considerable background noise and loud alarms (Patel, Baldwin, Bunting, & Laha, 2014).

1.3 Policy and Guidance

1.3.1 Early guidance

Early guidance for critical care from the Department of Health (DoH) was primarily focussed on care delivery within CrCUs and oriented towards improving survival and understanding short-term outcomes (DoH, 2000). The first major document to influence

critical care was the King's Fund Report, 'Intensive Care in the United Kingdom: Report from the King's Fund Panel' (DoH, 1989). The report highlighted the lack of evidence and knowledge underpinning critical care delivery in the UK and recommended further research into the efficiency and efficacy of critical care services. Four years after this report, ICNARC was formed based on a proposal by Professor Kathy Rowan to the Department of Health. The ICNARC Case Mix Programme is a comparative patient outcome audit that enables CrCUs to compare themselves with national quality standards and similar units.

In 1997 the Intensive Care Society (ICS), a body formed in the UK to promote education and research in intensive care medicine, published guidance in an attempt to provide quality and consistency in services throughout the UK (ICS, 1997). The guidance recommended which staff professions and roles should be involved in critical care delivery, and the types of equipment and operational processes for the day to day delivery of services. Many of these standards were based on expert opinion and individual unit practice due to paucity of evidence and it was not mandatory for hospital Trusts to adhere to these standards.

In 1998 the government commissioned a review of UK critical care services. The Audit Commission Report 'Critical to Success' (*Audit Commission*, 1999) reported the findings of a survey of all UK CrCUs and found that these units were not well integrated with other hospital departments, had little standardisation of practice and significant variations in outcomes. The report also revealed that few units were looking at outcome in terms of quality of life for survivors of critical illness, indicating a growing trend towards the consideration of what happens next for patients after discharge from the CrCU. The report highlighted that there was a legacy for those who had survived critical illness, with 84% of patients demonstrating psychological problems or physical limitations. At this time point, only 7% of units provided follow-up clinics for patients during recovery. The report also described anecdotal evidence from follow-up staff that these clinics appeared to benefit patients by improving both clinical and holistic aspects of care. The report highlighted a rehabilitation manual that was developed in a Liverpool hospital, which provided information and self-help advice for patients to use in hospital and at home following their transfer out of CrCU. Whilst the report highlighted areas of good practice, it did not explicitly recommend follow-up and rehabilitation, although it did suggest that patients should have a rehabilitation assessment on transfer out of CrCU.

1.3.2 Recent guidance

Following the Audit Commission Report, the DoH compiled an expert group of clinicians to make recommendations for the organisation of critical care services. The resulting document, *Comprehensive Critical Care* (DoH, 2000) made four key organisational recommendations regarding critical care outreach, facilities, bed management and long-term support and follow-up of patients. This publication steered critical care to look beyond the patients who were present on their units, coining the phrase ‘critical care without walls.’ The key message was for hospital Trusts to consider the whole journey of the critically ill patient, from identifying patients at risk of deterioration to long-term support of critical care survivors. ‘Comprehensive Critical Care’ recommended the establishment of critical care outreach teams to reduce CrCU admissions and avoid readmissions and to provide wider education for ward staff in managing acutely unwell patients. It also provided a number of models for follow-up services that NHS Trusts should review with an aim to providing appropriate services for their patients.

In 2015, the ICS and the Faculty of Intensive Care Medicine (FICCM), a body of UK doctors with a focus on medical training and education, published the Guidelines for the Provision of Intensive Care Services (GPICS, 2015). GPICS guidelines are the only source of reference for planning, commissioning and delivery of adult critical care services in England. GPICS 2 is the current set of standards and recommendations used as the basis for NHS England commissioning of critical care services (GPICS 2, 2019). The term *standard* is used to indicate something that is mandatory. For example, one standard states that patients must have access to a follow-up programme following discharge from CrCU which can include review of clinical notes, assessment of recovery using questionnaires and, for specific patients, a clinic appointment two to three months after discharge from hospital. Recommendations are statements that *should* be routine practice in the UK and are generally based on expert opinion. GPICS 2 has been the explicit focus of commissioning standards for NHS England in 2019, meaning that any standards and the associated resources are now requirements for services, rather than being indications of the quality of care. These standards cover the structure, workforce, process and delivery of clinical care.

1.4 The Legacy of Critical Illness

1.4.1 Prevalence and impact of post critical illness morbidity

The range of conditions that affect survivors of critical illness has been termed ‘Post-Intensive Care Syndrome’ (PICS) (Needham et al., 2012). PICS is defined as new or worsening impairment in physical (ICU-acquired neuromuscular weakness), cognitive (thinking and judgment), or mental health status arising after critical illness and persisting beyond discharge from the acute care setting (Desai et al., 2011; Elliott et al., 2014). The true incidence of these impairments is difficult to determine due to variation in patient groups and many different descriptive definitions throughout the literature (Needham et al., 2012).

Research suggests that the patient’s critical illness diagnosis, the presence of comorbidities, and pre-existing psychiatric conditions are all factors that can lead to a delayed recovery and poorer outcomes (Davydow, Gifford, Desai, Needham, & Bienvenu, 2008; Davydow et al., 2009; Elliott et al., 2014; Pattison, Dolan, Townsend, & Townsend, 2007). In addition, the nature of treatments (e.g. mechanical ventilation, benzodiazepine-based medications) together with the development of complications during the acute stage of illness (e.g. infection, episodes of delirium) also increase the risk of developing long-term complications (Davydow et al., 2008; Davydow et al., 2009; Pattison et al., 2007).

ICU acquired weakness (ICUAW) is a profound weakness following critical illness due to a combination of myopathy and neuropathy, and has a reported incidence of around 46% (Appleton & Kinsella, 2012; Stevens et al., 2007). The pathophysiology is multifaceted, involving lack of muscle use due to prolonged immobility, together with mitochondrial and micro-circulation dysfunction and inflammatory processes (Appleton & Kinsella, 2012). ICUAW has been found to increase both CrCU and hospital lengths of stay, and has an in-hospital mortality of 45% (Appleton and Kinsella, 2012). 32% of survivors do not make a complete functional recovery and 28% have persistent severe disability (Latronico, Shehu and Seghelini, 2005). To date, post-CrCU interventions have had minimal impact on patients and focus has shifted to reducing the extent of ICUAW by preventative interventions for patients during the CrCU stay (McPeake et al., 2017).

Following critical illness, survivors can experience cognitive impairment and report problems with new memory formation, attention and concentration deficits and

difficulties with executive function (reasoning/decision-making/problem-solving) (Hopkins & Jackson, 2006). Incidence varies considerably between different patient groups, with delirium and acute respiratory distress syndrome (ARDS) greatly increasing the incidence (Girard et al., 2010; Hopkins et al., 2005; Jones, Griffiths, Slater, Benjamin, & Wilson, 2006). Cognitive impairments usually improve during the first 12 months after hospital discharge, although among older critically ill patients 70% continue to experience problems at 12 months (Girard et al., 2010). With one in four patients experiencing cognitive impairment that is comparable to mild Alzheimer's disease, cognitive decline in older people is linked to a greater need for residential care and hospital admission, and increased societal costs (Pandharipande et al., 2013).

Studies involving survivors of critical illness often measure patient reported symptoms of anxiety, depression and post-traumatic stress disorder (PTSD) rather than having a formal assessment by a mental health professional (Hatch et al., 2018). This makes it challenging to determine the true incidence of mental health problems. In a postal questionnaire to survivors of critical illness involving 4943 respondents, 46% reported symptoms of anxiety, 40% symptoms of depression and 22% symptoms of PTSD, with 18% experiencing all three symptoms (Hatch et al., 2018). Depressive symptoms in survivors are associated with pre-CrCU mental health problems and evidence of distress during CrCU stay (Rabiee et al., 2016). Anxiety has been associated with extreme fear and stress reactions in the CrCU, together with hospital discharge, stressful nightmares and delusional memories (Nikayin et al., 2016).

Critical care survivors are as likely to develop PTSD as civilian survivors in warzones (Righy et al., 2019). PTSD follows exposure to a life-threatening event and manifests as intrusive recollections of the event, hyperarousal symptoms, and avoidant behaviour related to the traumatic event (Jones, Griffiths, Humphris, & Skirrow, 2001). PTSD is reported in one fifth of CrCU survivors (Battle, James, Bromfield, & Temblett, 2017) and incidence does not decrease significantly at 12 months post CrCU (Davydow, Zatzick, Hough, & Katon, 2013). Interestingly, younger patients with less severe illness have an increased risk of developing PTSD, together with those having a past history of mental health problems or who have experienced delirium during the CrCU stay (Battle et al., 2017). Patients with a lower illness severity are more likely to be aware of the stressful CrCU environment and to experience fear of poor outcomes than patients who are less conscious or more heavily sedated (Battle et al., 2017).

1.4.2 Services and support for patients and families during recovery

A wide range of primary and secondary care services may be involved in patients' care during recovery from critical illness. With little follow-up care specifically for post-CrCU patients, many may make unplanned visits to their General Practitioners (GPs), or attend counsellors, psychologists, occupational therapists, speech therapists and physiotherapists, either through NHS services or private practice. Patients often perceive that healthcare services are failing to address their physical and psychosocial problems following critical illness (Bench, Day, & Griffiths, 2011; Field, Prinjha, & Rowan, 2008; Pattison et al., 2007; Salmond, Evans, Hamdi, & Saimbert, 2011). Whilst follow-up services and rehabilitation are recommended by both NICE and GPICS 2 guidance, the provision and delivery of these services varies between CrCUs.

To co-ordinate care and enhance recovery for patients following critical illness, some hospitals have established critical care follow-up clinics (Modrykamien, 2012). The clinics can facilitate the identification and treatment of ongoing clinical problems experienced by patients during their recovery through referrals to appropriate specialities and services. They also provide an opportunity for collecting data on patient complications and outcomes, and a mechanism for feedback into CrCU to inform future care and treatment (Modrykamien, 2012). Despite creating the opportunity to lower hospital readmission rates and reduce healthcare costs by identifying post critical illness morbidity and organising timely referrals, surveys of follow-up provision in the UK have found that around 70% of CrCUs do not offer a follow-up clinic (Connolly et al., 2014; Griffiths et al., 2006). Financial constraints and lack of prioritisation of follow-up services were found to have prevented the development of follow-up services (Connolly et al., 2014; Griffiths et al., 2006).

Follow-up clinics are predominantly nurse-led, although some have developed combinations of intensivists (a doctor who specialises in intensive care medicine), critical care nurses, psychotherapists, physiotherapists and pharmacists to provide multidisciplinary follow-up. Funding restrictions usually limit the number of patients being offered a follow-up clinic appointment to patients with CrCU stays of longer than 3-4 days (Griffiths et al., 2006; Rattray & Hull, 2008). This arbitrary number of days is not evidence based or designed around patient need. Organisation of follow-up services varies widely as, to date, there is no accepted model of delivery (Modrykamien, 2012). A recent Cochrane review of follow-up services showed that four of the five services included in the review comprised nurse-led services and one involved a multidisciplinary team approach (Schofield-Robinson, Lewis, Smith,

McPeake, & Alderson, 2018). Patients were given consultations over the telephone, in outpatient clinics or at home and between two and eight consultations were provided, depending on the study. The review found little or no measurable benefit from offering follow-up services in terms of reducing mortality or reducing the physical, psychological and cognitive impairments associated with critical illness (Schofield-Robinson et al., 2018). This is in conflict with anecdotal reports from follow-up staff and patients who attend follow-up services, who feel that it is a valuable service.

Attention was focussed on rehabilitation and longer-term outcomes for patients following critical illness with the publication of the NICE guidance ‘Rehabilitation after Critical Care in Adults’ (NICE, 2009.). This guidance was updated in 2017, with no new evidence available to revise the 2009 version. The NICE guidance takes the form of four quality statements which focus on assessment of patient’s needs and the formulation of rehabilitation goals. It highlights that CrCU staff should hand over a structured, individualised rehabilitation programme when they transfer a patient from CrCU to the ward. It is also recommended that patients should have information about their rehabilitation goals prior to hospital discharge and that patients should have a review two to three months later. Many of the recommendations in the NICE guidance surrounding rehabilitation are based on the expert opinion of CrCU clinicians. Whilst there is much endorsement in favour of the concept of rehabilitation as an approach to recovery, there is little conclusive evidence to demonstrate benefits to patients.

A Cochrane review in 2016 measured the impact of physical exercise rehabilitation following CrCU discharge on quality of life and functional exercise capacity (Connolly et al., 2014). The six trials included varied widely in respect to the interventions they delivered, but all measured functional exercise capacity as the main outcome. The overall evidence was reported to be of low quality and no overall benefit of rehabilitation was found for either functional exercise capacity or quality of life. Similarly, a meta-analysis of enhanced physical rehabilitation interventions following CrCU discharge concluded that physical rehabilitation does not benefit patients in terms of improving quality of life or reducing mortality (Taito et al., 2019). In view of the limitations of current evidence, panels of clinical experts continue to meet to review, debate and provide recommendations for rehabilitation and follow-up services (Azoulay et al., 2017; Major et al., 2016).

1.5 Summary

This chapter has provided an overview of CrCU care and service provision. A relatively young speciality, up until recent years the focus has been on reducing mortality and only recently has attention shifted to the devastating physical, psychological and social impact on patients. Research on the legacy of survivorship, such as PICS, was limited to a small number of enthusiasts, who continue to drive the post critical illness agenda globally. Although widely recommended, the impact of critical illness follow-up services and rehabilitation still does not have any robust evidence that demonstrates benefits to patients. This means that provision and organisation of services varies across the country despite the publication of standards and guidance that have attempted to provide consistency and standardisation.

This chapter has provided the context for this study, which aims to improve the experiences of patients following critical illness. The next chapter explores more specifically the patient perspective, providing a review of the literature regarding patients' experiences during recovery from critical illness.

2 LITERATURE REVIEW

2.1 Introduction

In the previous chapter the background to this study was presented, introducing the legacy that survivorship following critical illness has for patients and their families. The dominant research in this area has made considerable progress in defining the clinical picture and scale of the problem. There is less evidence describing the experiences of patients during recovery or the best way to provide effective care and support. The aim of this chapter is to capture evidence that provides a better understanding of what life is like for patients after they have survived critical illness and how they interact with care and services provided during recovery.

This chapter provides a detailed exploration and synthesis of the relevant literature surrounding peoples' experiences during their recovery from critical illness. The chapter begins by outlining the search strategy devised for capturing the appropriate literature, and the results of this search strategy. The choice of critical appraisal tools is discussed, followed by a critical discussion of the main themes identified from the papers included in this review. The chapter ends with a synthesis of the findings.

2.2 Literature Search

2.2.1 Search strategy

The aim of the literature search was to identify all the relevant evidence on patients' experiences of recovery following critical illness. In order to identify the relevant literature to inform this review, the search strategy sought to find published papers limited to the English language and adults. As ICU/CrCU medicine is a relatively young speciality no date limits were applied to this search. Up until the 1990s, the focus of research was on survival and it was not anticipated that papers on patient experiences of recovery would be found before this date.

A computerised search was conducted on the databases Medline, CINAHL, Embase, PsychInfo and Cochrane. The lack of standardisation between electronic databases required the development of individual search strategies for each database (Hawker, Payne, Kerr, Hardey, & Powell, 2002). At the time of the literature review, no studies were found which specifically described patients' experiences' during recovery from critical illness. Conducting a preliminary search of each database yielded a handful of

papers with which to identify the MeSH and free text search terms used in each system to capture papers about recovery more generally. These papers helped to identify further MESH terms, key words and free text terms to build into the search strategy, and these are shown in Table 2.1.

Intensive care	CrCU	Intensive care unit
Crcu unit	Critical illness	Chronic critical illness
Follow-up	Follow-up studies	Aftercare
Recovery	Continuity of patient care	Patient discharge
Experience	Crcu follow-up	Intensive care follow-up
Crcu follow-up clinic	Intensive care follow-up clinic	Intensive care unit follow-up clinic
Post-intensive care syndrome	Post-intensive care unit syndrome	

Table 2.1 MESH terms, keywords and free text terms

An extensive search was carried out using the terms in Table 2.1. The search lacked specificity due to the variety of MESH terms and key words associated with recovery from critical illness, meaning that a broad range of literature was captured that needed to be individually sifted and inappropriate papers filtered out. In addition, the literature surrounding recovery following critical illness is substantial and includes many topics that have a bearing on a patient's recovery following discharge from CrCU. Some studies have a broad scope which includes the patients' experiences of the whole recovery journey, whereas others focus specifically on different elements of the journey, such as the general ward setting or CrCU follow-up clinics. Some of these studies reveal insights into specific parts of the recovery journey, so the inclusion criteria was deliberately kept broad enough to capture these relevant experiences.

The CrCU literature commonly encompasses patients with acute and serious conditions who require admission to either a general or speciality CrCU for supportive treatments. A wide variety of *general* and *sub-populations* of CrCU patients or units may be included in the literature. Studies categorised under the umbrella term *general CrCU* involve patients admitted with a wide range of clinical conditions. Other studies explore *specific* CrCU populations such as trauma, cardiorespiratory or neurosurgical. In addition, the literature reveals many studies which explore the experiences of patients recovering from a single condition, such as such as ARDS or traumatic brain injury (TBI). Patients are admitted to adult, paediatric or neonatal CrCUs, dependent on their age. In the UK, patients are admitted to adult CrCUs from age 16 years. This search focussed on studies involving adult patients, which is defined as either 16 or 18

years old, depending on the study. This search also sought studies involving patients with any conditions which required an admission to either a general CrCU or specific speciality CrCU, as any of these had the potential to capture the experience of recovery from a critical illness. Studies about patients' experiences following critical illness also explore specific phenomena, such as memories of CrCU, the use of patient diaries or the involvement of patients in the development or evaluation of services or interventions. Such studies sometimes include detailed descriptions of patients' experiences, so again the inclusion criteria had to be broad enough to capture such topics.

2.2.2 Search results

The search strategy yielded a wide range of literature including quantitative and qualitative research studies, systematic reviews, NICE guidance, review and opinion papers, service evaluations, editorials and conference abstracts. A total of 5663 records were returned from searching each of the databases. After applying the limits and exclusion criterial shown in Figure 2.1, and removing duplicates, a total of 292 records remained. An initial review of the titles of the remaining 292 records was undertaken in order to remove any records that were not specific to the area of recovery and the timeframe following discharge from CrCU. At this stage it was also sometimes necessary to review abstracts in addition to titles to fully determine the relevance to experiences during recovery, as the titles alone can often fail to capture the nature of a paper's content (Hawker et al., 2002). Studies were not included if they did not focus on patients' experiences following discharge from CrCU. This meant the exclusion of many papers which were focused on specific patient outcomes such as quality of life, screening or measurement of specific physical, psychological, cognitive or social complications or symptoms (for example, ICUAW or PTSD). Studies were also excluded if the focus of the research was more on patients' experiences during their CrCU stay or on treatments and therapies given on CrCU. Records about patients' experiences following discharge from critical illness which examined end-of-life, bereavement, palliative care and advanced directives were excluded, as they were not focused on recovery.

After a title and/or abstract review of the 292 records, 70 records remained which were considered appropriate for full text assessment. These included 27 qualitative papers, 15 quantitative, mixed methods or survey papers, 16 service evaluation, improvement or audit papers, 10 reviews, one NICE guidance, one 'report' and one descriptive case study. As this literature review was based on evidence from prior research studies, all

non research was eliminated, leaving 41 research studies. Decisions whether to accept or reject a paper were based on the study's relevance, context, and the source of the data (patients, families, healthcare professionals) (Hawker et al., 2002). The 15 quantitative papers comprised testing of rehabilitation packages or pathways, or surveys of follow-up provision. Whilst these were deemed informative to the area of recovery following critical illness they did not provide insight into patients' experiences and so were excluded from this review. Four qualitative studies were also eliminated at this point. One explored continuity of care but was not specific to CrCU patients. Another study described the content of diaries written by nursing staff during the patients' CrCU stays and was not relevant to follow-up. One study was eliminated as it explored relatives' experiences rather than those of patients. A final paper was eliminated as it captured CrCU nurses' perceptions of providing follow-up services rather than patient experiences during recovery. Figure 2.1 provides a flowchart detailing the full search strategy and results.

22 qualitative papers remained that provided insight into patients' experiences following critical illness. Six studies originated in the U.K., five from Scandinavia, three from both Australia and Canada, and one each from the US, Hong Kong, and New Zealand. The remaining study involved a collaboration between the US, Canada and the UK. 14 papers were non-specific qualitative designs, two studies used phenomenology, three used narrative enquiry, two adopted a grounded theory approach and one study was an open ended questionnaire. 13 papers involved patients alone, five included patients and families, three involved patients, families and healthcare staff and one involved nurses alone, but was included as it was a large scale study across several CrCUs about the provision of follow-up care that captured patients' experiences of services and care.

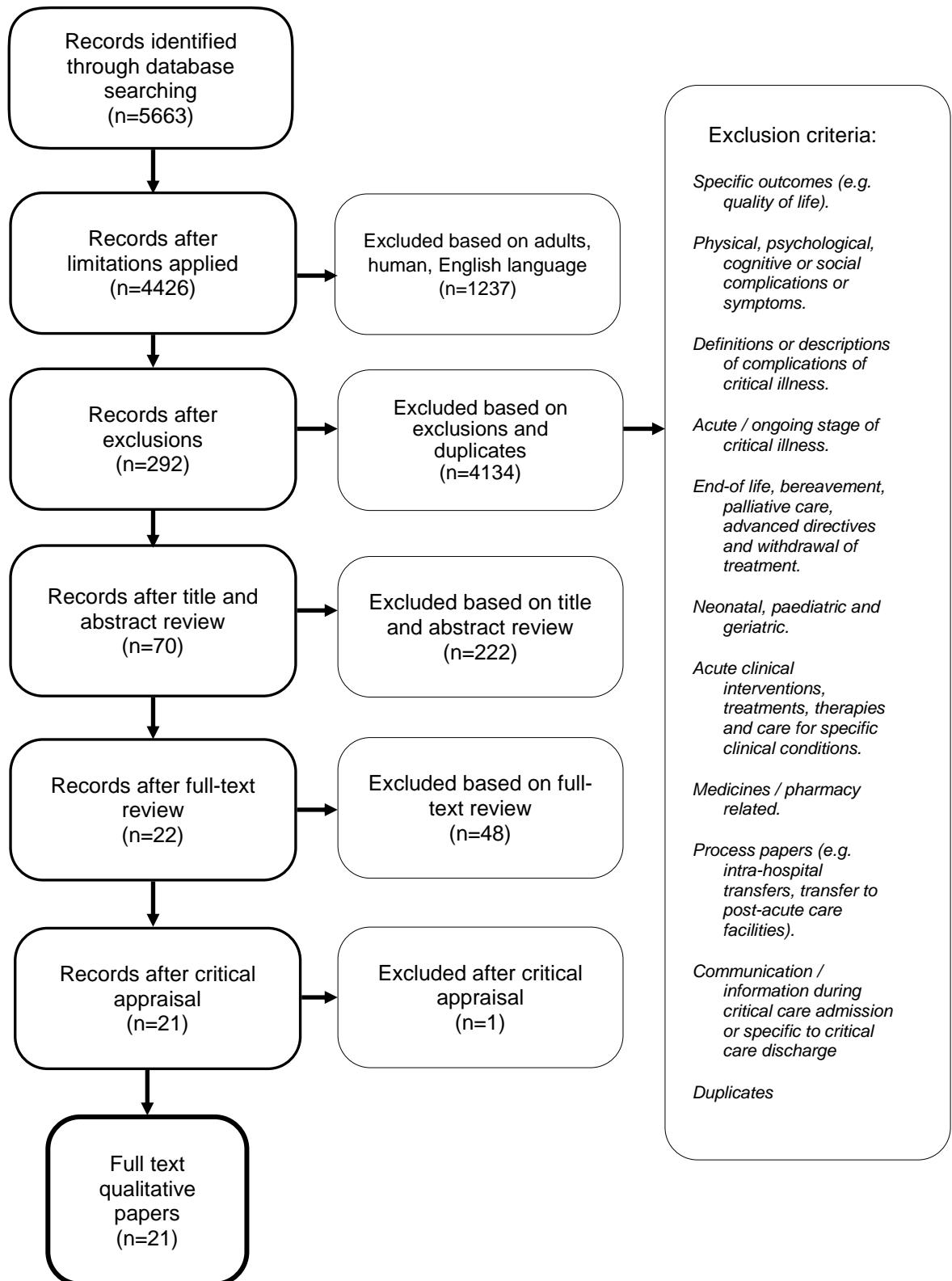


Figure 2-1 Flowchart of the search strategy and results

2.2.3 Critical Appraisal

The literature search revealed 22 qualitative papers for critical appraisal. Failure to appropriately assess the quality of research studies has previously led to biased and misleading conclusions (Cesario, Morin, & Santa-Donato, 2002). Many critical appraisal tools have been developed to meet the needs of different research designs and as each consists of a variety of different components, it is difficult to compare the results of studies if more than one type of tool is used (Crowe & Sheppard, 2011). An appropriate tool was needed for this literature review that would allow the different qualitative methodologies to be appraised using the same criteria in order for the quality of each study to be consistently assessed.

An evaluative review of critical appraisal tools was identified (Crowe & Sheppard, 2011) which categorised each tool based on the research design it was developed to appraise, how the tool was developed, whether the tool provided guidance for the user and whether the tool had been through validation and reliability testing. Eight out of the 44 tools were developed to appraise qualitative evidence, four of which went through a process of content validation and were considered for the critical appraisal of this review. The first tool was considered inappropriate as it was developed to aggregate qualitative data by meta synthesis of qualitative evidence (Reis, Hermoni, Van-Raalte, Dahan & Borkan, 2007). In addition, in reliability assessments, this tool demonstrated poor inter-rater agreement and required further refinement (Reis et al., 2007). A second tool (Cesario et al., 2002) was developed for use by nurses as an equivalent of the medically focused quantitative assessment tools. The focus appeared to be on replicating quantitative tools and featured a complex scoring system. The rationale and process of developing and testing the tool was not fully addressed and this tool was rejected as in presenting a qualitative reproduction of a quantitative process this tool failed to capture the essence of qualitative research. A third tool (Long & Godfrey, 2004) was developed by providing a template of key questions categorised under six subheadings: study overview; study setting, sample and ethics; ethics; data collection, analysis and potential researcher bias; policy and practice implications, and; other comments. With 44 individual questions to address, some of which appeared unnecessary in addressing the quality of a qualitative study, this tool was considered unnecessarily detailed and impractical for the purposes of this critical appraisal.

The final tool (Walsh & Downe, 2006) was selected to critically appraise all the qualitative studies in this review. This tool was developed to assess the quality of all qualitative designs. The process of development involved evaluation and combination

of the quality criteria identified in other tools. The criteria were then assessed and regrouped according to which were essential, desirable or unnecessary. As such, this tool aimed to provide simplicity and guidance to the user, and was chosen as it offered the best balance of comprehensiveness and practicality, and clear directions for its use. The tool applies a series of questions arranged under seven headings:

- **Scope and purpose**

Clear statement of, and rationale for, research questions, aims and purposes
Study thoroughly contextualised by existing literature

- **Design**

Method/design apparent, and consistent with research intent
Data collection strategy apparent and appropriate

- **Sampling Strategy**

Sample and sampling method appropriate

- **Analysis**

Analytic method appropriate

- **Interpretation**

Context described and taken account of in interpretation

Clear audit trail given

Data used to support interpretation

- **Ethical Dimensions**

Demonstration of sensitivity to ethical concerns

- **Relevance and Transferability**

Relevance and transferability evident

The questions prompt the appraiser to identify how well the key elements of the research process have been conducted, highlights where information is missing and helps to determine an overall impression of the quality of the study.

The Walsh and Downe critical appraisal tool was transferred into an excel database to facilitate the critical appraisal process. 22 individual spreadsheets, each comprising the tool, were generated to appraise each study individually and to summarise the findings of each paper. A table showing the results of the critical appraisal of the 22 studies is shown in Appendix 1. The overall quality of the studies were assessed as high, medium or low. Following assessment for quality of the 22 studies using this tool, 13 papers were assessed as high quality, and eight assessed as medium quality research studies and were accepted for inclusion in this literature review. One study was rated

as lower quality in terms of how the research was conducted and was excluded as it lacked methodological rigour. The excluded study, although well written and informative, used validated assessment instruments as part of patient outcome assessments, combined with the follow up interviews, which did not really capture insight into patient recovery experiences. This study appeared to focus upon patients' needs in terms of local services following critical illness. This study was therefore not included in this literature review. A summary table of the 21 studies included in the literature review is shown in Appendix 2.

2.2.4 Description of the literature

The identification of the key themes for this literature review began during the process of critically appraising and summarising the findings from each study. Key sections were manually highlighted on paper copies as each study was read and reread. The studies highlighted many variables which influenced critical illness and recovery. For example, there were different events and conditions which necessitated each patient's admission to CrCU. In addition, individuals varied in their responses to the treatments and supportive measures they received whilst on CrCU. They also encountered differing challenges and events during their recovery. Whilst this variability makes it difficult to define a typical recovery process in terms of chronology and events, common themes did emerge from the literature. Reading and rereading the studies helped to identify headings which captured the meaning of emerging themes around patient experiences. These headings were then grouped according to the key areas they related to (physiological recovery, psychological/emotional recovery, healthcare provision) and were inserted into new spreadsheets, one for each key area. Under each heading, the sources from the 21 studies which related to that theme were listed, together with notes about their contribution to that topic. This allowed a synthesis of the literature to be clearly organised and presented thematically.

This literature review begins with a focus on patients' experiences of the physical burden of critical illness and the impact of this on the recovery process. Following this, consideration is given to patients' memories of CrCU and the psychological reactions and impact on personal identity patients experience following critical illness. The final part of the review is focused on patients' experiences of healthcare provision during recovery, beginning with hospital based care and widening out to include their interactions with services in the community setting. The studies included in this review are all discussed using the term CrCU, though the units involved in the studies may be

named CrCU, ITU and ICU. In the literature the terms CrCU, ITU and ICU are usually interchangeable.

2.3 Experiences of Physical Impact

Following critical illness, most patients became abruptly aware of their physical debility and dependence on others, causing them to feel shock and loss of control (Minton & Carryer, 2005; Ramsay, Huby, Thompson, & Walsh, 2014). Patients were often unsure of what to expect after their illness and unprepared for the recovery process. This section will explore qualitative work describing how people experience the physical impact that critical illness has on their lives during recovery.

2.3.1 Physical debility and dependence

Patients were frequently unconscious or partially conscious during the most acute phase of critical illness, due to the consequences of their clinical condition and/or CrCU related treatments requiring analgesia and sedation (Adamson et al., 2004; Minton & Carryer, 2005). On waking, they had limited recall of the interventions involved in their treatment, the staff who cared for them or their admission to CrCU (Adamson et al., 2004; Minton & Carryer, 2005). Many patients did not realise they had been seriously ill and were confused about what had happened to them (Deacon, 2012; Minton & Carryer, 2005). Patients in a longitudinal study on recovery following prolonged critical illness, only realised they had suffered a severe or life-threatening illness once the acute stage of their illness was resolving and they awoke lying in a hospital ward (Ramsey et al. 2013).

The physical impact of critical illness, including weight loss and wasted muscles, weakness, fatigue and reduced mobility' meant that many patients could not independently perform their usual self-care activities (Ramsay et al., 2013). In a study involving interviews with patients following ARDS, patients experienced ongoing weakness, together with insomnia, fatigue, tremors and pain, for several months after critical illness (Cox et al., 2009). Even basic activities of daily living were interrupted by 'profound and jarring disability,' (Cox et al., 2009, p. 4). Patients of all ages relied on the general ward staff to help them with basic self-care and personal activities such as toileting and washing, and found their newly imposed dependence on others to be 'inherently demoralising,' (Ramsey et al., 2013, p. 6).

Whilst the realisation of a new physical debility and dependence on others often came as a shock to patients, for some the full consequences of critical illness only emerged

over time and led to feelings of hopelessness, depression and despair (Gardner, Elliott, Gill, Griffin, & Crawford, 2005; Lee, Herridge, Matte, & Cameron, 2009). Some patients became aware of one issue after another, such as weight loss, hair loss and inability to eat, which caused them emotional turmoil (Lee et al., 2009). The early stages of recovery were characterised by a cycle of progress and setbacks and these could obscure patients' perceptions of their gradual, overall improvement in condition (Gardner et al., 2005). Patients identified 'a sense of being sick' with experiencing several complications, such as recurrent infections, and these led to feelings of hopelessness and depression as patients feared they were never going to get better (Gardner et al., 2005, p. 264). For these patients, 'reaching a turning point' meant leaving behind the sick role and focusing on getting better and moving forward (Gardner et al., 2005, p. 246). This suggests that if patients were made aware of their progress, it may help them to adjust from being a patient to becoming person who is more active in regaining their physical and/or psychological health.

2.3.2 Unawareness of the recovery process

The literature revealed that weakness and fatigue had a long-term impact on physical strength, prolonging the time taken for patients to resume their previous energy levels and return to normal health (Deacon, 2012; Maddox, Dunn, & Pretty, 2001; Pattison et al., 2007; Prinjha et al., 2009; Ramsay et al., 2014). Patients were surprised by their physical exhaustion, tiredness, and the length of time it was taking to regain their previous energy levels (Maddox et al., 2001). Some patients blamed their exhaustion on the sleep disturbance they experienced in hospital rather than the muscle weakness and weight loss (Maddox et al., 2001). This suggests that, on discharge from hospital, some patients were either uninformed about the repercussions of critical illness, or had not retained or understood the information provided.

The process of recovery at home has been characterised as 'struggling for independence' (Ågård, Egerod, Tønnesen, & Lomborg, 2012). Three components of the struggle for independence have been described as 'recovering physical strength', 'regaining functional capacity' and 'resuming domestic roles' (Ågård et al., 2012, p. 110). During early recovery, patients were mostly unaware of the amount of personal effort their recovery would require. Initially patients were dependent on families and their efforts focused on regaining their premorbid strength in order to perform basic tasks. As patients began to work at simple activities (e.g., showering, dressing), and then more substantial activities (e.g., short walks outdoors) they became aware of how much physical training lay ahead. Finally participants grew independent of family

support and practiced more complex functions (e.g., shopping, gardening) which allowed them to resume their domestic roles.

The literature suggested that the urge to recover physical strength and functional activity was the major concern for the majority of patients during their early recovery (Ågård et al., 2012; Maddox et al., 2001) and their ability to accomplish physical tasks was an important indication of progress (Ågård et al., 2012). However, on hospital discharge, patients appeared to be unprepared for the longer-term repercussions of critical illness such as the time and effort that their recoveries might require (Ågård et al., 2012). Patients initially did not expect to experience ongoing fatigue and started the recovery process with unrealistic expectations about the length of time it would take to return to health (Pattison et al., 2007). Some CrCU patients also experienced cancer specific physical symptoms such as malabsorption and dysphagia, which compounded fatigue and further delayed recovery (Pattison et al., 2007). However, over time, patients learned to pace themselves more appropriately and modify their expectations.

The literature highlighted that being unprepared for the pedestrian nature of recovery had negative consequences for patients and suggested that preparing them to approach their recovery with realistic expectations might be helpful (Ramsey et al., 2013). Patients became frustrated and blamed themselves for the long time taken to recover, perceiving that they were making insufficient efforts (Ramsay et al., 2013). Patients who did not receive any follow-up may have had unrealistic expectations which left them speculating about why recovery was such a slow process (Prinjha et al., 2009). This led to unrealistic expectations and efforts to do too much too soon, causing frustration, anxiety and, ultimately, depression (Prinjha et al., 2009). Some patients have suggested that their prolonged recoveries would have been easier to accept had they been given sufficient information to prepare them for the impact of critical illness on their physical strength (Ramsey et al., 2013). Similarly, during periods when progress slows patients experienced ambiguity about recovery, becoming frustrated, and feeling helpless and depressed by their inability to do the things they wanted (Laplum, Angus, Peter et al., 2011). These uncertainties, frustrations and the depression patients experienced in relation to their physical recoveries indicates how clinical states can have indirect repercussions on patients' mental and social recoveries.

2.4 Memories of Critical Care and the Psychosocial Impact

During recovery from critical illness, memory gaps and delusional events frustrated patients' understanding of what happened to them in CrCU, and this made it difficult for them to separate real facts from unreal events (Adamson et al., 2004; Cox et al., 2009; Prinjha et al., 2009). Patients described psychological issues related to their CrCU experiences and their real and unreal memories and experienced transformative impacts on their identities (Adamson et al., 2004; Cox et al., 2009; Prinjha et al., 2009).

2.4.1 Delusional memories

Following critical illness, many people had intermittent or incomplete recollections of their CrCU and early ward-based stay (Adamson et al., 2004; Cox et al., 2009; Deacon, 2012; Gardner et al., 2005; Minton & Carryer, 2005; Ramsay et al., 2013). Complicating this issue were delusional or unreal memories. Patients experienced lingering fearful and negative dreams, hallucinations and flashbacks (Minton & Carryer, 2005; Pattison et al., 2007). For some patients, delusional memories were of a threatening and violent nature and gave rise to psychological problems such as anxiety and panic attacks, which could affect them for many years after their critical illness (Storli & Lind, 2009; Storli, Lindseth, & Asplund, 2008). Many patients experienced nightmares and hallucinations, which were vivid and frightening and these sometimes continued for months or years following critical illness (Adamson et al., 2004; Deacon, 2012; Maddox et al., 2001; Minton & Carryer, 2005; Pattison et al., 2007; Storli & Lind, 2009; Storli et al., 2008). Patients sometimes experienced the 'contradictory coexistence of general amnesia regarding their CrCU stay with the presence of terrifying dreams, flashbacks, and vivid memories,' (Cox et al., 2009, p. 4). These memories lasted for several months to years following CrCU discharge.

Whilst many CrCU survivors experienced fragmented memories and/or delusional events, their reactions and the impact of these varied (Ågård et al., 2007; Deacon, 2012; Maddox et al., 2001; Minton & Carryer, 2005; Pattison et al., 2007). Some people had a compelling desire to find out what happened to them during their CrCU stay, which helped in dealing with any longer-term psychological repercussions (Adamson et al., 2005; Storli et al., 2008). Other people wanted to leave their CrCU memories behind them and focus on the future and getting their lives back to normal (Ågård et al., 2007; Maddox et al., 2001).

2.4.2 Psychological issues

Unreal memories (memories of events that did not happen) caused considerable distress and embarrassment for some people during recovery (Deacon, 2012; Minton & Carryer, 2005; Pattison et al., 2007; Prinjha et al., 2009). Nightmares, hallucinations and delusional memories made little sense to the persons experiencing them, and patients found them difficult to share with others due to concerns about having a mental problem or compromising the recovery process (Deacon, 2012; Prinjha et al., 2009; Storli & Lind, 2009).

A relationship between the development of unreal memories and the longer-term psychological difficulties people experienced during recovery has been suggested, wherein patients' dreams and hallucinations were likely to become embedded in their memories if they were associated at the time with sensory experiences and strong emotions (Storli et al., 2008). Later on, sometimes for many years after the critical illness, frightening experiences and flashbacks could be triggered unexpectedly by harmless stimuli such as sounds or sensations associated with these memories. A phenomenological study suggested that powerful emotions, which may not even be experienced consciously, could make patients feel they were becoming mentally unstable (Williams, 2009). In these situations, people could be reluctant to seek help as they were overwhelmed by feelings of helplessness, numbness or shock and did not want to risk triggering further events (William, 2009). Narrative construction that was temporally, causally, emotionally, thematically and auto-biographically coherent was important for resolving traumatic memories (Williams, 2009, p. 285). This process helped patients regain control over their lives and recover their sense of personal well-being. Constructing the 'story' of their own critical illness was a framework from which patients were able to mentally transform the critical illness event into a meaningful and even beneficial one (William, 2009).

In contrast, some literature suggested that patients did not want to recall their CrCU experiences and focused instead on the future, on regaining their usual routines and returning to normal (Ågård et al., 2007, Maddox et al., 2001). Patients may not have had ongoing psychological problems or required psychological support during recovery, or they may have had difficulty recognising they had psychological problems or may have been able to successfully process these and move on (Maddox et al., 2001). Qualities such as inner strength and determination to survive and recover have been found to be important to patients in helping them to move on, and focus on the future rather than reflecting on past experiences of CrCU (Maddox et al., 2001). Prior experiences such as chronic illnesses also led to the development of coping

mechanisms, which patients relied on these during their recovery rather than community based services offering psychological support. Sometimes admitting the need for help was viewed as a personal failing which appeared to carry stigma or social disgrace (Maddox et al., 2001). Indeed, mobilising patients' 'inner resources' such as determination, has been suggested as an important aspect in supporting patients through healthcare transitions (Ramsay et al., 2013, p. 8). Patients were found to put on a brave face in order to attract the attention and assistance they needed, believing that staff helped patients who helped themselves (Ramsey et al., 2013). Patients have also been found to be motivated to 'overcome any obstacles on their road to recovery,' similar to the motivations of rehabilitating patients who experienced spinal cord damage and other less life-threatening injuries (Ågård et al., 2007). Rehabilitation settings may inspire an holistic approach to recovery, fostering a supportive approach which includes psychological support and motivating patients by setting achievable goals. Patients had strong feelings of reward each time they made progress and this increased the momentum to carry on working towards regaining their best physical and psychosocial function (Ågård et al., 2007).

During recovery, patients dealt with psychological symptoms from critical illness that, although less obvious than hallucinations, panic attacks and flashbacks, were still troublesome and hampered their recoveries (Gardner et al., 2005). Some patients described their feelings of hopelessness and depression both during their ward-based stay and recovery at home and felt depressed even though they perceived they should have felt happy, or questioned whether their low mood meant they must still be ill (Gardner et al., 2005).

Symptoms such as sleep disturbance, feeling low, inability to concentrate, feeling guilty and avoidance of reminders of critical illness have also been highlighted in the literature (see for example; Deacon, 2012; Pattison et al., 2007; Prinjha et al., 2009). However, qualitative studies suggest that when people describe their symptoms they can be somewhat vague, such as 'feeling low,' and as such could possibly remain unrecognised by patients and family members or undetected by healthcare staff. In the absence of programmes which actively screen and follow-up former critically ill patients, it has been suggested that these problems may linger and people might only start to recognise the need for help later on during their recovery (Deacon, 2012; Pattison et al., 2007; Prinjha et al., 2009). The inclusive attitude towards family members on CrCU may reduce the psychological disturbance for patients during recovery (Ågård et al., 2007). A grounded theory study has identified a continuum of

dependence and independence involving patients and their families (Chaing, 2011). Family presence on CrCU and during recovery helped patients to cope with their high stress levels and helped families to deal with their uncertainty regarding the patient's condition (Chaing, 2011). Initially dependent on their family members for psychological support, as patients regained physical independence, self-confidence and decision-making capacities, their need for psychological support reduced (Chaing, 2011). Chiang (2011) argued for CrCUs to facilitate optimum opportunities for families to be with patients by allowing flexible visiting practices.

2.4.3 Personality and identity changes

The literature suggested that some patients experienced life and personality changes as a result of their critical illness and recovery (Adamson et al., 2004; Cox et al., 2009; Gardner et al., 2005; Pattison et al., 2007). Irrespective of the causative event (e.g. cancer, sudden cardiac event, trauma) patients often experienced apprehension about the possibility of a recurrence of critical illness (Cox et al., 2009; Gardner, 2005; Lee et al, 2005; Minton & Carryer, 2005; Pattison et al., 2007) or whether they would ever return to normal (Gardner et al., 2005). Apprehension about the recurrence of illness led to feelings of powerlessness and continual questioning of why it happened (Adamson et al., 2004) and was accompanied by nightmares about readmission to hospital (Minton & Carryer, 2005).

For many patients, critical illness evoked a transformation in their self-identify which was both confusing and unsettling, and recovering their sense of well-being took some patients a long time (Adamson et al., 2004; Cox et al., 2009; Gardner et al., 2005; Lee et al., 2005; Prinjha et al., 2009). Patients noticed negative life changes, such as a new recognition of the ageing process or the fragility of life (Gardner et al., 2005). Survivors of ARDS described the transformative effects of disruption to their workplace and family lives, financial pressures, newfound disability, altered body image and ongoing medical care (Cox et al., 2009). Some survivors expressed resignation about their new limitations, and regret over missed opportunities, and others commented that people assumed they were well again because they appeared physically normal, even though they continued to feel unwell (Cox et al., 2009).

Lefebvre, Pelchat, Swaine Gélinas, and Levert (2005), in their study of TBI involving patients, family members and healthcare professionals found that brain injury caused distressing disruption to everyday life, family organisation and roles, and usual activities, such as playtimes with one's children. Patients adapted by reorganising their

everyday lives and revising their philosophy on life. The inability to return to professional life made it more difficult to adapt, as patients no longer knew what to do with their lives, or how to reintegrate within the community (Lefebvre et al., 2009).

Critical illness appeared to instigate the process of life-change and during the recovery period people had to rediscover or reassess their self-identity and sense of wellbeing. The literature indicated that some people were able to accept the critical illness events and integrate these with their life perspective, (for example see; Ågård et al., 2007; Maddox et al., 2001; Pattison et al., 2007). Patients expressed a greater appreciation of life, an enhanced perspective and a new vision of how they wanted life to be (Ågård et al., 2007; Maddox et al., 2001; Pattison et al., 2007), a new sense of connectedness with their partners and family (Ågård et al., 2007; Maddox et al., 2001), feeling stronger, more relaxed and less afraid of anything (Gardner et al., 2005) and a desire to give something back to the community by supporting others who had experienced the same illness (Lee et al., 2005). Some patients were able to adjust and move on even though they still had problems and restrictions and others became healthier than prior to their hospitalisation as they were taking extra care of themselves (Adamson et al., 2005). Community involvement and having the opportunity to contribute something to society developed patients' self-esteem and returning to study or taking part in leisure or voluntary activities reinforced the process of adaptation (Lefebvre et al., 2005).

Patients also greatly valued the care and attention given by families (for example see; Ågård et al., 2007; Deacon, 2012; Prinjha et al., 2009; Ramsey et al., 2007). Whilst patients acknowledged the massive impact that families had on their progress they often felt like a burden and were aware of the additional responsibilities they placed on their families (Ågård et al., 2007; Cox et al., 2009; Maddox et al., 2001; Pattison et al., 2007). Studies also suggested that former CrCU patients valued peer support from other patients, as this was associated with a shared understanding of what they were going through during recovery (Deacon, 2012; Gardner et al., 2005; Lee et al., 2005; Pattison et al., 2007). Patients valued their peers as they listened to their experiences and feelings without feeling the need to help them (Deacon, 2012). Studies also showed that companionship with other patients provided reassurance that their experiences were normal (Deacon, 2012; Gardner et al., 2005; Pattison et al., 2007), allowed sharing of support and advice (Pattison et al., 2007), provided answers and guidance (Lee et al., 2005) and boosted morale (Gardner et al., 2005). These findings suggest that the development of empathetic relationships between patients recovering

from critical illness may have been a valuable source of support and an important way to foster self-esteem, self-confidence and improved self-identity.

2.5 Patient Perceptions of Healthcare Provision

On CrCU, care was centred on the multiple needs of acutely ill patients overseen by CrCU doctors and supported by visiting specialities such as respiratory or renal. In contrast, beyond CrCU, patients were transferred to general wards, which were organised around specific specialities, for example surgery or medicine. Following this, on returning home, patients experienced care from community-based services. In this section the literature surrounding patients' experiences of healthcare services following discharge from CrCU will be discussed.

2.5.1 Relocation from Critical Care

The adjustment required in moving from CrCU, an area with a higher acuity of staff, was highlighted in several studies (Field et al., 2008; Lee et al., 2009; Pattison et al., 2007). Patients who were used to the quality of care on CrCU experienced fear and anxiety about transfer to the wards (Field et al., 2008; Lee et al., 2009; Pattison et al., 2007). CrCU patients felt secure due the close observation and monitoring from the staff and equipment and had become accustomed to the care routines (Minton & Carryer, 2004; Lee et al., 2005). Patients with TBI found transfer to be destabilising and disorientating due to the loss and separation from the professionals who had been supporting them and the stress associated with moving to a less structured environment than CrCU (Lefebvre et al., 2009).

Transfer was associated with frustration and emotional turmoil as patients adjusted to new healthcare teams, fewer staff, less monitoring and different care regimes. At this time, patients needed to do more for themselves and were becoming increasingly aware of their physical limitations (Pattison et al., 2007). Even though patients identified transfer as an improvement in their condition, some experienced fear and apprehension about being left to cope with less help from staff after being so critically ill (Pattison et al., 2007). Whilst the reassurance offered by the one to one nursing presence on CrCU was absent on the ward, the CrCU outreach nurse visits offered a familiar face and mitigated patients' feelings of abandonment and vulnerability due to loss of close relationships with CrCU staff (Pattison et al., 2007, Bench et al., 2011).

The literature suggested that whilst patients worried about their transfer from CrCU to the wards it was possible to mitigate their fear and anxiety, particularly for patients who

felt the transfer was premature (Bench, Day & Griffiths, 2011). Patients needed help to recognise that they had progressed even if they still felt ill, and that their conditions had improved enough to allow them to be transferred (Bench et al., 2011). Showing patients a medical summary of their progress or images such as photographs, pictures and mirrors was recommended help to prepare them for the general ward (Bench et al., 2011).

On transfer to the ward, patients accepted the need to become more independent but still required information about what to expect with the transfer process (Bench et al., 2011). As patients felt their critical illness to be an enormous emotional and physical experience, they thought consideration was needed about what information they required and how the information should be delivered (Bench et al., 2011). To deal with these issues patients and relatives suggested that they be provided with written information, accompanied by effective questioning and discussion with staff, and this process repeated frequently. Patients considered both CrCU and general ward staff were too busy or had inadequate knowledge and skill to provide information (Bench et al., 2011). Staff also considered patients to have limited concentration and difficulties absorbing information. Some staff considered that leaflets and booklets were inadequate as they may not be read or understood, might lack sufficient individualised information or ran the risk of replacing discussions between staff and patients both before and after discharge (Bench et al., 2011). Additionally, delayed and rushed discharges from CrCU could prevent adequate communication of information manner (Bench et al., 2011).

2.5.2 Ward-based care

Many qualitative studies highlighted patients' perceptions of the unsatisfactory ward-based care they received, especially considering their profound debility (Field et al., 2008; Minton & Carryer, 2005; Ramsey et al, 2013). The literature suggested that patients felt isolated and vulnerable following transfer to the general wards (Ramsey et al., 2013) and perceived ward-based staff as less available than CrCU staff (Field et al., 2008; Ramsey et al., 2013) and so busy that patients found it difficult to attract their attention and were reluctant to ask for help (Field et al., 2008). Patients needed to adjust from one to one personal nursing care on CrCU to being *one patient amongst many* in the ward setting and described feeling completely shocked, in tears and neglected (Field et al., 2008).

The care patients received on general wards varied in quality and was interspersed with several episodes of negative interactions with staff (for example, see; Field et al., 2008; Ramsey et al., 2013) and left many patients feeling distressed, shocked and traumatised (Field et al., 2008). Patients were unprepared for the hectic ward activity and experienced an array of basic care failings, perceiving that they did not receive the kind of care they expected or which was appropriate for their needs (Field et al., 2008). Patients thought that the ward staff viewed them as lazy and were unaware of the physical weaknesses and other complications that CrCU patients experienced (Field et al., 2008) and relied on relatives for several days to help them with their basic care needs, before their need for more help was noticed by the ward staff (Ramsey et al., 2013). Some patients considered this had jeopardised their short-term recovery (Field et al., 2008).

The literature identified the differing approaches of ward-based staff in terms of their responsiveness to patient needs and their compassion (Field et al., 2008; Ramsey et al., 2013). Whilst patients were often aware of the staffing constraints on the ward and were generally appreciative of the care they did receive, this did not prevent them from being affected when some staff appeared to be indifferent and insensitive to their basic care needs (Field et al., 2008; Ramsey et al., 2013). Some nurses were perceived to be caring and approachable whereas others made patients feel vulnerable by giving them the impression they wanted to be elsewhere (Field et al., 2008). The variability in responsiveness and compassion between successive clinicians caused patients to experience considerable uncertainty (Ramsey et al., 2013).

Ramsey et al. (2013) suggested that staff may have considered debilitation to be expected after severe illness and may have dismissed patients' concerns as 'a small price to pay for survival.' Interestingly, some CrCU patients also held this viewpoint. Many did not consider their condition as deserving of hospital resources, or as bad as other patients, particularly the frail and elderly, so they had sacrificed their own needs for the sake of other patients (Ramsey et al., 2013). The attitude of the ward staff could also effect some patients' motivation and self-esteem, with several staff assuming a 'stern approach' when patients were unable to care for themselves (Field et al., 2008, p. 6). Some patients found being unable to cope made them lose their self-respect whilst one patient had taken this as a challenge which pushed him to progress in his recovery (Field et al., 2008). These studies suggest that whilst the unavailability of the ward staff can leave patients struggling to raise the attention they require to meet their basic care

needs, the apparent uncaring and unprofessional approach sometimes had wider impact on patients' self-esteem and self-identity.

Patients rarely told ward staff about their concerns over their inadequate care and would not let their relatives do so either as they were aware of the power being with the nurses and did not want to cause any trouble that might affect the care they received (Ramsey et al., 2013). As such, staff may have been unaware that patients felt the way they did, and that their behaviour may reflect a lack of understanding of the patient's experiences or of the needs of post-CrCU patients (Ramsey et al., 2013). Whilst ward staff may have appeared to patients to be uncaring or indifferent, they could actually have lacked insight into how patients felt due to the reluctance of patients to voice their concerns (Ramsey et al., 2013).

Whilst CrCU survivors had complex needs which placed considerable demands on nursing time, they also demanded knowledge and expertise that could be beyond the skills of some ward-based staff (Field et al., 2008; Ramsey et al., 2013;). Ramsey et al. (2013) identified that some participants felt the ward staff lacked awareness about the psychological distress patients experienced upon discharge from CrCU, and that they did not have the skills to manage the early physical and psychosocial problems following critical illness. Several patients described how care was fragmented and not appropriate for their clinical condition (Ramsey et al., 2013). This extended to staff being unable to provide patients with even basic information about their illness and why they were in hospital. Interestingly, the failure of staff in providing adequate information was associated with patients feeling their safety was compromised (Bench et al., 2011). Conversely, the provision of effective information made patients feel safe, and in addition, mitigated their perceptions of neglect (Bench et al., 2011).

2.5.3 Hospital discharge and community based care

The literature identified that hospital discharge was associated with mixed emotions for survivors of critical illness (Laplum et al., 2011; Lee et al., 2005). Some patients reacted positively to discharge as they felt pleased to be going back to a familiar environment whereas others felt anxious and afraid due to the uncertainty about what to expect, especially if they had limited family or social support (Lee et al., 2005). Whilst discharge home represented a key achievement in their recovery process, the absence of professional monitoring and contact with healthcare providers simultaneously caused some people to focus on 'catastrophic fears' about their health (Laplum et al., 2011, p. 229). The removal of surveillance created vulnerability and fear

but many participants found the comfort of home surroundings and family presence created a different kind of safety that was reassuring (Laplum et al., 2011).

Most physicians and professionals involved in a study by Lefebvre et al. (2005) identified that the collaboration and communication between healthcare establishments was unsatisfactory. Many criticised the healthcare professionals' knowledge of the patient, highlighting ignorance of both the patients' prior history or future outcome beyond their own area of involvement with the patient, and blaming the lack of communication between establishments (Lefebvre et al., 2005). Continuity of services for patients with TBI was adversely affected by having incomplete patient information to hand over when the patients were transferred between services (Lefebvre et al., 2005).

The literature found that discharging patients back into the community setting without ensuring provision for their ongoing care was dangerous (Laplum et al., 2011). One patient likened hospital discharge as 'being thrown to the wolves,' and some patients had felt vulnerable as they had to suddenly take over responsibility for their own care in lieu of inadequate follow-up (Laplum et al., 2011) . Lee et al. (2005) suggested that healthcare professionals needed to involve both patients and family or primary caregivers in discussions about going home, yet stressed that the rapid way in which information was often delivered limited opportunity for discussion and time for it to be absorbed. Individual patient needs could be overlooked when staff followed standardised patient pathways in hospitals, and service pressures encouraged rapid patient turnover (Lee et al., 2005).

Patients did not know what to expect following discharge home (Deacon, 2012; Laplum et al., 2011; Pattison et al., 2007; Prinjha et al., 2009). This made them feel uncertain about whether their recovery was progressing normally (Deacon, 2012). Written information, whilst considered an essential tool for recovery, left many questions unanswered (Laplum et al., 2011). Information given at hospital discharge was oversimplified and did not include issues that were considered important to patients (Laplum et al., 2011). Patients struggled with vague details in care pathways that left the information open to interpretation and described fear and anxiety when they were unsure whether the symptoms they experienced during recovery were normal (Laplum et al., 2011). Some patients had felt a sense of personal failure when their recovery failed to match the recovery trajectory they had read about, leaving them feeling vulnerable and using hypervigilant, self-surveillance practices to alleviate their uncertainties and anxiety (Laplum et al., 2011). Patients wanted education about

discharge which was multi-dimensional and delivered in both the hospital and home settings (Laplum et al., 2011).

Lefebvre et al. (2005) identified that the complexity of TBI meant physicians and healthcare professionals were reluctant to provide too much information as they were often uncertain about the patient's prognosis and did not want to misinform patients. However, because this uncertainty was not discussed with patients or their families, this undermined the confidence of patients and their families and gave them the impression that the physicians and professionals were hiding something. This meant that patients and families received inadequate information and were worried about resuming control of their lives on discharge home (Lefebvre et al., 2005).

Following critical illness patients did not receive the continuity of care that promoted their ongoing recovery, experiencing fragmentation of services or scarcity of resources (Deacon, 2012; Laplum et al., 2011; Lee et al., 2005, Lefebvre et al., 2005, Prinjha et al., 2009). Many survivors of critical illness indicated that they felt emotionally unprepared for their return to their home environment, and lacked support, which resulted in increased stress and depression (Lee et al., 2005). Patients found some healthcare professionals were only interested in a single aspect of their condition, according to their speciality, and this reduced patients to an 'object of care,' lowering their self-esteem (Lefebvre et al., 2005, p. 592). GPs also had little awareness of what had happened to patients during their admission to CrCU and a result they were unable to answer patients' questions (Prinjha et al., 2009). In addition, the promotion of readjustment and social reintegration for patients with TBI was found to be compromised by lack of material and professional resources and inadequate follow-up which prevented their access to the services they needed and delayed both physical and cognitive recovery (Lefebvre et al., 2005).

Some former CrCU patients identified the need for community-based healthcare providers to support their physical and emotional recovery, resumption of everyday activities and preparation for return to work (Lee et al., 2005). In the longer-term, patients wanted psychological counselling and rehabilitation to improve recovery, as over time problems began to emerge that were not initially apparent, such as difficulties with reading, writing, memory or mood (Lee et al., 2005). Some patients felt abandoned following hospital discharge because they did not receive any CrCU follow-up and some said they had identified and accessed support groups of former CrCU patients to discuss their experiences as they had not received the counselling they needed

(Prinjha et al., 2009). Patients also recommended that a member of the healthcare team take responsibility for coordinating the whole rehabilitation process or provided patients with the contact details for a named member of staff, such as a CrCU nurse, who they could telephone if they felt they needed to speak to someone during their recovery (Deacon, 2012).

CrCU survivors and their relatives placed value on CrCU follow-up clinics for gaining reassurance from experts familiar with their CrCU experience (Egerod et al., 2013; Prinjha et al., 2009; Storli & Lind, 2009). Patients who attended follow-up clinics appreciated talking through their feelings about being in CrCU (Pattison et al., 2007) and hearing about common experiences provided them with reassurance (Engström, Andersson, & Söderberg, 2008; Pattison et al., 2007; Prinjha et al., 2009) and gave them information about the recovery process (Pattison et al., 2007). In this way CrCU follow-up helped patients to adopt realistic expectations and approach their recovery in a more informed and measured way (Pattison et al., 2007; Prinjha et al., 2009). Some patients who did not receive follow-up clinic appointments following critical illness perceived this had prevented them having an opportunity to discuss their problems and ask questions about their CrCU stay and ongoing recovery (Prinjha et al., 2009). However, other patients did not attend follow-up clinic appointment as they had not wanted to go back to CrCU, having become very paranoid about their experience (Prinjha et al., 2009). For some patients, re-exposure to the CrCU experience, whether through patient diaries, clinic appointments or CrCU revisits could risk re-traumatising the patient (Storli & Lind, 2009) .

Follow-up clinic also played a role in providing continuity of care by allowing the detection and treatment of problems and facilitating timely investigations and referrals to specialists (Prinjha et al., 2009). Clinic visits offered patients a forum to discuss their unreal and delusional memories of CrCU (Engstrom et al., 2008; Pattison et al., 2007; Prinjha et al., 2009). When patients shared delusional memories it helped them to make sense of these memories and increased their understanding of what happened to them in CrCU (Engstrom et al., 2008; Storli & Lind, 2009). Having their delusional memories taken seriously, and learning that they were common, had the effect of normalising such strange experiences and encouraged patients to disclose their experiences without fear of being judged as *going mad* (Engstrom et al., 2008; Storli & Lind, 2009). This credibility was important for patients' self-esteem and self-respect and helped them to cope through difficult times and move forward with recovery (Engstrom et al., 2008, Prinjha et al., 2009). However, many patients thought the first few months

after hospital discharge were the most difficult time for them and would have preferred their initial follow-up appointment soon after hospital discharge rather than waiting for several months (Prinjha et al., 2009).

Follow-up clinics allowed patients to meet with a ‘qualified listener,’ who encouraged them to put their experiences into words and who resisted correcting ideas that at first appeared to make little sense, such as their experiences of unreal memories of CrCU (Storli and Lind 2009). This offered a more thorough approach than attempting to simply fill in the gaps in patients’ memories or answering their questions. Allowing patients to tell their stories without interruption helped patients themselves to make connections between their delusions and what really happened, with staff supporting this process (Storli & Lind, 2009). Open discussion with a qualified listener helped patients to better interpret what had happened to them and find meaning in their experiences (Storli & Lind, 2009).

A re-visit to CrCU is an element of follow-up offered at some hospitals to help patients make sense of their critical illness experiences. The CrCU follow-up re-visit was for some patients the main component for ‘getting things to fall into place’ as they were re-exposed to the sounds, smells and feelings of the CrCU and this allowed them to make connections between the memories that were triggered and the CrCU environment (Storli & Lind, 2009). Some patients appreciated seeing the CrCU room they were in and learning what the equipment looked like and how it worked (Engstrom et al., 2008). Once patients were back in the situation, dormant experiences were invoked but the patient was now able to look at them in another way and integrate them into their life experiences (Storli & Lind, 2009). Relatives also appreciated the return visits, particularly as it meant that they could share in the process of filling in the patient’s memory gaps with the healthcare staff. This meant they were not the only ones responsible for dealing with the patients’ thoughts and questions (Engstrom et al., 2008).

2.6 Summary of Findings from the Literature

This literature review has explored what life was like for patients following critical illness and how they experienced the healthcare services they encountered. Patients are admitted to CrCU with various clinical conditions. The CrCU experience can span from an overnight admission for observation following elective surgery to a life-saving, complicated and extensive stay. It is therefore unsurprising that qualitative work has uncovered a variety of ways in which patients experienced the major physical,

psychological and self-identity changes which healthcare and community services were often ill adapted to support.

Central to patients' experiences were the unexpectedness of their physical debilitation and their unpreparedness for the recovery process. Whilst the literature suggested that it was helpful for patients to understand what to expect in order to avoid unnecessary frustration, disappointment and demotivation, it remains unclear exactly what influences the expectations about recovery that patients develop. It is certainly reasonable to suppose that being unable to recall the acute illness or CrCU stay makes it difficult for patients to contextualise their muscle loss, weight loss and fatigue. However, it is unknown whether this hinders patients' ability to plan their recoveries realistically. It may be that people need time to mentally and emotionally process their critical illness experience before they are able to readjust and make progress. There is a gap in current understanding regarding the best way to support people adjusting to the process of recovery following critical illness.

The literature suggested that many patients either had limited recall of their CrCU stay or remembered both real and unreal or delusional events from their critical illness. These patients may be vulnerable to problems during recovery such as delusions, nightmares, hallucinations, anxiety, depression and symptoms of PTSD such as hypervigilance, avoidance and panic attacks. Patients' responses to their experiences appeared to be polarised. On the one hand some patients found it difficult to leave behind their critical illness experiences and wanted to make sense of what had happened to them. For other patients, the CrCU experience was something they do not want to revisit and they had a desire to move forward with recovery. It is possible that patients' responses could be influenced by past experiences and the coping mechanisms they have formed. In addition, the presence of psychological symptoms may be difficult for patients to acknowledge to themselves or others as they fear that they are *going mad* and feel embarrassed, which may delay the identification and treatment of problems. Further understanding of patients' psychological responses to critical illness and their longer-term outcomes could inform the way in which to provide psychological support during recovery.

An interesting insight revealed by patients' experiences is that critical illness appeared to instigate a life transforming process. In addition to the transition from sickness to health, some survivors experienced lifestyle and role changes and experienced a process of transition in their life perspective and self-identity which, as well as being

unsettling and confusing, may be mistaken for psychological morbidity. Whilst this area has received little attention in the literature, some patients appeared to have negative life changes following critical illness, whereas others experienced positive changes similar to the post traumatic growth found in survivors of trauma, serious and chronic illness. Understanding these differences may highlight important ways to support all people undergoing transition from critical illness back to health and wellbeing.

Patients' experiences of healthcare services during recovery from critical illness revealed a lack of appropriate professional and physical resources and poor continuity of care which caused vulnerability, fear and stress for both patients and their families. Transfers within and between healthcare settings were times of anxiety and worry for patients as they required a move away from the perceived safety of familiar staff, monitoring and care routines and required increased self-care and independence. In the ward setting, staff shortages, attitudes and skills meant that patients' basic self-care needs were not being met. Ongoing debilitation and lack of autonomy meant that many patients were unable to secure the help they need which caused them to be emotionally distressed and demoralised. Once back in the community setting patients found it difficult to identify and obtain the ongoing support they need from professionals with appropriate experience. Information provided by healthcare services generally lacked enough detail to appropriately inform the recovery process, meaning patients faced considerable uncertainty about their health status and fear about what was normal and what to expect next. Despite studies involving patients in the development of discharge information many remain unprepared for the physical and psychological difficulties they face in each new environment. Ways in which to successfully ease patients' transitions across healthcare and community boundaries remain unclear.

Some hospitals provided CrCU follow-up clinics and many patients appreciated these services for improving their continuity of care by providing timely access to services and support and meeting their multidimensional needs. When these services were not offered, some patients felt that their ongoing needs were not being met and were left searching for alternative ways to access support. Other patients did not wish to access follow-up clinics and the reasons for this were unclear. This has not been the focus of research and is an important area of investigation. Without understanding of the experiences of patients who do not attend follow-up services it becomes problematic to design services that accommodate the diverse range of patients in need of support during recovery.

2.7 Key Themes Identified from the Literature

Peoples' experiences during recovery point to major physical and often psychological debility and burden that is not being fully addressed within the healthcare services they encounter. A person's clinical and social history, the critical illness scenario and complications, the healthcare encountered within various settings and family and social support all influence a patient's transition from sickness back to health. Away from the CrCU setting, people perceive that shortfalls in the expertise and experience of some staff involved in their complex recovery process mean that physical and psychological issues may remain unidentified and untreated. Care pathways and service pressures sometimes appear to drive the recovery process rather than individual patient's requirements. Compounding this is a fragmentation of services, with lack of forward planning, inadequate communication between service providers and single specialities all directing aspects of care. The key themes identified in this literature review are summarised in Figure 2.2.



Figure 2-2 Key themes identified in the literature review

This literature review has identified that patients experiencing recovery from critical illness have often complex and long-term issues remain unidentified, or unprioritised within healthcare and community services. The need to better understand patients' varying needs and expectations and how to configure services to better meet these needs formed the purpose of this study, and influenced the study design. In the next chapter, a detailed outline of the methodological approach and study design that was undertaken to meet these needs is presented.

3 METHODOLOGY AND METHODS

3.1 Introduction

This chapter discusses the methodological approach and methods used in this study. This chapter begins by outlining the overall aims and objectives of this study, taking into consideration the key themes identified in the literature review, before proceeding to explain the research framework and approach selected to address these aims and objectives. This leads to a discussion of the study methodology, considering the choice of qualitative approach and a justification for the choice of the experience-based co-design (EBCD) methodology, together with an overview of this approach. Following this, the research methods and ethical considerations are presented in further detail.

3.2 Research Problem

Patient experiences could serve to motivate healthcare professionals to improve care and incentivise healthcare organisations to design services and infrastructure around patients' needs during recovery. Research to date reveals that there have been limited 'real time' avenues for patients' critical illness and recovery narratives to directly feedback to the healthcare professionals who have a role in providing care during their recoveries. Providing an overview of the patients' recovery experiences would allow staff to appreciate the significant impact on patients when services do, and do not, meet their short and longer-term needs. This is an important area for research as it offers an opportunity for healthcare provision to synchronise with patients' recoveries and improve their experiences, and ultimately, outcomes following critical illness.

3.2.1 Aims

This study aims to capture and understand patient experiences following critical illness and to co-design healthcare services with staff, patients and carers to improve care provision for recovering patients.

3.2.2 Objectives

To capture patient experiences of recovering from critical illness to understand what shapes their expectations of the recovery process.

To explore patient experiences of hospital based care and wider support in the community setting following an episode of critical illness.

To explore and describe the experiences of the staff who care for patients following discharge from CrCU.

To map the emotional touchpoints for patients and identify patient/family and staff priorities for improving patient experiences of hospital based care and support in the community.

3.3 Research Framework

3.3.1 Methodological approach

A principal decision in undertaking research involves whether to adopt quantitative or qualitative approaches, or a combination of both, to address the research aims and objectives. Each approach will guide the types of research questions asked and how the data will be collected, analysed and interpreted (Creswell, 2013). Equally, the research question, aims and objectives inform the methodology and design of the study, to ensure that the exploration of the phenomenon is attainable. The first consideration when designing this study centred upon the evaluation of both quantitative and qualitative strategies.

The majority of quantitative research conducted in biomedical science uses a positivist scientific approach (Creswell, 2013). Positivism is an ontological paradigm which presumes that the universe and everything in it is objectively real and that physical causes must have physical effects. The researcher proposes a theory and formulates this into a hypothesis which can then be tested by methods which use measurement and quantification (Willis, 2007). Using quantitative approaches, researchers of critical illness have identified and measured many physical, psychological and cognitive complications for patients following critical illness. Quantitative research has described issues such as muscle wasting and weakness, inability to sleep, disturbed dreams and delusional memories, poor working memory, and delayed return to work (Davydow, et al., 2008; Davydow, et al., 2009; Pattison, et al., 2005). This has in turn influenced the focus of further quantitative research on testing interventions to treat these consequences of critical illness and improve outcomes for patients.

Whilst quantitative methods have exposed the physical, psychological and social problems patients face following critical illness, these methods have not explored patients' experiences of facing these challenging problems within the context of current service and care provision. Quantitative research does not tend to reveal how social relationships, interactions and individual sense-making influences recovery and this

limits the usefulness of quantitative approaches when addressing issues involving organisational cultures and healthcare practices (Giacomini, 2010). As a result, there is a growing interest within the healthcare arena for the use of qualitative approaches to improve the planning and provision of health care services (Giacomini, 2010).

According to Brinkmann and Kvale (2015) the qualitative stance offers a non-technical approach to research which discovers phenomena about experience by focussing on how people think, learn, know, act and understand themselves within their normal worlds. This stance is aligned with an ontological position of naturalism, which does not consider that the world pre-exists, but that it exists only when humans interact with it (Crotty, 1998). It was crucial to this research to gain an understanding of patient experiences, which required collection of their subjective narratives and not objective data. This lent itself to an inductive qualitative approach that set out to create ideas based on the subjective insights of patients who had lived experience of critical illness and recovery. This contrasts with quantitative approaches to research, which test researcher pre-assumptions rather than gathering original insights. Qualitative methods focus on the ways in which people interpret the social contexts and are more oriented towards generating theory about the social world (Bryman, 2012). As such, a qualitative stance was suited to exploring the world from the perspective of patients and healthcare staff in order to understand their experiences of care, the challenges and constraints of delivering the service and to generate achievable and meaningful priorities for service improvement.

Qualitative research approaches provide the opportunity not only to embrace the lived experiences of patients and families, but also to capture staff insights, and to encourage collaborative engagement between staff and patients. A qualitative approach was chosen for this study as the purpose was to improve services for patients, based upon the needs and priorities that mattered most during recovery from critical illness and what they considered to be the positive and negative aspects of the care and services they received.

3.3.2 Philosophical assumptions

The ontological and epistemological approaches taken in this study are within the philosophical realms of constructivism. Constructivism states that 'each individual constructs knowledge and his or her experience through social interaction,' (Costantino, 2012, p. 116). The constructivist tradition applies to research in which the researcher and research participants construct reality together (Denzin & Lincoln,

2013). The role of the constructivist researcher is ‘to understand multiple social constructions of meaning and knowledge,’ (Robson, 2002, pg. 27). To understand the subjective meanings people have about particular objects or events the researcher needs to gather the participant’s views of the situation and use these inductively to generate understanding (Creswell, 2013). In addition, the researcher uses their own individual experiences as a filter through which to understand the experiences of other people. This casts the researcher as an interpreter, who ties together their own clinical and academic experiences with the experiences of organisational members (Hatch & Cunliffe, 2006).

Constructivism is suited to this research study as it requires an appreciation of the views, feelings and significances of patients and staff whose real life experiences are central to addressing the aims and objectives of the study. Guba (1990) explains constructivism as a stance which is appropriate when research participants’ subjective views about the meaning of their experiences are more relevant than the need to demonstrate objective truth.

3.3.3 Justification for the Experience-Based Co-Design methodology

The aims of this study were to capture and understand patient experiences following critical illness and to co-design healthcare services with staff, patients and carers to improve care provision for recovering patients. Several qualitative methodologies were taken into account to address these research aims and objectives, including phenomenology, narrative enquiry, grounded theory, and participatory action research. The traditional methodology used in exploring, understanding and describing experiences is phenomenology (Holloway & Wheeler, 2010). Phenomenology is concerned with creating in depth understanding of how individuals feel, experience and act in relation to each other, to the world, and to their circumstances (McWilliam, 2010). Whilst the exploration of patients’ experiences, was an important aspect of this current study, the focus was not specifically on capturing their lived experiences of a shared phenomenon in order to create an in depth understanding. As the aim was both to capture and to use patient experiences, and phenomenology was not considered as the best fit for this study.

The intention to use patients’ experiences also led to consideration of narrative enquiry, as capturing and analysing patients’ stories was a key element in understanding their experiences. Narrative research involves the collection and interpretation of stories of life experiences (Schwandt, 2014). Not only are patient narratives a rich source of

information, they also allow engage healthcare staff in the change process (Bate and Robert, 2007). Whilst patients' stories are a rich source of information, and narrative interviewing was used in this study to understand patients' experiences, narrative enquiry was not used as a standalone methodology for this study as an important objective was to use the information from patients' stories in a process of service improvement.

In a similar way, when considering grounded theory, concern about the limited emphasis on service improvement was a key factor to take into account. One benefit of grounded theory lies in the integration of data collection and analysis (constant comparative method) which means that emerging issues can be explored in depth by selecting participants who can inform the emerging theory (theoretical sampling) (Charmaz, 2006). Grounded theory offers a systematic approach to the conduct of the research (Denscombe, 2007). However, this approach affords limited interaction with patients beyond the data collection stage and the intent of this study was not generating theory, but to improve services, so this methodology was also not considered suitable.

Participatory action research entails a continuous cycle of research and intervention activity characterised by a cycle of planning, acting and observing, reflecting, re-planning, acting and observing again, reflecting again (Kemmis & McTaggart, 2008). Participatory action research is undertaken as a social and educational process in order to study, reframe and reconstruct social practice and, whilst it focuses on actual rather than abstract practices, it can transform both theory and practice (Kemmis & McTaggart, 2008). Participatory action research was considered to be a suitable approach for this study, allowing collaboration between patients, families, staff and the researcher and active participation in developing services. The EBCD methodology is a form of participatory action research which features 'user-centred design,' an understanding of user experiences of poor interactions with a service and subsequent collaboration between users and providers to co-design solutions (Robert, 2013). These elements are each influenced by different research methodologies which marry together to provide an innovative approach to changing services. In essence, an EBCD approach uses patient experiences to understand both what works well, and not so well within a service (Bate & Glenn, 2006, Robert, 2013). This process leads to the identification of areas of care provision that need to be changed and provides a framework through which improvement activities can be undertaken (Robert, 2013). As

such, the EBCD methodology was considered the most suitable approach for this study.

3.4 Theoretical Underpinning

EBCD as a methodology is informed by four interwoven component ideas; participatory action research, user-centred (participatory) design, learning theory and, narrative-based approaches to change. These component ideas are in turn related to dialogic organisational development (OD) approaches (Bate & Robert, 2007; Donetto, Tsianakas, & Robert, 2014) which aims to bring a non-traditional approach to organisational change by prioritising the experiences of those who receive and deliver services.

3.4.1 Participatory action research

Literature involving EBCD studies often position this methodology within the participatory action research approach as this encompasses the practical ‘doing of’ the research study. Participatory action research is an approach which addresses ‘*complex human and social problems*,’ (Robert, 2013; p. p. 141) and is centred upon improving the understanding and delivery of practice through collaboration and active participation between researchers and those who are the focus of the research (Robson, 2002). EBCD is a form of participatory action research because it captures how patients/families and staff feel about a service and then makes them equal partners in redesigning the service (Tollyfield, 2014). Participatory action research is aligned to all stages of this current study which require active participation and action to change patients’ experiences during recovery.

3.4.2 User-centred/participatory design

User-centred (participatory) design highlights that both service users and service providers should be involved in service design, and that services should be designed around the experiences of service users (Robert, 2013). Paying attention to the patients’ subjective experiences of a service, rather than the objective evaluation of the care pathway, this study adopts a user-centred approach by focussing on delivering better experiences for patients during recovery, not merely improving processes or systems (Bate and Robert, 2007), although understanding patients’ experiences may ultimately do both. The EBCD methodology is enhanced by phenomenological influences which promote a reflective gaze on experiences. EBCD embraces the retrospective sense-making (Weick, 2000) afforded by phenomenological insight and the learning this generates, as ‘hindsight’ gives ‘insight’ and ‘insight’ gives ‘foresight,’

(Bate and Robert, 2007, pg. 38). EBCD also uses the phenomenological insight from capturing experiences to help people to understand what an experience must be like for another person, to be able to relate to that experience without personally having lived through it (Bate and Robert, 2007). This was an important aspect of this study which required staff to be able to understand and appreciate patients' experiences of their care and services during recovery.

User-centred design also draws from ethnographic research methods such as observation and narrative interviews to capture experiences and design principles have introduced tools such as touchpoints and emotional mapping (Robert, 2013). Bate and Robert (2007) propose more emphasis be placed on understanding the experiences of service users, including the events, people, and issues they encountered in the service, and less on the stages and activities involved in care pathways. In this study user-centred design in particular encompasses both the collection of patients' experiences of interacting with services during recovery, and their active participation with staff in exploring changes to services that will improve their experiences.

3.4.3 Learning theory

Robert (2013) cites many influences from learning theory that have informed EBCD, drawing from works about organisational learning, art-based creative learning pedagogies, the art of having better conversations and community engagement and collaboration (Argyris & Schön, 1978; Kerr, 2010; Kerr & Lloyd, 2008; Wheatley, 2010). Learning theories inform EBCD by emphasising that staff should be trained to be 'reflective practitioners' (Robert, 2013). This would enable them to '*draw back*' and critically reflect on practice, allowing space for the appreciation of the viewpoints of others. Within EBCD this relates to being able to focus on what staff and patients want and to provide a safe space to '*practice new ways of thinking, feeling, doing and relating,*' (Robert, 2013, pg. 142).

3.4.4 Narrative based approaches to change

Narrative based approaches to change, which use subjective and socially constructed narratives within a social context, underpin participatory action research, user-centred design and learning theory (Bate & Robert, 2007, pg. 65). Narrative approaches involve people telling stories about their experiences that make sense of their social reality and produce knowledge about the human world (Brinkmann & Kvale, 2015). The healthtalkonline project, a collaborative project between the DIPEx charity and the University of Oxford Primary Health Care Research Group, provides an illustration of the use of patient narratives (Sue Ziebland & McPherson, 2006). The intention of the

healthtalkonline project was to inform patients and carers about illness and healthcare and to share patient experiences in order to educate health and social care professionals (Zeibland and McPherson, 2006). The healthtalkonline website makes the narrative interviews available as short videos and summaries. Patient narratives are used in healthcare to inform clinical practice and service delivery, improve the therapeutic relationship between patients and professionals (S. Ziebland, 2013) and as a therapeutic approach to benefit patients following trauma (Pennebaker, 2000). The use of patient narratives in this current study was essential not only to understand patients' experiences of CrCU recovery services, but also to illustrate the whole recovery journey and important touchpoints for patients.

3.4.5 Dialogical organisational design

EBCD is influenced by organisational design theories. Organisational Design (OD) approaches advocates interaction between like-minded people in a system so that new ideas can emerge from their collective thinking (Bushe & Marshak, 2009). In dialogic OD, stories from individuals in the organisation are used to reveal what contributes towards unproductive interactions and communications within the organisation in order to identify solutions (Bushe & Marshak, 2009). Whilst OD originated within objectivist and positivist assumptions, in dialogic OD there is an assumption that organisations are socially co-constructed realities which hold that there are no ultimate truths that can be known or right ways of doing things (Bushe & Marshak, 2009).

The classical branch of OD still focuses on the collection of valid empirical data from within an organisation in the attempt to capture an underlying objective reality about the organisation that can be used in the process of change (Bushe & Marshak, 2009). This approach is the basis for much improvement work that takes place in healthcare. What is happening in an organisation is established by measuring and classifying the behaviour of people and systems (Hatch & Cunliffe, 2006) and when problems have been diagnosed, pre-determined solutions are imposed to bring about change (Bushe & Marshak, 2009). In contrast, in dialogic OD any given behaviour or action can be defined in different ways by different people, and by the same person over time, and this implies that the social world is dynamic and relativist (Bryman, 2012). This aligns dialogic OD with a constructivist epistemology, which supposes that people derive their understandings from their interaction with other people, and from their cultural and biographical histories (Bushe & Marshak, 2009, Creswell, 2013). The model is well-aligned to this study in which patient narratives and staff interviews are used to capture both perspectives and engage them in small groups to co-design services. Dialogic OD

focuses on collectively changing the symbols (images, stories and texts) that people use to make sense of matters, which has a knock on effect on their behaviour and actions and thus potentially changes organisational function (Bushe & Marshak, 2009).

When the focus of change shifts from changing the behaviour of members of the organisation to changing the way they actually think about things, change reflects peoples' shared ideas and ambitions and thus their commitment to it increases (Boyd & Bright, 2007). As such the dialogic OD approach has particular resonance with this study in which a short trigger film of patients' experiences of a service is shown to the staff who provide the service to motivate them to rethink how care is delivered and engage with patients to redesign services. In this respect the EBCD approach aligns with the dialectical development theories which underpin dialogic OD. These theories suggest that change processes require confrontation and synergistic engagement between the contradictory values and opposing forces at work in organisations as this will bring about new perspectives and outcomes (Van De Ven & Poole, 1995; Bushe & Marshak, 2009). The value of EBCD lies in challenging organisational priorities and professional hierarchies, yet is dependent on the whether an institution can tolerate diological innovation (Farr, 2017).

3.4.6 Origins and implementation of Experience-Based Co-Design

EBCD has its origins in design science and was developed by the NHS Institute for Innovation and Improvement to place patient experience at the centre of service design by focusing on how the patient and family interact with a service and how it is felt or experienced (Bate & Robert, 2006; Wolstenholme, Cobb, Bowen, Wright, & Dearden, 2010). This approach arose out of frustrations that 'patient experience' received limited attention in healthcare practice compared to 'clinical effectiveness' and 'patient safety,' even though all three approaches were advocated in the UK government's policy framework for improving healthcare quality (Robert, 2013). An additional concern was the preference for drawing on quantitative data collection methods in service improvement initiatives as these were often unsuitable for capturing the reality of patients' experiences (Bate & Robert, 2007, Robert, 2013). Rather than measuring patients' attitudes, which might not reveal patients' experiences of using a service (Robert, 2013), EBCD focuses on capturing patients' real experiences to inform quality improvements in healthcare organisations (Robert, 2013).

The EBCD method combines a user centred orientation (experience-based) and collaborative change process (co-design). Palumbo (2016) suggested that co-design

might improve relationships between users and providers of a service with resulting increased engagement with healthcare and a subjective improvement with the satisfaction of a service. The EBCD approach is intended to encourage realistic engagement between patients and healthcare providers to develop patient-centred services by understanding each other's stories of receiving and delivering care. The use of patient experience as a quality marker is also positively associated with clinical effectiveness and patient safety (Doyle, Lennox, & Bell, 2013).

EBCD is relatively new approach to service improvement, first developed and piloted in health service improvement in 2005 (Donetto et al., 2014). The initial use of the EBCD concept as first described by Robert and Bate (2006) was to redesign a head and neck cancer service at an NHS hospital in England. By the end of its' first decade of use, the EBCD methodology had been reported in 80 individual projects internationally (Donetto., et al, 2014) and has now become a more structured methodology which is mostly used for service improvement in local settings (Green et al., 2020).

Evidence on the value of EBCD in improving health outcomes is not conclusive due to a lack of rigorous evaluation of the methodology in acute healthcare settings (Clarke, Jones, Harris, & Robert, 2017). A recent systematic review of EBCD studies (Green et al., 2020) has shown a significant variance in the application of the method with many studies not utilising all stages of the process. Despite the capture and use of patient experience as a trigger for discussions being an intrinsic part of the methodology, in the 20 studies included in the review, there was significant variation in the methods used to capture and analyse patient experience, with some studies omitting these phases due to financial and time constraints. A study describing Accelerated Evidence-Based Co-Design (AEBCD) showed that using a nationally produced 'trigger film' could be as effective at improving services as conducting local data collection to capture patient experiences (Locock et al., 2013). The AEBCD model was an attempt to counter the criticisms that the co-design process can be both time and resource intensive.

3.5 Research Design

The study used an EBCD methodology incorporating narrative interviews with patients and a service improvement process.

3.5.1 The Experience-Based Co-Design methodology

This study was based around the six-staged EBCD framework.

Stage 1 A core team is established, the goals of the project are set and the administrative arrangements made.

Stage 2 Staff are interviewed about their experiences of delivering a service and in addition may be observed interacting with patients in the workplace. A staff meeting may also be held to establish staff priorities for service improvement.

Stage 3 Filmed narrative interviews are conducted with patients to capture their experiences of care and to produce an edited short film to establish the touchpoints. Touchpoints are moments of patient interaction with a service or engagement between patients and healthcare professionals which are associated with heightened emotions and provide an understanding of how patients' experience care and support during recovery. The patients/carers meet at a patient feedback event to review the film and patients' associate emotions with the touchpoints previously identified (emotional mapping) and establish priorities for improving services.

Stage 4 A joint meeting is held with patients, carers and staff and the film is shown, following which joint priorities for improving care and services are agreed.

Stage 5 A programme of co-design meetings are arranged in order to design/implement service improvements.

Stage 6 A celebratory meeting for everyone involved in the EBCD process is held to share progress and make plans for moving forward.

This process is outlined in Figure 3.1.

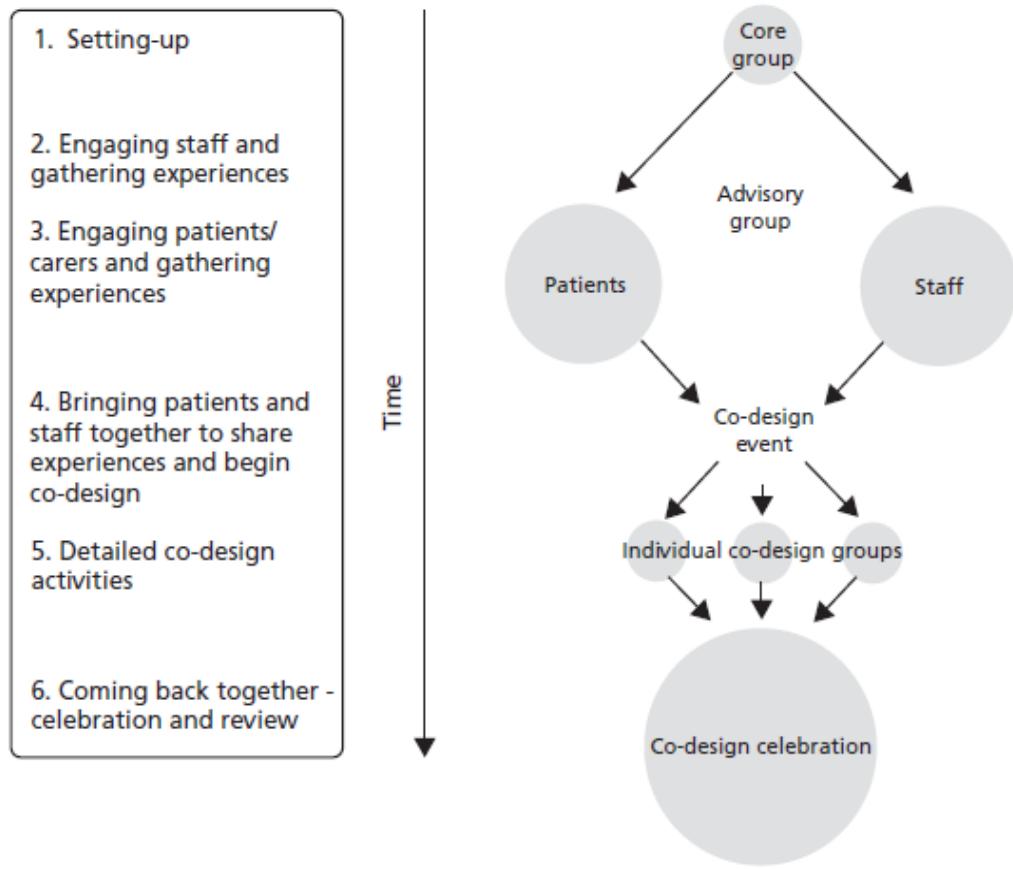


Figure 3-1 The six-stage EBCD process

3.5.2 Adaptation of Experience-Based Co-Design to this study

This study is based around EBCD stages one to four. A pragmatic decision to adapt the EBCD process was made to allow for the conduct of this study within a part-time PhD programme. The alterations to the process meant that stages two and three were conducted simultaneously and stages five and six were not within the remit of the PhD at all in order to meet the researcher's time schedule. As a result of these adaptations, the implementation phases of EBCD process are taking place outside of the boundaries of the PhD. The adapted study schedule comprised the following phases:

PHASE 1 Capturing the experience

Filmed narrative interviews were conducted with patients and audio-recorded semi-structured interviews with staff.

PHASE 2 Understanding the experience

Patient and staff interviews were analysed using thematic analysis. For the patient interviews, the analysis identified key touchpoints of the recovery journey. The films of the patient interviews were edited into a short patient experience film which represented the touchpoints of patients' experiences.

Staff semi-structured interviews were analysed using thematic analysis to identify the key issues for staff of providing care for patients following critical illness, their understanding of the patient's illness pathway and how they perceived patients experienced the services and support they provided.

PHASE 3 Improving the experience

A patient feedback event was held to give patients and their carers the opportunity to get to know one another and form a collegial group prior to the co-design meeting. At this event an emotional map of the highs and lows of their care experiences was created to identify key priorities for service improvement.

A joint patient and staff event was held at which patients, family members/friends and staff exchanged their experiences of receiving or providing care and used the film and design techniques to inspire service improvement activities and prioritise key areas where development was needed. The study flow chart is shown in Figure 3.2.

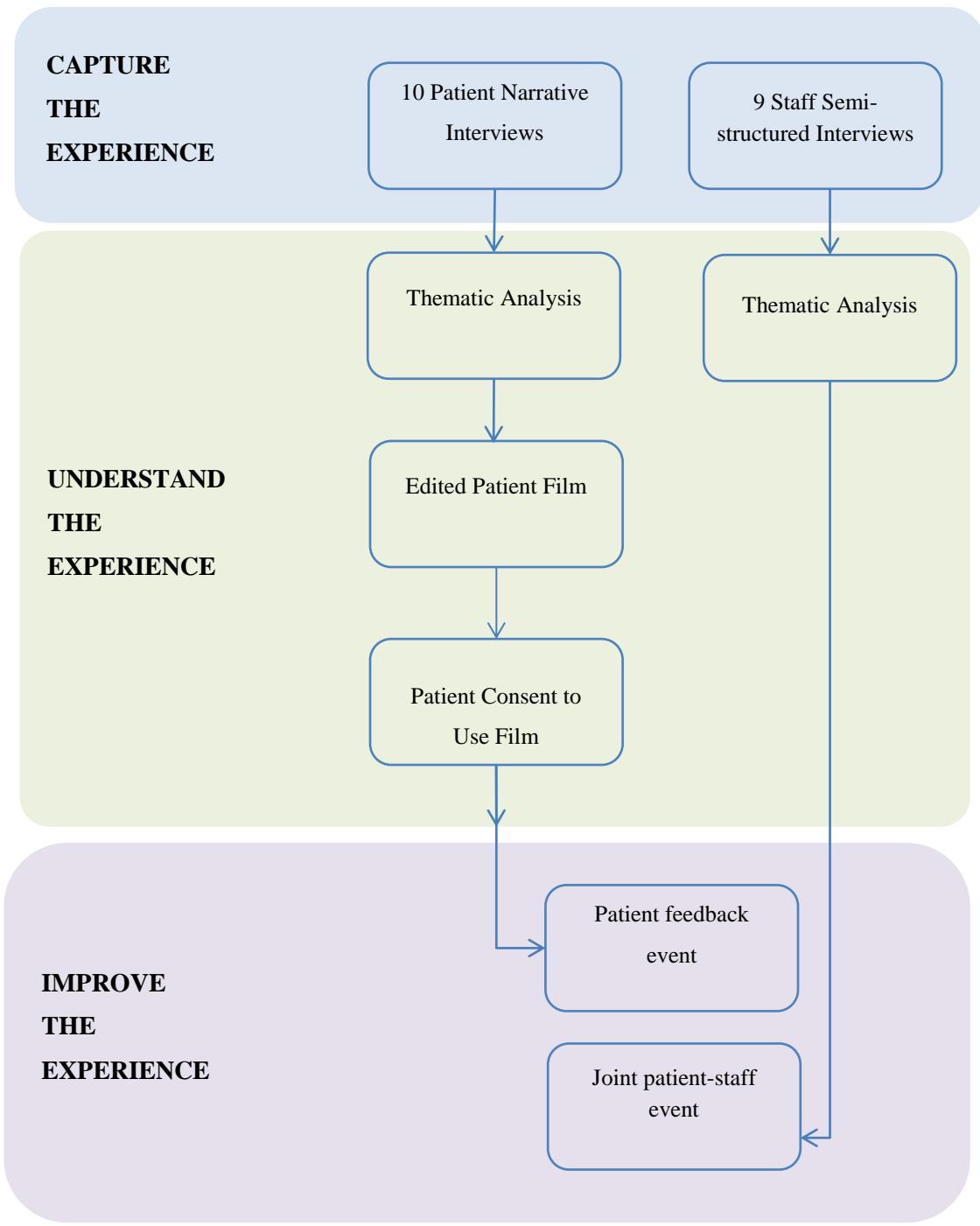


Figure 3-2 Study flow chart

3.6 Study Setting

The population for this research study was patients recovering from critical illness who had been discharged from CrCU and the staff involved in their care in a large teaching hospital in the Northwest of England. These choices centred upon the researcher's familiarity and access to the setting and its suitability to address the research aims and

intentions. Knowledge of this healthcare organisation facilitated access to appropriate patients and staff and also supported the process of data collection and the patient and staff events.

This study took place in a large teaching hospital which provides CrCU services for major trauma, neurosciences, renal, specialist complex cancer surgery (upper gastrointestinal, head and neck, urology and gynaecology), vascular and medical patients. This setting provides the means to capture the experiences of a range of patients. The CrCU has increased in size from an 8 to a 24 bedded unit in the past 20 years, requiring a large increase in the nursing staff from 25 to 225, and the recruitment of newly qualified nurses to achieve adequate numbers of staff. Despite the increase in bed numbers, bed occupancy is still very high. Hence patients will only be admitted when they require organ support rather than those who are at risk of deteriorating and need close observation.

The CrCU developed from a four-bedded post-operative care area so was positioned near to the theatre complex on the lower ground floor. The fact that it is in the basement level of the hospital and has a lack of natural light and low ceilings leads to the unit being described as “dark” and “down in the depths.”

Follow-up care provided by the critical care service is divided between the inpatient and outpatient setting. In the CrCU the discharge co-ordinator role was recently introduced to improve the timely flow of patients between CrCU and the wards by smoothing the transition process and encouraging CrCU staff to prepare patients for discharge and ensuring that ward staff are informed of the impending admission and the plan of care for that patient.¹ The CrCU outreach team provide early follow-up to patients for 24 to 48 hours after transfer from CrCU, with patients occasionally receiving more prolonged visits if they are at risk of clinical deterioration. The outreach team mostly consists of senior nurses with a CrCU background and, more recently, a CrCU physiotherapist. The outreach team’s main remit is assessment of the physiological status of the patient and monitoring for indications of deterioration. The development of CrCU follow-up by the outreach team locally was driven by a quality standard to reduce the number of patient readmissions to CrCU in the first 48 hours following transfer to the ward and an emphasis on identifying clinically deteriorating patients.

¹ The discharge co-ordinator role was not established when the cohort of patients for this study were patients on CrCU.

The critical care in-reach service was set up to provide psychological care to patients on the CrCU and in the ward setting and is provided by the CrCU psychologist who also manages the psychological aspects of care in the CrCU follow-up clinic. Patients are referred to the psychologist either directly by CrCU staff or by a formal process of referral completed by CrCU or ward-based staff. Patients can have one or multiple visits with the psychologist during their hospital stay depending on their needs.

The CrCU follow-up clinic is an outpatient clinic for patients run by a CrCU nurse and the clinical psychologist. Patients with a CrCU stay of four days or more receive a letter of invitation to attend on an 'opt in' basis, where the individual patient decides whether they would like to ring to arrange an appointment. The patients attend clinic around three months following their discharge from CrCU. The clinic appointment includes psychological assessment tools based on identifying anxiety, depression or symptoms of PTSD and a review of the patient's general condition and recovery progress. Patients are also offered the opportunity to address any memory gaps of their stay in CrCU and given the option of revisiting the unit. The consultant lead for follow-up and nurse lead for follow-up have responsibility for service delivery but only the nurse lead is part of direct service delivery.

A CrCU support group is a meeting run by a CrCU nursing sister and ward clerk for former CrCU patients and their families. The idea for the group came from a former patient who was involved in the initial set-up and ran several of the meetings. The meetings are held at the hospital once every six to eight weeks and patients and family members can attend the group meetings as frequently as they wish to discuss informally with other patients and families their experiences of critical illness and recovery. The recovery pathway is shown in Figure 3.3.

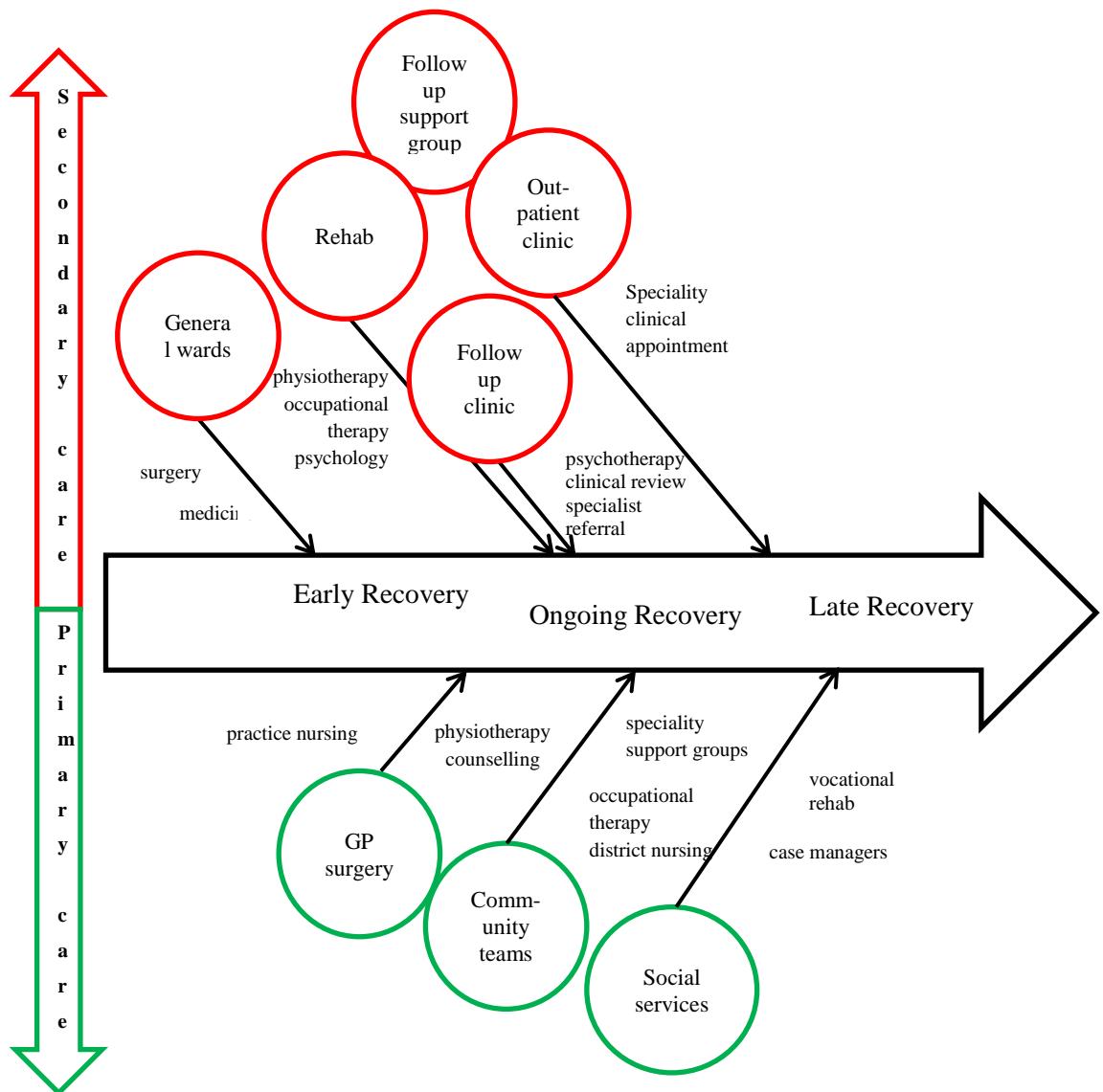


Figure 3.3 The recovery process

3.7 Sample and Recruitment

3.7.1 Patients

The sample to be included in this study involved patients with a range of critical care experiences. Capturing patients at a range of time points was intended to allow a picture of their experiences over time to emerge and any meaningful experiences patients shared to be explored (e.g. the development of physical and psychological symptoms, cognitive and functional impairments, and social difficulties such as delayed return to work and decline in economic and social status). The intention was also to capture variation in patient demographics and characteristics (length of time since

hospital discharge, age, length of CrCU stay, availability of family support, type of admission (e.g. planned, emergency). Initially patients were selected based on convenience and anyone who was eligible and interested in participating was recruited. The intention was that following this initial approach, patients would be sampled to provide a balance between two patient groups, less than 12 months post CrCU discharge and greater than 12 months post CrCU discharge. Patients were screened based upon the inclusion and exclusion criteria shown in Table 3.1.

Inclusion Criteria	Rationale
1 – 48 months following CrCU discharge	To capture a wide trajectory of recovery experiences
Full mental capacity	To enable informed consent process and participation in narrative interviews
Aged 18 years and above	Adult critical illness scenarios and recovery process differs from paediatric clinical scenarios and care pathways
> 4 day stay in CrCU	To capture critically ill patients most likely to require care and support post CrCU
Exclusion Criteria	Rationale
< 18 years old	Adult critical illness scenarios and recovery process differs from paediatric clinical scenarios and care pathways
< 4 day stay in CrCU	To exclude uncomplicated elective surgical patients who are unlikely to have longer term recovery problems
Palliative patients and patients with a poor prognosis	Patients follow a different post CrCU care pathway to recovering patients

Table 3.1 Inclusion and exclusion criteria

Due to the unpredictability of patient interest in participating in the study, a comprehensive strategy was devised to support the identification and recruitment of potential patients from follow-up clinics, a patient support group and the CrCU. The strategy is shown in Table 3.2.

Strategy 1	CrCU Follow-up Clinic
Practice	<ul style="list-style-type: none"> • Patients with CrCU stay \geq 4 days invited to follow-up clinic • Appointment letters routinely sent 2 to 3 months following CrCU discharge • Appointments usually attended 3 to 6 months following CrCU discharge • Patients with ongoing issues may have more than one appointment • Patients sometimes cancel or do not attend appointments. The reasons are not routinely investigated or recorded • Patients with continuing illness/prolonged hospital admission may not be seen in clinic for several months following CrCU discharge
Recruitment	<ul style="list-style-type: none"> • Clinic office staff send a study letter of invitation and patient information leaflet giving full study details with routine clinic

	<p>appointment letters</p> <ul style="list-style-type: none"> In addition, clinic office staff send a letter of invitation and patient information sheet to all former patients who were eligible to attend follow-up clinic over the past three years to capture patients who may or may not have attended clinic If there is a low response rate to the letters of invitation, prospective patients will be reminded of the study by the follow-up clinic nurses or psychologist/psychotherapist when they attend their clinic appointments and details given of how to contact the researcher
Objective	<ul style="list-style-type: none"> Likely recruitment into < and > 12 month groups Sending out the study information to all prospective patients invited to attend the clinic, and retrospectively to patients invited over the previous 36 months should to recruit a sample of clinic attenders and non-attenders
Strategy 2	CrCU Patient Support Group
Practice	<ul style="list-style-type: none"> 6-8 weekly patient and family support group held at hospital Patients invited by CrCU staff and/or via Critical Care Network in Northwest Group also welcomes patients and families from other hospitals around the Northwest Patients range from 1 month to several years following CrCU discharge and attend once or several times CrCU staff facilitate group meetings together with a former patient who was central to its set-up Northwest critical care network publicise meetings on website
Recruitment	<ul style="list-style-type: none"> Researcher also to attend group to raise awareness about the study and address any questions from interested patients and family members Study leaflets and patient information sheets provided at each meeting
Objective	<ul style="list-style-type: none"> Likely recruitment into < and > 12 month groups The support group will allow recruitment of patients discharged from CrCU up to several months or years following CrCU discharge and will include a mixture of patients who have and have not been invited to critical care follow-up clinic
Strategy 3	CrCU Inpatients
Practice	<ul style="list-style-type: none"> Current CrCU inpatients Patients stabilising from acute phase of critical illness without treatment limitations or withdrawal status and anticipated to recover and to be discharged to the wards
Recruitment	<ul style="list-style-type: none"> CrCU nurses asked to identify patients who are potentially eligible for study and appropriate to participate using inclusion and exclusion criteria CrCU research nurses embedded on the unit will give appropriate patients a letter of invitation to participate in the study and a patient information leaflet Patients left details about how to contact the researcher if they wish to participate Patients can be recruited prior to hospital discharge and informed that they will be contacted by the researcher for interview within a 12

	month timeframe, depending upon the characteristics of the sample recruited using recruitment strategies 1 and 2
Objective	<ul style="list-style-type: none"> • Should capture patients who both attend and do not attend CrCU follow-up clinic • Most likely recruitment into < 12 month group

Table 3.2 Recruitment strategy

Whilst convenience sampling was intended only as an initial stage, there was a good patient response to the first batch of information letters sent out to patients. The patient information sheet is shown in Appendix 3. Upon briefly discussing the patients' characteristics and experiences over the phone prior to recruitment, there was sufficient variation to allow an initial 10 respondents to be recruited. When patients expressed an interest, either by telephoning or emailing the researcher, the study was discussed with them to answer any questions and go through the patient information sheet with them. Interviews were conducted in the clinical research facility at the hospital Trust or in the patient's own home. Written informed consent was taken on the day of interview.

3.7.2 Healthcare professionals

Using a convenience sampling approach a sample of up to 10 healthcare professionals was considered suitable to generate a broad spectrum of experiences from a variety of staff (e.g. nurses, doctors, psychotherapists and/or psychologists, physiotherapists, healthcare assistants) in different settings (e.g. general wards, follow-up clinics). Posters within clinical areas and information posted on the hospital intranet website were used to raise awareness about the study. The researcher also requested the assistance of the CrCU research nurses to raise awareness of the study amongst healthcare staff and discuss the study at staff meetings they attended. Healthcare professionals were invited to contact the researcher if they wished to participate. Nine healthcare staff with different roles and professions were recruited. Plans to recruit a tenth staff participant, a ward-based nurse, were unfortunately abandoned due to difficulties arranging a suitable time and pressures to move forward with the next stages of the study.

3.8 Data Collection Methods

3.8.1 Patient narrative interviews

Whilst there is widespread philosophical and theoretical diversity in how researchers use narrative approaches (Andrews, Squire, & Tamboukou, 2008), in practice the boundaries between the approaches overlap and can be adapted and combined

(Riessman, 2008). In structuring the interviews according to narrative methods the intent was to enable patients control over what they chose to share, whilst also allowing the literature and emerging evidence to be incorporated into the enquiry. Zeibland (2013) suggests that health researchers often combine narrative interviews with semi-structured interviews, the approach used to capture data for the DIPEx (personal experiences of health and illness) project. In this current study, a similar interview approach was used. Whilst there were plans for patient interviews to be videoed, audio recorded or for hand written notes to be taken, all the patients consented for their interviews to be videoed. Consent was also taken to allow the use of the filmed interviews for the co-design process, and also for education purposes.

The interview process required the researcher to purchase and learn how to use filming equipment in order to capture high quality videos of the patient interviews. The equipment was financed through PhD funding. The researcher consulted the EBCD resources on the King's Fund website and attended an EBCD training session to learn the practical aspects of how to film interviews (now available on the Point of Care Foundation website, <https://www.pointofcarefoundation.org.uk/>). For interviews conducted at the hospital, the filming equipment was set up prior to the patient arriving for interview, and lighting conditions optimised by arranging the equipment near to large windows to optimise the natural light. Patients were advised to avoid wearing highly patterned shirts or jumpers as these appeared to move around on the camera and distract from the dialogue of the interview. 'Do not disturb' signs were placed on the door to prevent inadvertent interruptions. Patients were initially invited to tell their stories of recovery from critical illness and the care they received, free from interruption from the researcher. In order to reduce interviewer disturbance on the patient experience film, the interview process allowed the patient to speak at length without interruption. This technique was useful for identifying patient touchpoints as the patient was given the opportunity to speak at length about poignant moments during critical illness and recovery. The capture of these very emotive moments on camera, which were often associated with expressive body language, assisted the researcher in understanding the degree to which key events and experiences had impacted patients. In addition, filming the narrative interviews provided an illustration of the recovery process which was used to inform how patients are impacted and respond to issues during recovery.

Narrative interviewing intends to create detailed stories rather than short answers and statements, and this requires a different approach to interviewing than the conventional

brief question and answer style (Riessman, 2008). To achieve this intention, the researcher established a climate which allowed stories to flow by briefing patients prior to interview that they were free to speak for longer periods than in everyday conversational situations (Riessman, 2008, p. 23). For Riessman (2008), this requires the researcher to adopt a conversational approach, giving up control of the interview to follow the patient where the conversation leads, being emotionally attentive and engaged, and reciprocating in the conversation. Filming the interviews really helped this process as interruptions were minimised to help the film editing process following the interviews. In EBCD, the narrative interview elicits the patient's experiences of care and is based flexibly around a temporal account of their illness and recovery story (Bate & Robert, 2006). As the story is recounted, particular 'touchpoints' (good or bad moments that shape patients personal experiences of the service) can be explored using minimal prompting. Additional questions followed the narrative part of the interview, based on points raised by the patient during the interview or themes identified in the literature review. These questions were focussed on patients' perceptions of how their recoveries were progressing, such as any high and low points they experienced, important stages of recovery and what they found to be helpful or felt could be better. The interview guide for the patient interviews is shown in Appendix 4.

3.8.2 Healthcare staff semi-structured interviews

EBCD methods elicit the experiences of both patients and staff in order to engender a truly collaborative and fully-informed co-design process. Interviews with staff about their experiences of caring for former CrCU patients and their opinions of how they feel patients experience the service can reveal new touchpoints and help in highlighting themes to raise in ongoing patient narrative interviews (Bate & Robert, 2007). For Bate and Robert (2006) the experiences of both service givers and service receivers are equally relevant and important. Involving staff in EBCD early in the process helps familiarise them with the EBCD concept, builds trust and goodwill for the project, prepares them for change, and helps them to understand their role in making it happen (Bate & Robert, 2006).

Varying shift patterns, busy work schedules, time-pressure due to staff shortages and high patient turnover place considerable demands on healthcare staff in hospital settings. For this reason, a semi-structured interview approach was selected for the staff interviews. Using this approach, a balance was achieved which addressed the research questions whilst allowing staff freedom to introduce their own ideas. The semi-structured approach also allowed scope for brief and general answers to be given

alongside more detailed accounts where more focus and insight was necessary. Individual interviews were arranged to fit in with staff schedules and located conveniently in healthcare settings but away from the immediate workplace which allowed staff to relax and remain uninterrupted during the interviews.

The focus of the staff interviews was to understand the service they delivered, for them to share their experiences of caring for former CrCU patients and to capture their views on how they felt the service was experienced by patients. In addition, staff understanding of the whole recovery process of critically ill patients was explored. The interviews were intended to give staff the opportunity to discuss freely the topics they felt were appropriate, whilst ensuring that the issues identified through the literature review and arising from patient interviews were addressed.

Each patient and staff interview was fully transcribed. An application for an amendment to the original protocol was made to the ethics committee to allow for external transcribing of the interviews as time constraints prevented the researcher from performing the transcriptions.

3.9 Data Analysis

In this section, the data analysis process for the patient and staff interviews is presented, together with the development of the patient experience film. The analysis process for the patient feedback event and joint patient and staff event is described in chapter 6.

Schwandt (2015) describes data analysis as a process of understanding, interpreting and theorising which involves moving back and forth between data and ideas. This process involves breaking down the data into constituent parts and then determining patterns within these parts which are interpreted by the researcher and used to answer the research aims (Schwandt, 2015). The ultimate task for any research project involves identifying the larger story that the whole data set is telling (Zeibland, 2013).

3.9.1 Thematic analysis

The method of analysis for the patient and staff interviews was a progressive process, which developed in response to the data sources and the aims and objectives of the research. As such, the approach to analysis was informed by a range of sources in order to understand and capture the findings from narrative interviews, semi-structured interviews and video recordings. The coding process was informed by 'The Coding Manual for Qualitative Researchers' (Saldana, 2012) which particularly helped in

understand the types of coding that could be applied to the data. For example, ‘versus’ coding could be used to help to identify experiences of disparity or conflict (e.g. patient vs doctor) which helped in developing the themes around loss of autonomy and control. Another example was ‘emotion’ coding which identified patients’ expressed emotions and helped to categorise positive and negative events and facilitated the development of the emotional grid (see chapter 6) used at the patient feedback event.

As the patient interviews were narrative in approach, narrative analysis methods were reviewed. Riessman (2008) discusses four approaches to analysis of narrative interviews. Firstly, thematic narrative analysis which analyses ‘what is spoken.’ Structural narrative analysis examines ‘how’ stories are told with an emphasis on form and language. Dialogic/performance analysis looks at the interactive construction of speech by the researcher and participant or the active performance of the participant (by plays or poetry). Finally, visual analysis involves the interpretation of images (photographs, photovoice – participant guided films, participant artwork) alongside words. Review of these approaches suggested that none of these methods was entirely appropriate to meet the research aims and objectives. Although this study used patient stories, the EBCD methodology is focused upon identifying the priorities for redesign of services based upon the emotional impact of patients’ interactions with the services and staff they encounter.

Further exploration uncovered the data analysis process described by Ziebland and McPherson (2006). This approach was used to analyse the filmed interviews of patients on the healthtalkonline website. This included analysis of both transcripts and film, incorporated within a thematic analysis approach and was used to guide the analysis of the patient and staff interviews and the editing of the patient experience

film. This process is summarised in Figure 3.4.



Figure 3-4 Data analysis based on Zeibland & McPherson (2006)

This process was undertaken using the Atlas Ti a computer assisted qualitative data analysis software package (CAQDAS). CAQDAS was used to assist qualitative data analysis. The original intention was to use NVIVO for the management of qualitative data but, following attendance a CAQDAS training course, Atlas Ti was recommended for working with film, audio and transcripts simultaneously. No local courses were available for Atlas Ti so the analysis was informed by an Atlas Ti Qualitative Analysis Manual (Friese, 2014) to support the use of the software. Video training sessions on the Atlas Ti website (<https://atlasti.com/>) and on Youtube were also utilised.

Analysis of the healthcare professional interviews followed a similar process of thematic analysis to that described above, with audio recorded data rather than filmed materials also being transcribed verbatim, and a coding and axial coding process using the same computer software programme undertaken.

The researcher analysed the data using the CAQDAS programme for data management. Analysis generated initial codes, and these were collapsed into a smaller number of codes and the meaning of each code was described. The CAQDAS programme also facilitated the one sheet of paper stage of the coding, wherein the researcher collated all the patients quotes and notes relevant to each code together under each individual code. At the axial coding stage, the researcher adopted a more 'hands on' approach to identify broader themes and patterns in the data, as illustrated in Figure 3.5.

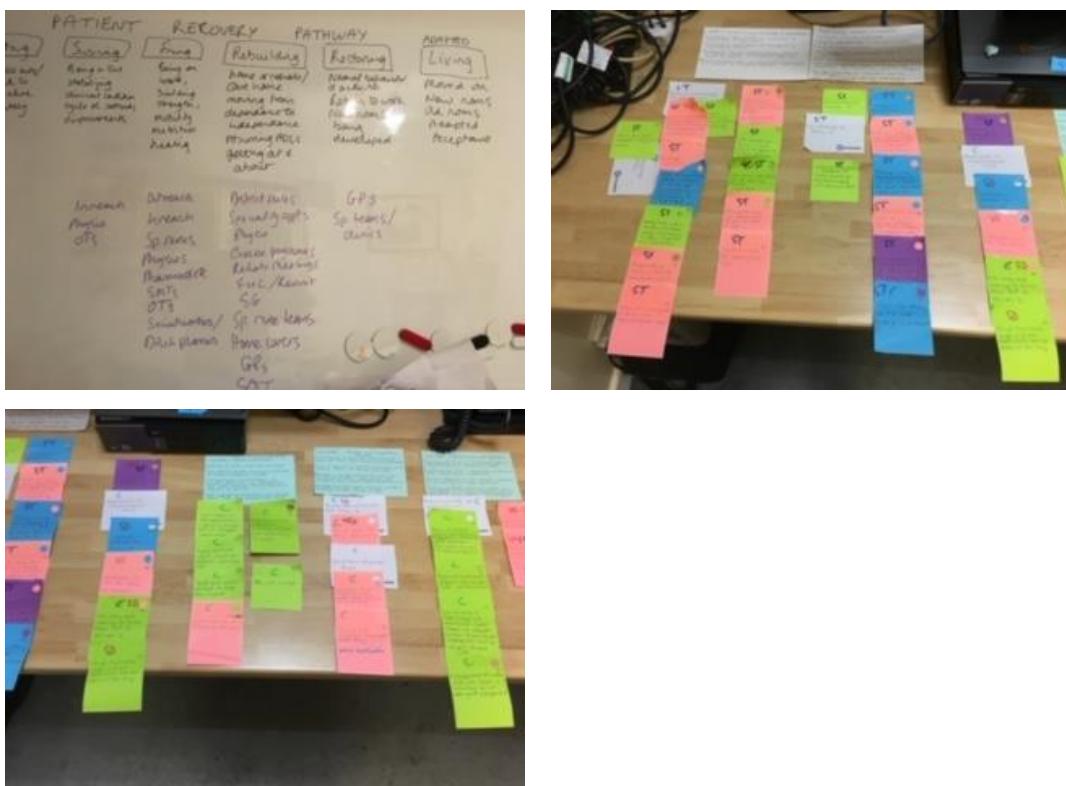


Figure 3-5 Manual development of major and minor themes

The staff interviews were analysed first as they were shorter and comprised only transcripts without films. The first round of coding generated over 400 codes, and the low frequency codes were condensed into broader codes in a second round of coding. The study objectives for the staff interviews were specifically to explore and describe the experiences of staff who cared for patients following discharge from CrCU. However, the staff interviews generated a wide range of topics as staff members had different roles and experiences and the researcher was supported by the supervision team in identifying a basic framework to structure and make sense of the data. The framework was developed by revisiting the whole transcripts and re-reading through them to uncover the broader themes in the interviews. This process identified a number

of broad themes, which then facilitated the grouping of the data into major and minor themes, together with key quotes that illustrated these themes. An example is shown in Appendix 5.

Initial attempts to analyze the first patient interview simultaneously with the film data to try and identify touchpoints proved to be a difficult and time consuming process. Subsequently, a more practical approach was taken which involved analysing the interview transcripts first to describe the codes and identify key themes in a similar manner to the staff interviews. Within these key themes, the patient touchpoints were then easier to determine and illustrations of these could be easily cross referenced to the appropriate sections in the patient films. It was clear from the initial coding of the first three patient interviews that there was a vast wealth of codes and information arising from the interviews with over 500 initial codes. This stage of the analysis was challenging as the researcher wanted to honour all the stories, information and experiences shared by the patients yet also needed to meet the research aims and objectives. Following completion of the initial primary coding of the first three patient interviews, the codes were collapsed and merged. This enabled more focused coding of the remaining transcripts and reduced the incidence of "messy" coding that had occurred by labelling the data with similarly themed codes under slightly different names. Care was taken not to mislabel or miss the nuances of the codes in this process. Subsequent viewing of the patient films enabled confirmation of the emotional impact and, in some cases, added to the depth of meaning and relevance of the codes to ensure that the written transcripts accurately captured the significance of the experiences. This process enhanced the understanding and analysis of the transcripts.

An observation from the process of analysis of the patient data was that patients tended to understand and retell their experiences from the point their critical illnesses began even though they were asked to discuss their recoveries. For all patients, this appeared to set the context for their critical illness and recovery stories. The process of collapsing, merging and categorising codes identified the major themes from the patient interviews. Key themes appeared that were associated with memories, real and constructed, and the different focuses patients have at different stages of their recovery. At this stage, the conceptual themes surrounding the patient recovery journey emerged, initially labelled 'living,' 'fighting,' 'surviving,' 'fixing,' 'rebuilding' and 'adapted living.' At this stage of the analysis the emerging themes and similarities in storytelling approaches used by the patients suggested a key idea for presenting the findings of the patient interviews in the form of a recovery journey, with touchpoints

representing the key events and experiences for patients along the journey. This approach in essence reformed the patients' stories into a recovery narrative and complimented the objective of developing a patient experience film to represent the experiences of recovery. These themes were further consolidated into four major themes together with a number of minor themes, and are presented in Chapter 5. The process of developing the touchpoints from the patient recovery journey is described in Chapter 6 as it evolved in preparation for the patient feedback event.

3.9.2 Edited patient film

Following the textual data analysis the patient videos were edited to produce a short film that clearly and emotively exemplified the 'touchpoints' of the patient recovery journey. In editing the patient interviews the objective was to find the significant events (the highs and lows) in the patients' narrative accounts. The editing process is intended to tell a story of the patients' experience of care within a service (Adams, Robert, & Maben, 2015). As the purpose of the film is to trigger engagement and reflection in the audience it needs to be concise, intelligible, have aesthetic quality and emotional appeal (Adams et al., 2015).

In undertaking the editing process a number of varying patient accounts needed to be included to illustrate each touch point. This creates a film which includes many patient voices and an assortment of views, thus ensuring that the film is not dominated by one participant or viewpoint (Adams., et al, 2015). This process takes careful consideration as some people are more charismatic and articulate in their descriptions of care experiences than others (Adams et al., 2015). At the end of the process there should be an illustration of the key stages of the patient journey and the touchpoints associated with this journey.

The film was edited from over 15 hours of video recordings of the patient interviews and designed to give staff a deeper understanding of the emotional and practical impact of each touchpoint. This was an iterative process which involved using the patient interview analysis, the patient videos and the interview transcripts. The interview analysis was used to identify all the important touchpoints that should be included. Then a combination of reading the interview transcripts and watching the video recordings was used to find clear examples of key touchpoints and identify highly emotive illustrations of these. The editing was completed using the iMovie software package on a Macbook computer. Each patient film was loaded onto the computer and relevant sections were cut from the whole until a shorter film for each patient remained

in the software programme. Then each touchpoint was illustrated by combining film clips from several patients. Several drafts of the film were repeatedly edited until a final 30-minute film was completed which included clips from all the patients interviewed.

Once the film was completed, each of the patients who appeared in the film were contacted to offer them the opportunity to view the film and to request permission to use the clips. All participants provided written consent to use their clips. Four of the patients were visited in person and shown their video clips; all were happy for any parts of their interviews to be used in the trigger film. The remaining participants did not find it necessary to view their clips and were happy for any of their video footage to be used for the film.

3.10 Ethical Considerations

The protection of study participants necessitated National Research Ethics Service, university and hospital Trust approvals to be in place before any research related activity commenced. A copy of the research ethics approval is shown in Appendix 6. As this study primarily employed qualitative interviews the framework outlined by (Brinkmann & Kvale, 2015) was used to reflect on, and justify, ethical decisions made in this study. The framework specifies a number of questions to be addressed in four main topic areas: informed consent; confidentiality; consequences; and, the role of the researcher.

3.10.1 Informed consent

Two principles guide the informed consent process; individual autonomy and beneficence. The intention is that when people are invited to take part in research study they are entitled to know exactly what taking part will involve for them and what the study intends to achieve (Brinkmann & Kvale, 2015; Locke, Spirduso, Silverman, & Fund, 2007). The researcher must respect the autonomy of potential participants in deciding if they wish to participate (Gelling, 1999).

For the purposes of this study, all participants were fully informed in person and in writing about what the study involved, specifically: why it was being conducted; what their contribution involved; possible risks and benefits to participation; how their identity and information would be handled confidentially; the voluntary nature of their involvement and that they could decide to withdraw at any time. Due to the interactive nature of the study, which had both data capture and service improvement aspects,

only participants with full mental capacity were included and written informed consent taken prior to beginning any study procedures.

Due to the multiple layers of involvement for patients and staff, their consent to continue was reconfirmed each time they were scheduled to take part in a study related activity. Participants were reassured that they could discontinue their involvement at any time and in such circumstances would be asked permission to use any information collected up until the point of data analysis. If patients wished to withdraw, it was made clear that their information would be removed and destroyed. However, participants were informed that following data analysis their individual data would be integrated with the whole dataset and it would not possible to remove their contribution.

The filmed materials were potentially a rich and valuable resource for informing and educating staff and future patients on the patient recovery process, in particular the difficulties they faced and their ways of coping and moving on. In view of this, further permission was sought to use sections of the patients' films as training materials for staff or supportive information for other patients and family members. The intention was to inform healthcare professionals and future patients and family members about a patients' whole recovery process, how their experiences of care affected their recovery and their insight into how they coped. In order to do this, sections of the filmed materials could potentially be used within hospital, university or CrCU network media such as magazines, intranet and websites and in publications. Patients were informed about this supplement to the research study when they were initially recruited and were given the option to participate in the study with or without the supplementary aspects. Written consent was secured from patients for the use of filmed materials for the EBCD service improvement process, and where permitted, written agreement was secured for their use in the supplementary aspects of the study.

In order to avoid coercion of patients to participate in the study, a direct approach was not made by the researcher. Instead, patients were informed about the study by members of the clinical teams and by information presentations, leaflets and letters. If patients were interested in taking part they were given the contact details of the researcher and advised to express an interest and obtain further details. The researcher was not directly involved in the care of the patient population for this study. Whilst the researcher had worked professionally with some of the staff participants in a prior role, (such as the CrCU outreach and follow-up staff), no professionally

acquainted staff members were directly managed by the researcher, thus limiting the potential for coercion to participate.

3.10.2 Confidentiality

It is a usual principle of research practice that participants have their identities protected and their data anonymised (Brinkmann & Kvale, 2015; Locke et al., 2007). This study centred upon the collection and analysis of qualitative interview data. This meant that during the transcribing and reporting processes, care was needed to protect the identity of participants by anonymising the transcripts. Exerts and direct quotations from the transcripts will be used locally in educational and healthcare settings, and more widely in at events and conferences, and submitted for publication in peer reviewed journals, so care will be taken to ensure that these remain anonymised.

Taking part in the interviews and the use of filmed materials for study and supplementary purposes could also result in the identification of patients by subsequent audiences. In addition, to ensure there was complete clarity regarding uses of the filmed materials during the recruitment process, every effort was made to limit the degree of trespass into the patient's privacy during editing of the films and ensuring personal details were not divulged. It was necessary to hold patient personal contact details to make arrangements for participation in the various aspects of the research process. These were held securely on a password protected Trust computer and only accessible to the researcher. All participants were given a study number and pseudonyms for the purposes of transcription.

3.10.3 Consequences

Research needs to be conducted in accordance with the principle of non-maleficence that obligates the researcher from causing harm to others (Beauchamp & Childress, 2013). It is important that all participants in a study understand the possible risks and benefits to them from taking part (Creswell, 2013; Brinkmann & Kvale, 2015). The researcher needs to recognise their entry into the participant's personal life is an act of 'informed cooperation' and be especially respectful of the risks posed by the chatty, informal or intimate atmosphere of qualitative interviews (Locke, Spirduso & Silverman, 2007, p. 30-31). They also need to remain mindful of the power imbalances that exist between the interviewer and participants which can make it easy for the interviewer to define the content and control the interview process (Creswell, 2013, Brinkmann & Kvale, 2015). Part of managing these potential risks to participants is being aware that they can happen in order to recognise and pre-empt their occurrence during the

interview process. Judging the balance between empathy and candour when dealing with distressed patients, their families and staff members has been a feature of the researcher's professional background in CrCU nursing. This experience helped in dealing appropriately and ethically with patients and healthcare professionals during the interviews.

One risk to participants lies in their disclosure of more information than intended, which they may later regret. The researcher is faced with the balance between appearing sensitive and running the risk of inviting even more intimate or distressing confessions, or appearing aloof, and gaining only preliminary or superficial material (Brinkmann & Kvale, 2015). There is a further threat to participants' privacy if highly sensitive or personal material could reveal their identity when their account is made public through report or publication. Participants had the opportunity to stop, edit and delete their film or audio recording and to review their films and transcripts prior to co-design events to enable removal or clarification of sensitive, highly personal or unfavourable material.

Retelling their critical care and recovery experiences was an emotional experience for patients. A sensitive interviewer may unwittingly invite a therapeutic relationship with the participant in which they are expected to provide support they are not qualified to give (Brinkmann & Kvale, 2015). When patients became distressed during the interviews they were given time to stop and recover their composure. They were reassured that they could postpone or withdraw from the interview if they wished, though all of the patients were happy to continue with the interviews. Patients were also advised that arrangements could be made for an appointment with the CrCU psychotherapist or their GP if they wanted further psychosocial support. The researcher made an appointment with the CrCU psychologist for one of the patients and followed up on their situation whilst making arrangements for the patient feedback event.

As the co-design approach centres upon prolonged interaction between patients and healthcare professionals, who all bring their own experiences and opinions to the process, there could be disagreement or conflict, and a risk of power asymmetry between healthcare professionals and patients which restricts patient-centric improvement. One important aspect of the process was that the patient feedback event took place prior to joint patient and staff event. This allowed the patients to bond as a group and view the film in a non-threatening environment, and to become comfortable with the co-design process and activities in preparation for engaging with staff (Bate &

Glenn, 2006). Similar numbers of patients, families and staff were represented at the meeting and tables arranged so that a balanced number of patients and staff were seated at each. This endorsed the atmosphere of partnership. In addition, three facilitators were available at the meeting and on occasion ensured that the patients' and families' voices were heard if staff appeared to misunderstand a point or change the subject.

Beneficence is an ethical principle which, in essence, is about doing good to others (Beauchamp & Childress, 2013). Creswell (2013) discusses the importance of reflecting how participants will gain from research studies and how it is possible to give back to them for their time and effort. Whilst it was made clear to patients and staff that participation in this research was not intended to benefit them, both patients and healthcare professionals reported benefits from their involvement in the service improvement activities. In previous EBCD projects patients valued being able to discuss what they wanted to say and in being part of change process itself, which was both empowering and rewarding (Bate & Glenn, 2006). Healthcare professionals also valued being able to work alongside the patients, building up a good relationships and working with them as equals (Bate & Glenn, 2006). This study endorses these findings. Some patients reported their involvement as therapeutic, helping them to find closure, to reframe their experiences and to feel validated by their interactions with supportive peers. One patient reported the value of the sessions with the clinical psychologists that was arranged through participation in the study. Patients also reported being given information which answered long-standing questions. Conversations between the researcher and staff who attended the meeting suggested an overwhelming appreciation for being involved. The patient staff event gave them a rare opportunity to receive comprehensive feedback about care and services and a number of staff have continued to involve the researcher in developing plans for service improvement work.

3.10.4 The role of the researcher

Creswell (2013, p215) indicates that qualitative researchers bring their 'cultural, social, class and personal politics' to the research process. These positions need to be made explicit and their influence upon the research considered and described (Denzin & Lincoln, 2008). This process, known as reflexivity, directs the researcher to discuss their experience with the research topic being explored and how these experiences shape their interpretation of the findings (Cresswell, 2013). Engaging in action research is in itself a continual process of evaluation and reflection on practice together with the development of theory based on application (Koshy, Waterman, & Koshy, 2010).

Reflexivity is a significant element in establishing the validity of a project (Koshy et al., 2010).

The researcher works as an academic researcher within an NHS Trust, and had previously been a CrCU nursing sister in the Trust in which this study was undertaken. The role of academic research nurse allowed the researcher to design and support a further EBCD study within the hospital Trust in the specialism of chronic pain. Whilst undertaking this PhD has undoubtedly influenced the use of the choice of this methodology in the chronic pain project, undertaking an additional project has provided the researcher with further practical experience of using the EBCD methodology.

Being a practitioner and a researcher can influence the interpretations the researcher makes and create biases which may affect the research process (Koshy et al., 2011). As a researcher with a background in CrCU nursing, it was important to acknowledge and continuously reflect on the ways in which this influenced the choices made in conducting this study. Reflexivity was achieved in a practical sense throughout the study through the process of PhD supervision and self-reflective process of research memo writing during the study. The researcher had no direct experience of providing care for patients following discharge from CrCU but some understanding that the care and treatments received in the CrCU setting could influence the longer term health and well-being of patients. In essence, the researcher was familiar with the patient group, but unfamiliar with the topic of the research.

3.11 Assessing Trustworthiness

Debate exists as to whether credibility matters in qualitative research (Silverman, 2001). Different qualitative researchers pose varying perspectives on the importance of validation in qualitative research (Creswell, 2013). The criteria to choose for evaluating the trustworthiness or ‘goodness’ of a qualitative study can stem from the epistemological position (Miles, Huberman, & Saldana, 2014). Even the terminology surrounding the ‘validation’ of qualitative research varies amongst researchers (Creswell, 2013). However, Miles et al. (2014) emphasise that as social research affects people’s lives, it should be subject to scrutiny and suggest five overlapping issues to be addressed when assessing the trustworthiness and authenticity of naturalistic research and these are presented in the following section.

3.11.1 Objectivity

The area of objectivity is concerned with researcher bias and being explicit about the possible bias which exists in the study. To address this issue, this study has selected a clearly defined methodology and described in detail the methods employed in carrying out the study, including any adjustments made to the methods. A clear and linear sequence is presented to demonstrate how the data were collected, processed and analysed and data examples which illustrate the findings are clearly illustrated in each findings chapter. Researcher reflexivity enhances confirmability and has been described in the previous section. The data, including video and audio recordings have been retained in agreement with the study approvals, together with electronic data and manual analysis documents.

3.11.2 Reliability

Reliability addresses issues about the quality and integrity of the study over time and considering changes to the practice setting over the timeframe of the study. The study methodology and design was reviewed within academic, NHS and health research ethics organisations for scientific rigour and approved within each organisation prior to commencing the study.

Lincoln and Guba (1985) recommend that the study methods and procedures are described in adequate detail to be audited by an outsider. The researcher has described the study process and decision-making extensively. The supervisory team for this PhD study have provided guidance, validation and debriefing throughout the study, and supervisor notes provide an extensive audit trail of the research in addition to the memos and notes taken by the researcher and the annual progression documents that summarise each year's research activity in detail. The study supervisory team have been instrumental in ensuring that data collection, analysis and interpretation have been carried out in accordance with the study protocol and consistently throughout the study timeframe.

Staff role changes meant that some of the original staff interviewed were unavailable for the joint patient and staff event. The members of staff who replaced them were invited to attend instead. Any changes made to the original intentions of the study have been clearly outlined and explained.

3.11.3 Credibility

Credibility is concerned with whether the findings are credible and make sense to the readers. Triangulation of methods and member checking are methods that increase the

credibility of the findings (Lincon & Guba, 1985). In this study triangulation involved using multiple sources of data, from all three phases of the study. The progressive nature of the phases meant that the findings from the patient and staff interviews were ‘sense checked’ at the co-design event.

Patients were sent the touchpoints identified from the data analysis to review prior to the patient meeting and advised that they could add to or edit the list if they felt anything was missing. Some patients also viewed the chosen video clips prior to the patient meeting and this confirmed that the researcher had identified meaningful experiences and events. The touchpoints captured in the narrative film, which originated from the qualitative data, produced an obvious emotional resonance with patients and staff.

The findings were presented in themes and subthemes to ensure separation and understanding of key concepts with accompanying quotations to demonstrate the origins of the data. Negative evidence and rival explanations were also sought. For example, the data relating to patients’ autonomy, loss of control and learned helplessness was also considered in relation to the theme of ‘resilience,’ but the data did not support the development of this into a major theme. Emergent themes from the initial coding were not pursued if they could not be shown to be adequately captured in the data. Comparison of the findings with wider literature showed that the findings aligned, albeit with some originality and the discussion chapter integrates the findings with existing literature.

3.11.4 Transferability

Transferability is associated with providing ‘thick’ description, that is description that is meaningful and context-rich (Geertz, 1973) and allows the reader to understand how the findings might apply to settings other than the research study setting (Guba & Lincon, 1985). The study setting is described in detail in this chapter and the characteristics of both the patients and the staff are described in the relevant findings chapters to allow comparison with other studies and also to demonstrate the degree to which the sample represents the wider patient group (namely survivors of critical illness). Descriptions of the staff roles and experience allow judgements to be made about the remit and expertise of the opinions in the staff interviews. The sample selection was designed to capture a range of patients’ experiences albeit with recovery from critical illness being a defining and limiting characteristic. Particular mention is made of the local critical care environment as this was found to have had some impacts on patients, though all of the experiences described by the patients have been

reported in the wider literature in other CrCU environments. There are significant differences in follow-up services across the UK, so support services for patients will vary between settings and the local model of follow-up is extensively described to allow comparisons to be made.

3.11.5 Application

It is important to understand the impact of the findings of studies and what studies do for the participants. The impact and implications of this project are discussed at length in the discussion, Chapter 7.

3.12 Summary

This section has described the research framework, methodology and methods informing this study and summarised the decision-making around the selection of EBCD as the most appropriate methodology to answer the research questions. This qualitative methodology, incorporating participatory action research, was selected to provide deeper insight than previous quantitative evidence exploring the effectiveness of services during recovery by showcasing patients' experiences as a foundation for care and service provision. This chapter has described the stages of EBCD including the qualitative methods which identified key themes from patient and staff interviews. EBCD placed patients at the heart of an empowering and often therapeutic design process and created the potential to achieve informed changes to follow-up services that have remained true to the models described over 20 years ago. The next chapter describes the findings from the staff interviews. .

4 FINDINGS FROM THE STAFF INTERVIEWS

4.1 Introduction

In this chapter, findings from the analysis of the staff interview data are presented. Nine healthcare staff, whose roles carried a direct responsibility for the care of patients during recovery following critical illness, were interviewed individually as part of this research study. The characteristics of the healthcare staff participants are shown in Table 4.1, followed by a brief description of their current roles and relevant past experiences.

ID number	Profession	Role	Background
S01	Nurse	Sister in Critical Care Outreach	Long-serving sister in the critical care outreach team with previous experience as a sister on CrCU.
S02	Nurse	Sister in Critical Care Outreach	Previously role as a nurse in critical care, and a nurse educator in the Trust.
S03	Nurse	Critical Care Sister and Discharge Coordinator for Critical Care.	Discharge co-ordinator was a new role to facilitate the transfer of critical care patients to the general wards.
S04	Nurse	Consultant Nurse for Critical Care	Lead for critical care outreach team and critical care rehabilitation. Previous experience as a nurse educator and senior sister in CrCU.
S05	Nurse	Nursing Lead for Critical Care Follow-up Clinic and Critical Care Support Group, Critical Care Sister	Nurse lead for follow-up clinic and volunteer lead for Critical Care Support Group.
S06	Psychologist	Clinical Psychologist for Critical Care and Critical Care Follow-up Clinic	Provides psychological in-reach to critical care patients and lead for follow-up clinic.
S07	Doctor	Consultant in Intensive Care Medicine	Former medical lead for follow-up. Provided medical input into follow-up clinic sessions.
S08	Nurse	Sister for Follow-up Clinic, Critical Care Sister	Regular nurse input into follow-up clinic sessions.
S09	Doctor	Consultant in Intensive Care Medicine	Current medical lead for follow-up.

Table 4.1 Characteristics of staff participants

Four major themes were identified from the staff interviews, each with a range of sub-themes, as shown in Figure 4.1. The major themes were ‘planning for change,’ ‘continuity,’ ‘needs and expectations’ and ‘information provision.’

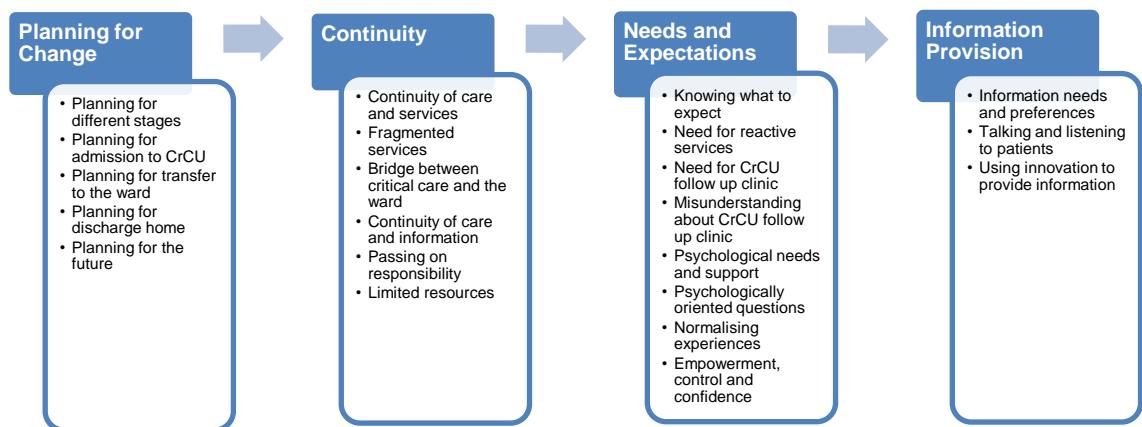


Figure 4-1 Major themes and subthemes from the staff findings

4.2 Theme 1: Planning for Change

Staff identified that, following critical illness patients experienced a series of transitions in the location of care and level of support. The importance of planning for these changes emerged as a major theme. Five sub themes associated with planning for change were ‘planning for different stages,’ ‘planning for admission to CrCU,’ ‘planning for transfer to the ward,’ ‘planning for discharge home’ and ‘planning for the future.’

4.2.1 Planning for different stages

Staff perceived that moving from one healthcare location to another made many patients feel vulnerable and unsafe and caused apprehension for both patients and families. They discussed how each stage of care required careful planning to ensure patient safety and continuing progress. Staff considered that such planning required teamwork between healthcare professionals, patients and their families. Involvement of patients in planning for their care transitions was perceived to benefit patients by giving them back some control over their circumstances and empowering them to identify and ask for help from staff in new settings:

‘It’s just about continuity and safety again, isn’t it? It’s just making them feel that they’re not just a parcel that’s just being moved around and things are being done to them, but that they’re actually a part of it...’ (S01, Outreach Sister).

Staff also felt reassured that patients would be safe in moving from higher to lower levels of care when they carefully planned for each transition. Better planning was perceived to enhance the patient's ongoing recovery progress by reducing the risk of experiencing setbacks:

"...you've got a bit more peace of mind that everybody does know what they're doing...and hopefully reducing the risk of them bouncing back to critical care, because you've put all that work in place before they've actually left." (S03, Critical Care Sister, Discharge Coordinator).

The discharge coordinator (S03) described how safe and efficient transitions required co-ordination between many members of the multidisciplinary team both on CrCU and the ward, especially for the longer stay CrCU patients. Several staff suggested that the discharge coordinator role had streamlined and expedited the planning process by early identification and preparation of patients with complex needs. The discharge coordinator suggested that such patients often had more than one speciality involved in their treatment and needed parallel plans in place:

"So it's making sure that when they leave the unit they've got a plan in place from orthopaedics, a plan in place from plastics, or a renal plan, if that's what they need." (S03, Critical Care Sister, Discharge Coordinator).

Patients with complex needs were also considered more likely to need extended physiotherapy, occupational therapy and other allied healthcare professional involvement. Several staff felt that patients had benefited from the coordination of multiple healthcare professionals in planning for changes in care. For example, one staff member thought the discharge coordinator role had reduced the number of complex patients being transferred to the ward during the night when lower numbers of staff were available to observe and manage them. Transfer to the ward meant that patients were less closely observed than in CrCU as there were fewer staff, especially during the night:

"We were still getting these complex patients who had been on the unit for 40, 50 days and then they get discharged at 1 o'clock in the morning..." (S01, Outreach Sister).

Another staff member suggested that the discharge coordinator role had increased the opportunities for patients to meet the staff who would continue to provide their care in the ward setting before they were transferred from CrCU:

"...so they [ward nurses] do come and introduce themselves to the patient. And today they actually collected the patient and took her up to the ward." (S03, CrCU Sister, Discharge Coordinator).

In addition to the processes initiated by the discharge coordinator, the outreach nurses discussed how their role allowed them to plan for the seamless transition of patients from CrCU to the ward. The outreach nurses described how they visited patients on CrCU 24 hours before they were due for transfer to assess their clinical condition and suitability for ward-based care. This process allowed them to highlight any potential risks to patients, for example frailty, agitation or fluctuating consciousness. They discussed how this initial assessment allowed them to plan for appropriate care to be in place in the ward setting or to negotiate on the patient's behalf to prevent or delay an inappropriate transfer. The outreach staff also described scenarios in which lack of planning meant that patients had been compromised. When a CrCU bed was needed for an urgent admission, preparation of other patients for transfer to the ward was sometimes hurried. This limited the time available to change CrCU based treatment and care to ward based regimes. For example, for patients on CrCU, medication may be administered intravenously whereas on the ward it would be delivered orally. Sometimes the requirement for the CrCU bed meant that patients were transferred before they had become fully stable:

"We didn't establish her on a normal insulin regime as she was discharged to the ward...and she just deteriorated very rapidly, very rapidly, and ended up coming back, [to CrCU] rather than us making a decision to do it before she went." (S04, Nurse Consultant).

Rushing the transition process in this way sometimes meant that patients deteriorated on the ward and resulted in the need to readmit them to CrCU. Both the discharge coordinator role and the outreach roles had partly been developed to prevent readmissions, yet they could not always mitigate against the consequences of rushed transfers to the ward.

4.2.2 Planning for admission to critical care

Planning for change also encompassed the patient's transition from the ward onto CrCU. Several staff considered that admission to CrCU should be a carefully planned process based on what was the right decision for that patient. The medical consultants suggested that the decision to admit to CrCU was appropriate for pre-planned surgical admissions, or when patients were normally fit and well, in order to expedite a full recovery. However, they felt the right decision was often less obvious in emergency scenarios or when patients had multiple health issues as there was more uncertainty about survival. With such patients, focussing only on survival might not be in the

patients' best interests. They suggested instead that doctors needed to consider the longer-term impact of critical illness:

"...often we just think about admitting people, getting them through intensive care and that's good enough for us, whereas actually...you're not just consigning them to a week of intensive care. You're basically saying, for the next 12 to 18 months, if you survive you're going to deal with the consequences of these illnesses and the burden of the illnesses." (S07, Consultant in Intensive Care Medicine).

One medical consultant suggested that planning for CuCU admission should happen in the earliest stages of the patient's hospital stay, before advanced treatments and interventions were started, and should be a multidisciplinary decision. They also felt the patient and family should be part of the decision-making process as they added important information about the patient's wishes and quality of life. In practice, such planning was felt to be infrequent and was typically started too late. As a result, patients were too ill to participate in discussions and relatives unavailable as CrCU referrals frequently took place in the evenings and overnight.

4.2.3 Planning for discharge to ward

All staff identified the patient's transfer from CrCU to the ward as a significant transition. They perceived this to be a big change which stirred up mixed feelings for patients. Staff discussed how patients found the ward environment to be pleasant compared to CrCU and how they felt the move meant they were making progress. However, staff also considered that the ward was a drastic change of environment for patients who had been accustomed to one-to-one nursing care on CrCU:

"I would have to say on the whole people look forward to being discharged from critical care because it's that forward step isn't it?... But it's just so very different isn't it being in a ward area to being in critical care where you can see a member of staff virtually all the time." (S02, Outreach Sister).

Most staff discussed the smaller numbers of nurses available in the ward setting which meant that patients would have to press a buzzer and possibly wait for long periods to get attention. Staff felt this was daunting for patients and made many feel vulnerable and unsafe, especially if they were still very dependent on staff. Some staff considered that hi-tech monitoring equipment and invasive access were continued for longer than needed in CrCU as they made it easier for staff to care for the patient. As a result, patients felt anxious when this continual observation was abruptly stopped for their transfer to the ward setting, and felt apprehensive about their safety:

"I think some of it is cultural, that we're in critical care, and we depend upon a monitor...and taking lines out and things, they like to keep them in because we still might need to take bloods...and it's time saving in some respect, but at the same time it's the worst thing for the patient to suddenly remove all that monitoring and then go, "Yeah, you're fine now, you can go to the ward." (S03, CrCU Sister, Discharge Coordinator).

Some staff suggested that the CrCU nurses could improve their planning for transfer by gradually reducing their close observation and one-to-one care. The discharge coordinator emphasised the importance of preparing the patient both mentally and physically for the transition from higher to lower levels of care, a process referred to as stepping down. Mental preparation centred upon open discussion with the patient about plans to move them to the ward, what happens during the transfer, the changes to be expected in the intensity of care on the ward and providing answers to any questions. Physical preparation involved reducing the frequency of observations, changing documents such as fluid charts and equipment such as intravenous pumps to the ones used on the wards, and helping the patient and family prepare for ward-based routines:

"So today, we've had a girl who has major trauma and she's been with us for 41 days, so it's took a week of preparing her for the ward, talking to her about there is going to be this transition, and she will be going to the ward, and encouraging staff to start stepping her down..." (S03, CrCU Sister, Discharge Coordinator).

Elective, post-operative patients were perceived to have a swift recovery in CrCU which meant they were sometimes moved to the ward before there was time to properly prepare them. However, several staff discussed how sometimes the transfer from CrCU to the wards was rushed because the staff on CrCU had not made appropriate and timely plans. Staff suggested this was due to a lack of awareness that they should be adjusting their activity in line with ward-based practice so that when the patient was moved, everything was ready:

"I think there's a potential lack of awareness that we should be working towards discharge[from CrCU] as soon as possible and preparing the patient and preparing family...But I think probably we underestimate the importance of the discharge [from CrCU] process and what an impact it can have on recovery." (S02, Outreach Sister).

Some staff perceived the transfer to the ward to be daunting for families as well as patients. They described how families spent long periods with patients on CrCU, often meeting many simple care needs and providing patients with company and support. Families also became acquainted with CrCU staff and other families and accustomed

to accessing regular information and updates. Family members were felt to be anxious about the patient's safety and ability to cope in the ward setting as there were fewer staff. Staff also described how ward routines and practices restricted family access to the patient, and caused the family to worry about whether the patient would receive adequate care and support:

4.2.4 Planning for discharge home

Several staff considered that planning for discharge home from the ward should start whilst the patient was on CrCU. Some staff mentioned the CrCU discharge pathway, a patient care plan that was started on admission to CrCU and indicated activities that promoted both CrCU and hospital discharge. However, they felt that in CrCU the focus was only on transfer to the ward:

"We've always sent them to the ward thinking the ward sorts out the [home] discharge, so we don't look at that, do we, from critical care? (S03, CrCU Sister, Discharge Coordinator).

Some staff suggested that patients had long waits before going home from the ward due to delays in carrying out routine, discharge related actions that could have been anticipated. Activities such as taking blood samples and ordering take-home medications were not coordinated to allow a timely discharge home and staff described how it was evening before many patients left the ward to go home. Staff also felt that GPs were not given enough consideration in discharge planning. GPs were thought to be responsible for managing patient care following hospital discharge, yet staff felt they received little useful information about the CrCU stay that helped them to make informed decisions during the patient's recovery. Whilst a CrCU discharge letter was sent to GPs when the patient was transferred to the ward, some staff considered that this might not be considered relevant by GPs compared to the ward discharge letter and could remain unread. Reiterating that the patient had been in CrCU might help the GP identify common post-CrCU problems such as fatigue, depression and PTSD. Staff also felt that discharge letters from CrCU focussed on providing information relevant to the ward staff, rather than the GPs, and that discharge letters sent out from the wards might fail to mention the CrCU episode at all.

4.2.5 Planning for the future

Many staff discussed the provision of longer term patient care and felt that planning this was even more challenging. There was a perception that there was limited availability of support to meet both physical and psychological needs in the community setting:

"I don't think there's very much out there for them at all at the moment."
(S01, Outreach Sister).

Many staff considered that CrCU staff should have continued involvement in planning and carrying out longer term care for patients:

"...we still haven't really taken on board that kind of continuum...It's making sure that these patients recover to the best of their potential, that they don't get [re] admitted, that there's things like really good handovers so that GPs get the information. That treatment episode doesn't just finish with them when they come in through those walls or leave them." (S07, Consultant in Intensive Care Medicine).

Participants discussed how the CrCU team should anticipate the patient's likely long-term needs and start to develop plans that identify and meet those needs from an early stage to optimise their chances of making an effective recovery. Speciality nurses such as cardiac, diabetic and respiratory nurses, were perceived to be involved with patients prior to their CrCU admission and to maintain care throughout the patient's recovery. However, there was felt to be a lack of dialogue between CrCU teams and speciality nurses:

"...there are a lot of nurses who are already seeing many of our patients and we probably don't have conversations with them...A lot of those people will go on to see these patients for a long time after we've [critical care team] seen them." (S04, Nurse Consultant).

Staff considered communication between CrCU and members of the multidisciplinary team was disjointed and that effective planning for patients' longer term needs required all healthcare staff to be aware of each other's input and to understand the priorities for recovery.

4.3 Theme 2: Continuity

All staff discussed the challenges associated with providing seamless care and services for patients during their recovery from critical illness. The major theme of 'continuity' emerged from these discussions. Sub themes associated with continuity were 'continuity of care and services,' 'fragmented services,' 'bridge between CrCU and the ward,' 'continuity of care and information,' 'passing on responsibility' and 'limited resources.'

4.3.1 Continuity of care and services

Staff discussed ways in which continuity of care and services were organised. One recommendation was to involve staff whose roles spanned the boundaries between CrCU and other settings:

"Just as a point of contact, as a link...somebody who is able to make contact with that patient on a regular basis who bridges the gap between them progressing down the rehabilitation route with their appropriate goals and support and resources to get them home, but it also gives them that bridge back into critical care to be able to say, 'I'm still having a dream about such and such,' or, 'I still get worried about such and such,' or whatever it is that's bothering them." (S04, Nurse Consultant)

Staff described how the roles of the outreach nurse, the clinical psychologist and the discharge coordinator could bridge some of the gaps between CrCU and the ward. The outreach nurses visited the patient, and often the family, the day before they were moved to the ward to discuss the additional support they would provide for the patient until they were stable on the ward. They reflected that anecdotal feedback suggested patients were pleased with what they perceived to be a special service just for them. Staff discussed how patients appreciated seeing a familiar face who they felt comfortable in asking questions about their CrCU experiences or sharing concerns about care on the wards. They were also reassured that their clinical condition was being monitored and assessed for signs of deterioration, which helped them to feel safer in the ward setting. They were also reassured that their care was still being monitored by a CrCU specialist.

Staff also described how the clinical psychologist provided psychological inreach to CrCU patients which often continued when the patients were moved to the ward. The clinical psychologist suggested that on CrCU they often developed a relationship with the patient which established trust and allowed patients to express themselves and discuss their critical illness experiences with a CrCU expert who could explain their experiences and potentially lessen the impact on them.

Staff also considered that the development of the discharge coordinator role could, in the future, lead to visits with the patient on the ward towards the end of their hospital stay prior to discharge home. The purpose of this visit would be to answer any new questions that patients had about their critical illness and to provide information about the CrCU follow-up clinic. This would signal to patients where they might find support if they needed this later in their recovery process.

Whilst the psychologist, the outreach nurses and the discharge coordinator roles all provided a valuable contribution to patients, staff felt they did not coordinate the ongoing rehabilitation needs of CrCU patients once they were discharged to the ward. There was a perception that services needed to be organised to promote a seamless recovery for patients across healthcare boundaries by allowing rehabilitation goals to be set and progress towards those goals maintained. Staff described how their own communication with other services involved in the patient care had failed to provide helpful information to those services such as a summary of the clinical history which highlighted priorities for ongoing care:

“...communication between all our multidisciplinary team, I do think sometimes it’s very disjointed and I think if you improve that, you would get a more efficient service.” (S03, CrCU Sister, Discharge Coordinator).

Some staff discussed how the recent introduction of multidisciplinary team meetings (MDT) on CrCU by the discharge coordinator was improving this situation for all the longer-term patients. At MDT, multiple specialities were able to contribute their expertise into planning and prioritising each patient's forthcoming care:

“...we get physio, OT [occupational therapist], speech and language, dietitian and pharmacy and the clinical psychologist, all come every week...so we are getting an MDT approach to the patient now.” (S03, CrCU Sister, Discharge Coordinator).

A further service initiated by the outreach team, which was felt to support continuity of care, was the Call4Concern service. The outreach team described the service as a ‘safety net’ (S01, Outreach Sister) for patients and families, who were given a contact number to call if they had any concerns following their transfer to the ward setting. Two purposes of the service were discussed. Firstly, Call4Concern reassured and empowered patients by giving them the ability to make a self-referral if they felt they were not receiving the care they needed on the ward. Secondly, the service provided an avenue for patients to ask questions of experienced staff about their CrCU stay, and to be given appropriate information and referrals as needed. However, the outreach staff considered that the service was both underused and inappropriately used:

“...the call for concern is all about a contact number for you to talk about your critical care stay if you want to, to ask us questions, this is the number you can always contact us, we’re always linked to critical care, we’ll always find somebody to refer you onto if we can’t answer the question, etc. But we’re not getting those calls.” (S04, Nurse Consultant).

Some suggested that the Call4Concern leaflets and pocket cards given to patients were easily lost in the transfer process to the ward and easy to forget amid the multitude of information given at that time. Another staff participant suggested that they felt uncomfortable talking about Call4Concern in the ward area as it appeared they were being critical about ward based care and always recommended that the first point of contact should be the ward nurses or manager, with Call4Concern only used if there was nobody else they felt they could talk to.

Staff also discussed how infrastructure could be used to help bridge the gap between CrCU and the ward. The outreach staff preferred to transfer CrCU patients directly to step-down areas, such as the major trauma ward or respiratory ward within the hospital, which they considered to provide an intermediate level of care. Staff in these areas were perceived to be more competent in caring for CrCU patients which reduced the risks associated with a sudden change from higher to lower levels of care. Step-down areas were also felt to provide a link between the need for specialised rehabilitation and CrCU related needs:

“...so having perhaps step-down areas so you could really have a cohort of a ward team who were focussed in on rehabilitation, critical illness, so they weren’t scattered far and wide.” (S04, Nurse Consultant).

There were also challenges associated with step-down areas. Staff described how step-down areas tended to be a small section of a larger ward and so they were not staffed independently from this main ward. As staff rotated between the step-down area and the general ward area, it became difficult to maintain continuity of care for patients and to train a dedicated team of specialised staff who had the skills and knowledge to manage patients following critical illness:

“...so the major trauma ward, for instance, you might have nurses who are working in there one week but then out on orthopaedic ward the next week, so you are not getting the continuity. So, investing in knowledge and skills development within that team is going to be very disjointed...” (S04, Nurse Consultant).

Staff suggested that step-down areas should have protected resources and dedicated staff, which would enable appropriate training for a cohort of staff in one area rather than individual skilled staff being located “far and wide” across the hospital setting. Another proposition was for a named person within the MDT to become a point of contact for each patient and be responsible for coordinating the patient’s rehabilitation pathway and addressing their CrCU related concerns.

4.3.2 Fragmented service

Several staff discussed how the service provided to patients was disjointed, which they considered to be a barrier to continuity of care. Several suggested reasons for this fragmentation. One proposed that CrCU did not coordinate well with other speciality clinicians because many clinical specialities did not visit the CrCU to review their patients. In addition, as a group, the CrCU consultants were felt to make assumptions that other speciality clinicians knew what to expect for their patients following critical illness. As a result, when patients were transferred to the ward, speciality clinicians had to manage the patient's care and their complications without having any previous exposure to their clinical condition, or being given sufficient information to guide them:

“...we seem to assume that they know what happens after intensive care. We seem to assume that they know everything that’s going on during that admission period...A lot of the specialties – certain specialties - don’t come down and review patients in intensive care so they don’t see them when they’re sick, and then they’re supposed to be looking after them afterwards.”
(S07, Consultant in Intensive Care Medicine).

Other staff felt that the ward nurses also lacked the information they needed to provide seamless care for the patient. They discussed how a patient discharge pathway was started on admission to the CrCU to provide a comprehensive handover to the ward staff. Whilst this was perceived to support a reasonable verbal handover, there was a perception that ward staff were given too much information without any prioritisation of what was important for the patient's continuing care. Staff also suggested that the ward nurses might find it difficult to access the patient's CrCU medical records because the ward staff did not use this electronic records system, and so they were not trained in how to find the information they needed, and might not have time to do so:

“I don’t know whether they’d go onto the intranet and look at everything that we’ve [CrCU] done. I don’t know whether they’ve got the time to do that.”
(S08, CrCU Sister, Follow-up Clinic Sister).

Adding to the problems associated with provision of patient information, ward nurses were perceived to have limited understanding of the impact of critical illness on patients. Some suggested that many ward staff might have had limited exposure to CrCU patients during their training and subsequent practice. They felt this might make them unsure about what CrCU patients were capable of and hesitant to deliver important care activities, such as mobilisation. As a result, the patient's rehabilitation progress took a backward step when they went to the ward:

“But if they’re totally dependent they are very reliant on people getting them out and nurses on the ward understanding and knowing that they can actually get them out in the chair because I think there is a degree of, “Oh they’ve just been in critical care, can’t get out in the chair until somebody tells me that they can”” (S04, Nurse Consultant).

One staff participant recommended that ward nurses visit the patients on CrCU so they could see their capabilities and restrictions and discuss their care with CrCU staff before the patient was moved to the ward. However, this was only perceived to happen occasionally for some of the longer-stay patients.

Staff also felt that the coordination of resources between CrCU and the ward was problematic. Equipment that had been available on CrCU, for example, mobility aids and specialised eating utensils, were in scarce supply on the wards. This meant that patients had to wait for the physiotherapists or occupational therapists on the ward to requisition equipment and for those resources to be delivered before the patients could continue with their rehabilitation plans.

4.3.3 Bridge between critical care and the ward

Staff perceived that patients who had a stay on CrCU were often fearful about the contrast between the CrCU and ward environment. In addition, the trauma of critical illness, delirium and hallucinations caused ongoing anxiety. Some staff felt that many ward-based staff lacked an understanding of what patients experienced on CrCU, which meant they could not make necessary connections between CrCU and the patient’s behaviour. They described how ward staff might think patients were demanding and attention seeking as they did not recognise their fears and anxieties associated with CrCU and what they had experienced:

“...they could have that degree of delirium or hallucinations, and I think the ward staff probably don’t appreciate that or they don’t know why. There’s an education gap there, isn’t there, really, the ward nurses knowing what kind of environment they’ve come from, and recognising why they are demanding. Because it’s like they’re demanding because they’re scared and you’ve suddenly put them into a totally different place. Whereas sometimes I think the ward nurses think they’re demanding because they’ve had a nurse by their bedside.” (S03, CrCU Sister, Discharge Coordinator).

Staff felt that ward-based staff lacked education about CrCU related conditions such as delirium, meaning they did not know how to handle the patient appropriately or who to refer the patient to for help. One staff participant recalled their own experience as a junior nurse on the ward when they had been unable to link a patient’s agitation with delirium and had called security to help manage the patient. They felt that, because the

ward-based nurses did not attribute patient stress and anxiety to their critical illness experiences, they lacked empathy for CrCU patients and viewed them as a problem, which added to their busy workload:

“...but that makes me realise that the ward nurses now probably don’t have a great deal of insight into the major impact that a critical care stay can have on a patient’s recovery...” (S02, Outreach Sister).

Ward-based staff and CrCU staff were perceived to lack awareness of each other's roles and expertise because there was no crossover of information between the two areas. Staff felt that this created a service in which some of the patients' needs were met, whereas others, such as those associated with CrCU experiences, would remain unresolved. Staff also described how, over time, healthcare professionals became blinkered to what it was like to work in other areas of the hospital:

“And I know that when I worked on the unit that I had very different eyes for looking at patients to what I bring to them now...they’ve [band 7 CrCU nurses] worked on critical care for a long time so they haven’t got those ‘ward eyes.’” (S01, Outreach Sister).

CrCU staff were felt to be ignorant about the pressures ward nurses were placed under when they received patients with complex care on their wards. One staff member considered that all nurses should work in the ward setting before working in CrCU to gain insight into the impact of transfer to the ward on patients, and to improve the relevance of information handed over from CrCU to ward nurses:

“So I’ve always been an advocate for nurses working in a medical or surgical area prior to working in intensive care because you don’t know what it’s like to work in a ward area and I think that impacts then upon your communication with them.” (S02, Outreach Sister).

One staff participant discussed an initiative to bridge the gap between the CrCU and the ward by creating ward based link nurses. This intended to develop relationships between staff with different working practices and establish a group of people familiar with CrCU patients in the ward environment. The priority for this initiative were those wards where more complex CrCU patients were sent, such as patients with tracheostomies, so that common objectives for the patient could be shared and ward staff could identify what they needed to meet these objectives.

4.3.4 Continuity of care and information

Staff discussed how it was especially difficult to maintain continuity of care between CrCU and primary care, particularly as there was no direct link established with

community services. Some staff suggested that healthcare practitioners in the community setting were unfamiliar with CrCU and had little or no critical illness expertise:

“...a GP in the community could be a very experienced GP, but he may have spent 12 months in a hospital during his training and may never come across ICU patients at all, and we’re assuming that when these patients pitch up in the community, that he knows what to do with them, he knows the significance of the complications and the sequelae.” (S07, Consultant in Intensive Care Medicine).

Many GPs and community nurses were felt to be unaware of the needs of former CrCU patients and unable to identify the most appropriate support for them:

“...unless GPs are knowledgeable enough about the [follow-up] clinic to refer people back into the clinic...I think people could fall through the net somewhat.” (S06, Psychologist).

In addition, staff expected that community-based practitioners would not encounter former CrCU patients very often in their day-to-day practice and would need to take time to reflect on what their specific needs might be. Some staff suggested that CrCU was not helpful in this respect as staff did not provide GPs with enough relevant information about the patient’s CrCU experiences. Important information for GPs would emphasise that the patient had been in CrCU and signpost the types of issues or complications the GP could anticipate during that patient’s recovery. In this way CrCU staff might steer GPs into providing better support for the patient.

Staff considered that the CrCU treatment episode should not end for the patient just because they had been transferred from the unit. All staff felt that CrCU should be involved in the provision of some form of care beyond the hospital setting though some acknowledged this was a move away from the traditional survival attitude of CrCU staff:

“We spend a lot of time saving people and trying to make them better and then, you know, why should that care finish at the door when they leave the ward? No other speciality would envisage that. Surgeons wouldn’t, medics wouldn’t, you know, they wouldn’t dream of discharging somebody without thoughts of any follow-up.” (S07, Consultant in Intensive Care Medicine)

One staff participant recommended gathering information about what happened to CrCU patients after they had left hospital as a starting point as there was no central place where this was recorded. Another felt that a healthcare practitioner with CrCU expertise should be a coordinator of care, making sure that patients’ needs could be identified and referred to relevant healthcare specialities as needed.

4.3.5 Passing on responsibility

A further sub theme associated with continuity centred upon staff's perceptions that they were accountable for providing some aspects of care and not responsible for others. Staff descriptions of the care they delivered centred upon specific time-points in the patient's recovery journey rather than continuous care throughout the recovery process.

The CrCU medical consultants discussed how as a group, they were more focussed on admission to CrCU and care delivered during the critical illness period. They felt that significantly less time and effort was directed towards the patient's recovery:

"I think a lot of the time intensive care consultants, they like the treating medically bit and I think then they seem to not focus on the bits afterwards." (S07, Consultant in Intensive Care Medicine).

Staff suggested that the culture on CrCU was on managing the acute stage of the critical illness episode and there was an expectation that ward staff dealt with longer term recovery. There was a perception that CrCU nurses were motivated by the prospect of saving lives, whereas there was less enthusiasm for rehabilitation:

"And by nature critical care nurses don't necessarily like looking after those patients on a longer term basis." (S04, Nurse Consultant).

CrCU staff were also felt to focus on the short-term plans rather than longer-term outcomes when managing patient care. For example, CrCU nurses planned for transfer to the ward but did not think about arranging for discharge home. The discharge coordinator suggested that CrCU staff should explore the patient's home circumstances, home based support, and whether they might be expected to return back home following critical illness. They felt this would allow CrCU staff to anticipate and initiate appropriate interventions to accommodate the patient's hospital discharge:

"...we just accept that there's a patient in that bed and they need this, this and this doing, and I don't think we particularly look every day and think, "What do I need to do to get this patient home?" and to me, that's what we should be doing...I think sometimes we're doing things to keep them in hospital..." (S03, CrCU Sister, Discharge Coordinator).

The discharge coordinator discussed how their aspiration for the role had been to coordinate the continuing care of patients following transfer to the ward yet their priority had become achieving the patient's safe and timely transition from CrCU. The funding for this role was provided to achieve a four-hour CrCU discharge target, which meant all patients would reach the ward within four hours of the decision to transfer them. This

meant that the role was mostly focussed on improving planning for transition to the ward and streamlining processes within CrCU to accommodate timely transfer:

“...I think what kind of we’ve highlighted is that if we tick all our boxes first and trigger the patients [to the ward] more appropriately, you can kind of have more of a chance of getting them out in that timeframe.” (S03, CrCU Sister, Discharge Coordinator).

Staff perceived the outreach nurses provided a smooth patient transfer to the ward and close assessment and observation of their clinical condition during the early days on the ward. The outreach team discussed how the way they provided their service varied depending upon who was on duty and the pressures on the shift each day. Some of the outreach team were felt to dislike assessing patients following CrCU transfer to the ward and preferred to focus on the acutely unwell patients on the wards:

“I know that there are some who go up to the ward [to assess former CrCU patients] and I know that some of them are very dismissive.” (S04, Nurse Consultant).

Some staff perceived that whilst all outreach team members would address the patients’ physiological needs, only a few would take time to discuss psychological issues with patients or talk to patients about their longer term expectations. Outreach staff also identified that they were not trained to meet the rehabilitation needs of patients and left that aspect of care to ward based allied health professionals who they felt were better trained to deliver rehabilitation:

“Rehab isn’t pushed forward well in the team. I’m not sure how to address that. I know that there are some who go up to the ward and I know that when we talk about it at the team meetings some of them are very dismissive about, well, yeah I wouldn’t know what to do. And I guess that’s because they don’t understand what’s expected of them. And they all do it slightly differently.” (S04, Nurse Consultant).

Most staff indicated that when they identified any potential psychological issues they referred the patient to the clinical psychologist. Whilst staff recognised that patients recovering from critical illness had physical, psychological and social needs, many felt that their responsibility was meeting patients’ physical needs:

“I think so the physical side of going to see them and making sure that everything, the obs [observations] are fine and they’re passing urine and that side of it is probably reasonably well-met because we’re looking at that and the medical teams are going to focus on that...So I think it’s probably the psychological sides that aren’t so well-met.” (S01, Outreach Sister).

Staff also felt that the clinical psychologist had more specialised skills in managing the patient's psychological needs than they themselves did:

"We've not got the skill set that [clinical psychologist] has got." (S05, CrCU Sister, Follow-up Clinic Lead).

"And then I suggest that they see [clinical psychologist] when she comes because she does the important stuff." (S01, Outreach Sister).

The clinical psychologist considered that patients who presented as withdrawn, tearful, anxious or angry were often unnecessarily referred to a psychologist when all they really needed was time to talk:

"Actually I think what I do is give them time to talk about their concerns, so the way that they're thinking and feeling and how that's affecting their behaviour..." (S06, Psychologist).

The clinical psychologist prioritised psychological care for inpatients over other aspects of their CrCU role because nobody else was dealing with those patients. Focussing on inpatient services, they felt, diluted the service provided to patients at the follow-up clinic. The clinical psychologist discussed how the number of inpatient consultations had increased since the Trust had become a major trauma centre, but without any additional resources for CrCU psychology provision being allocated. This meant they were no longer able to provide patients at the follow-up clinic with a course of therapeutic treatment, such as cognitive behavioural therapy sessions. When they did identify a patient needing higher level psychological input they had to refer them to their GPs instead.

4.3.6 Limited resources

Staff felt that resources determined and limited the care and services received by patients. Limited resources affected pre-admission planning for elective CrCU admissions, reduced the availability of psychological support for patients in hospital, focused the outreach team on prioritising physiological assessment, expedited discharge due to bed pressures, and, constrained the scope of CrCU follow-up clinic provision.

Some staff talked about how elective patients in past years had been pre-prepared for their impending CrCU stay. On occasion, patients were admitted to CrCU pre-operatively to familiarise them with the setting and the CrCU staff:

"We did used to go to the ward and interview patients that were going to be coming to the unit and then we stopped doing that, because, obviously, the

workload and the unit expanded.” (S08, CrCU Sister, Follow-up Clinic Sister).

The clinical psychologist discussed how psychological support was given lower priority and funding within CrCU because of the prioritisation for treating clinical conditions in care provision:

“And it is limited what it can do therapeutically in the sense that, you know, most people who provide psychological therapies are sat in a room with two comfortable chairs and it’s not disturbed. That’s not the environment in critical care is it? Even when I’m having a conversation with people quite often...doctors and other members of [staff] that visit the unit will just walk in and disturb what we’re doing so that’s a bit disruptive really, you know, there’s not a recognition really that sometimes patients need to be allowed time with me.” (S06, Psychologist).

Staff also described having to prioritise short term interventions within CrCU at the expense of training staff, education and support for families, development of resources and materials for patients, evaluation and development of the service and general administration:

“I feel like I touch the tip of the iceberg, I feel that’s all that I have time to do is touch the tip of the iceberg.” (S06, Psychologist).

The outreach staff described how they were regularly following up patients who had been discharged relatively early from CrCU with inadequate preparation for the ward environment and their recovery journey. They felt this was often due to pressure to get new patients into the unit because the demand on beds was so high.

“It’s pressure of beds usually, they’ve got patients that need to come in, this patient seems to be okay so they’ll send them to the ward.” (S02, Outreach Sister).

Due to the multifaceted nature of their role, the outreach staff felt that every day they were forced to make decisions regarding the prioritisation of how they utilised their time. They often had to focus on the physiological aspects of care and particularly identifying patients at the risk of deterioration rather than psychological and rehabilitation orientated care:

“It changes day to day. So you might have that you haven’t got any [sick patients], you’ve only got follow-ups to do so you can spend time with them.” (S01, Outreach Sister).

Other staff described that this prioritisation affected the patients that were trying to recover from critical illness, or commented that limited physical resources such as appropriate chairs or cushions often delayed patients' recovery efforts:

'If they [outreach] were just concentrating on those critical care patients I think it would be more rehabilitation, but it's not.' (S05, CrCU Sister, Follow-up Clinic Lead).

"Resources at ward level are shocking. Hoists and the processes they have to go through to get a pressure relieving cushion for their chair and... sponges for knives and forks... there is too much effort. We need to make it easy for people to do the right thing... if they decide that they are well enough to get out of the chair that day, they shouldn't have to stay in bed for another 24 hours while we wait for a cushion for the chair." (S04, Nurse Consultant).

Limited resources were felt to affect the CrCU follow-up clinic. Several staff commented on the restriction in patient selection for invitation to the clinic as there were not enough resources to allow all CrCU patients the opportunity to receive a clinic appointment:

'I think it's done on the cheap. I'm sure there's proper clinics out there that run better but I think we do the best we can with the resources we've got.' (S05, CrCU Sister, Follow-up Clinic Lead).

"...we've picked out the five-day stay, haven't we, in critical care, four nights, five days, but we've done that on resources and everything is based on resources." (S04, Nurse Consultant).

One of the medical consultants described how he had staffed the clinic on a voluntary basis for three years, providing the service without pay and in his own hours, because there was no finance for a medical contribution to the service. Another member of staff described a nurse triage system to try to identify the patients who would potentially benefit most from the limited clinic slots and also as a possibly less resource-intensive way of supporting recovery patients. The clinical psychologist commented that they had previously been able to provide patients with a series of therapeutic interventions over several clinic appointments but they were no longer able to offer this service because of increased inpatient workload:

"I did used to offer patients short-term therapeutic interventions for sort of up to six to eight appointments, however, the demand on the 0.4 time has increased over the years that I've been in post and that time has never been increased. And I found it's more and more difficult actually because of an increase in seeing inpatients to see outpatients that have been identified at clinic." (S06, Psychologist).

Most staff felt that follow-up and rehabilitation services were not given the priority they deserved on a local hospital level or nationally.

"The same kind of people are on both NICE guidance and developing the intensive care standards, so again they're obviously not particularly follow-up people in my mind, because they seem to have missed a trick and actually I don't think have been prescriptive enough, but also don't seem to have highlighted the real need for this area." (S07, Consultant in Intensive Care Medicine).

'We don't put the business care for the resources, because the focus has been on other things.' (S04, Nurse Consultant).

Many staff commented that they had made individual decisions about where they should prioritise their time and directed their efforts to where they felt they were most effective or where they were they perceived that they were the only staff member who attended to a particular aspect of care.

4.4 Theme 3: Needs and expectations

Staff reported that patients and families did not know what to expect after critical illness. They described their perceptions of the most obvious needs that patients and families experienced during the recovery process. The major theme, 'needs and expectations' is associated with eight sub themes: 'knowing what to expect,' 'need for reactive services,' 'need for CrCU follow-up clinic,' 'misunderstanding about CrCU follow-up clinic,' 'psychological needs and support,' 'psychologically oriented questions,' 'normalising experiences' and 'empowerment, control and confidence.'

4.4.1 Knowing what to expect

Most staff discussed how long it took for patients to recover from critical illness and felt that patients and relatives did not understand or expect this. They felt that patients had little to base their recovery expectations on as they had limited and often confused recollections of their CrCU stay. Families were considered to have more realistic expectations than patients because they had seen how ill the patient had appeared in CrCU. However, staff felt that families were sometimes impatient for patients to recover as they wanted their own lives to return to normal and this placed patients under pressure to get better as quickly as possible:

"I think because of the lack of understanding of the duration of critical illness, it's not a three week thing, it's an 18 month thing, I think there's a hell of a lot of pressure on people to get better quickly. And especially from relatives because, with the best will in the world, when you've been in to visit

somebody every day for the last six weeks and you're looking after them and everything, these relatives, they want to get back to their own lives..." (S07, Consultant in Intensive Care Medicine).

Staff considered that patients expected to feel ill for a short while after being in hospital but did not anticipate the longevity of their recovery. When patients were taking longer than they expected to return to their pre illness condition, they became frustrated and this raised questions about why recovery had such a long duration. Many staff discussed how patients' ignorance about the recovery timeframe led them to make unrealistic plans. Patients then experienced distress and despondency when they failed to achieve their plans:

"When they leave the unit I'm not so certain that they do know what timeframe to anticipate in terms of recovery...people express really unrealistic expectations about recovery, they'll express significant distress about the fact they're not back to normal yet." (S06, Psychologist).

Some staff considered that patients were unaware of the physiological and psychological impact of critical illness which in turn left them uncertain of what to expect during their recovery. It was considered unusual to have discussions with patients on CrCU about their expectations for recovery as most CrCU staff in that setting did not pay attention to the longer-term impact of critical illness. Senior nurses were thought to avoid discussing long-term expectations with patients as they were too busy, whereas junior nurses were perceived to lack the knowledge and the confidence to discuss long-term recovery:

"...a lot of new and inexperienced nurses...haven't got the experience to be able to give the patient that information...so they would perhaps avoid it...you do need probably like a more senior role, a more confident nurse because if you're trying to prepare a patient for the future or what to expect, I think you've got to have had some life experience yourself...to kind of be able to offer that support." (S03, CrCU Sister, Discharge Coordinator).

Medical staff were perceived to avoid conversations about recovery as the pressures of their workload left them little time for more prolonged discussions with patients. There was also a suggestion that such conversations may be discouraging for patients during the earlier stages of their recovery.

Some members of the outreach team stated that they would take the time on their follow-up visits to talk to patients about their long-term recovery. They discussed their interest in supporting patients' wider needs and how they opted to visit the follow-up patients and spend more time with them if the pressures on the shift would allow:

“If the bleep’s not going every two seconds you can actually spend some time talking to patients...and give them an opportunity to talk, which is what they need sometimes.” (S01, Outreach Sister).

Several of the staff felt that patients’ longer term expectations were appropriately addressed at the CrCU follow-up clinic. Staff from the follow-up clinic discussed the importance of reminding patients of how far they had progressed and reassuring them that it was normal for recovery to be a long process. The clinical psychologist used a pie chart to illustrate to patients and families the stages of recovery and demonstrate what they had already achieved and how far they still had to progress. Patients were also given the opportunity to revisit the CrCU, which was considered to help patients realise how ill they had been so they had a baseline from which they could develop more realistic expectations for recovery:

“...and it’s very obvious people are not sat up reading the newspapers and pottering about and you can see there’s a recognition of, “Oh gosh everyone’s really poorly here.”” (S06, Psychologist).

However, some staff suggested that, as patients did not attend the CrCU follow-up clinic until three months after their hospital discharge, this delayed the opportunity for patients to be given reassurance and advice about their longer term recovery. In addition, as not all patients attended the CrCU follow-up clinic, they felt many patients would have no opportunity to discuss their expectations.

4.4.2 Need for reactive services

Staff identified that patients had varying recovery journeys and experienced different needs at different time points. They discussed the difficulty of planning services that met patients’ needs throughout the whole of their recovery process:

“It’s really difficult to generate a pathway which will meet the needs of the patient at the time that the patient needs their needs met. I don’t think – we’re not doing it now at all, but I think to be able to get it right 100% of the time feels unrealistic.” (S09, Consultant in Intensive Care Medicine).

Some staff suggested that because patients needed support at varying stages, services needed to be reactive to their needs and delivered in a more flexible way and to accommodate this variation:

“But I think that realisation can come at different timeframes for people, and that’s why you need that kind of reaction in timeframes, I think. If I decide five years down the line that suddenly I need help, you know, I’m fed up of it, then I need to be able to access that service. Equally, if I’ve decided a week after I’ve been discharged that I think I need massive help then I think there

needs to be some kind of service that's reactive to it." (S07, Consultant in Intensive Care Medicine).

Some staff suggested that there should be ongoing communication between CrCU and the patient to triage the patient and identify any issues that arise during their recovery. This was considered especially important for identifying psychological issues such as delirium, as this can have a significant and unanticipated impact on patients:

"But I think that for most people, that mental health aspect of delirium and everything is the first time they've experienced that degree of – yeah, it comes across to them as a mental illness, I think. And I think it's so far away from feeling depressed or feeling anxious, that kind of psychotic aspect of it, that it really shakes up a lot of people, and a lot of relatives as well." (S07, Consultant in Intensive Care Medicine).

One proposal was for all patients to be contacted over the telephone and to assess their physical and functional capabilities, their quality of sleep, identify complications and address concerns. In this way, patients' could be given expert advice or referred to appropriate support services such as physiotherapists, speech and language therapists, social workers or psychologists. Another proposal was for every patient to be invited to a CrCU follow-up clinic run by a specialist nurse. The nurse could identify those patients who needed referral to a clinical psychologist, and other types of support, and again, appropriate referrals could be made.

"...the kind of top tier suggestion is going to be that everybody comes to a follow-up clinic but they're not seeing a specialist. So, they'll see a specialist nurse or a nurse and then you can then filter out only those that require psychological support, but then start to push things like speech and language, social and OT and physio." (S09, Consultant in Intensive Care Medicine).

Some staff recommended that patient involvement was needed in planning and designing services to ensure they were well aligned to meet patients' changing needs. They felt that services currently provided to patients were designed by CrCU nurses, doctors and psychologists, whose preconceptions and assumptions might be misaligned with what patients and families wanted:

"...most of what I've said is based on patient participation, isn't it, so they've got to be involved in planning the service. Because the fact is if you plan a service that they don't like they're not going to come to it, are they?" (S09, Consultant in Intensive Care Medicine).

Staff also considered that finding a broad range of patients to inform the planning of services was important, so that the views of patients who might be less likely to engage in follow-up services were represented.

4.4.3 Need for critical care follow-up clinics

Several staff shared their thoughts about the eligibility criteria for the CrCU follow-up clinic. Some staff described the four day or greater CrCU stay as based on probability rather than evidence. They described how patients who were sicker had longer CrCU stays, and longer CrCU stays were more likely to be associated with longer-term complications. Whilst this was intended to filter out patients who did not need the service, leaving the resource for those who did, some staff suggested that current criteria included patients who they felt did not benefit from the service:

“Well, my experience is some patients don’t need it at all. They just do okay, don’t they? And there’s the ones you’ll see for a further surgery afterwards, you know, no problems at the time they went to critical care, no problems afterwards.” (S09, Consultant in Intensive Care Medicine).

Most staff felt the criteria sometimes excluded patients who did need the service and recommended alternative criteria for CrCU follow-up clinic invitations. One suggestion was that the criteria should take into consideration an assessment of the events that had happened to each patient during their CrCU and ward stay, such as delirium or sepsis:

“...there’s not very much patient assessment saying, “Well, that patient had specific things within their stay, or they’ve had specific problems on the ward, therefore they’re more likely to need follow-up clinic.” (S07, Consultant in Intensive Care Medicine).

However, there were differing opinions about which CrCU events predicted the need to attend CrCU follow-up clinic. Some staff suggested that patients who had experienced delirium, altered perception or lack of memory would be most likely to need psychological support or the opportunity to explain what had happened on the CrCU unit. Others felt that patients who did not remember their stay were unlikely to gain much benefit from the clinic:

“There are some that have come [to CrCU follow-up clinic] that don’t really need a lot of input from the clinic. I think possibly they’re the ones that don’t remember their experiences.” (S08, CrCU Sister, Follow-up Clinic Sister).

Some members of the follow-up clinic team felt it was difficult to anticipate who might benefit as patients had differing reasons for attending:

"Now we've had some patients that have come to clinic that said I didn't think I needed this but now I've come I'm really glad I have...they're often the ones that say it was really helpful...the fact that we've normalised their experiences, validated their own personal experience, the fact that they've been able to talk about it. For some people it's about getting information." (S06, Psychologist).

One medical consultant suggested that if patients knew to expect CrCU follow-up (just as with other specialities) then they might be better prepared to anticipate that difficulties may arise during recovery. They suggested that all patients should expect to come to a CrCU follow-up clinic appointment, or at the very least a triage assessment during their recovery:

"I think that [a follow-up clinic invitation] gives a signpost that there might be difficult things ahead." (S07, Consultant in Intensive Care Medicine).

Staff also described various ways in which CrCU follow-up clinics had provided support for family members. Several staff felt that family members were often more traumatised than patients following critical illness, as they had a greater recall of distressing events on CrCU. This meant they needed separate support and information to help them to deal with their experiences. They discussed how families appreciated the opportunity to talk to someone about their own experiences whilst the patient was on CrCU:

"Don't forget all the relatives involved in this kind of process can often be more traumatised than the patient themselves...a lot of people don't remember anything at all about intensive care and they were just basically straight away, "Well, I don't remember anything so it doesn't bother me." But the relatives are going, "Yeah, but you were really ill. You nearly died." And they're going, "Well, I don't remember anything about it." And that kind of – almost the relatives are trying to convince them how sick they were and how close to death they were." (S07, Consultant in Intensive Care Medicine).

As family members often became the primary carer for patients during their rehabilitation at home, the CrCU follow-up clinic provided them with information about resources to help them support the patient's recovery. Sometimes they reinforced the care that families were providing to patients, at other times they advised families to reduce their support so that the patient might take more responsibility for their rehabilitation. Staff also provided families with explanations about the care given on CrCU and about patients' delirium episodes, which they felt families often found distressing to witness. The clinical psychologist had on some occasions provided therapy sessions to family members at the follow-up clinic. However, providing care to both patients and families was felt to be a further pressure on limited resources.

There was recognition of the value of the CrCU follow-up clinic in providing education and feedback to staff. They acknowledged opportunities to informally train staff in the management of delirium, educate staff about the longer-term impact of critical illness, and also to inform service improvement. Several senior CrCU nurses provided CrCU follow-up sessions as part of a rota. Extending the role of follow-up clinic nurse to more CrCU staff was felt to have been beneficial in enhancing their day-to-day role on the unit and being able to share their experiences more widely with other staff members:

“So, they’re more aware of delirium and patient experiences and I do believe that’s filtered back to the unit staff more...I just think they’re more aware of what people experience when they leave critical care so they can maybe prevent it happening a little bit more on the unit, or at least prepare the relatives for it...” (S05, CrCU Sister, Follow-up Clinic Lead).

Several staff described the impact of hearing former patients talking about their experiences, which helped them understand patients’ experiences of their care and informed them how to improve their practice:

“We’ve had ex-patients that have come in [to follow-up clinic] and they’ve told their side of the story and their experience, and it’s totally opened your eyes. It makes you question your own practice and you think, “Oh God, do I do that?”” (S03, CrCU Sister, Discharge Coordinator).

Staff discussed how information from follow-up clinic visits was recorded in a diary which was kept on the CrCU and used to feedback patients’ experiences to nurses:

“We have a diary...if certain patients stand out and they’ve got something to say that we think the rest of the staff will benefit from then we’ll share it with them.” (S08, CrCU Sister, Follow-up Clinic Sister).

More memorable patient appointments were used to feedback to staff in the form of advice and suggestions that might improve everyday practice:

4.4.4 Misunderstandings about critical care follow-up clinics

Staff considered that patients did not always understand the reasons for their invitation to attend the CrCU follow-up clinic, particularly when they had many different clinic appointments to attend. Some staff felt that many patients were not properly informed about the clinic by hospital staff and were confused about the nature of the appointment. For patients who did not recall their CrCU experiences, staff felt that they may not realise the appointment would help them redress their memory gaps. Staff also suggested some patients avoided clinic as they did not want to revisit traumatic experiences:

“...I think some people are actually afraid to attend and revisit that episode of their experience of ill health because that’s the part that’s most confusing, upsetting, traumatising in some.” (S06, Psychologist).

Some staff felt that the process for inviting patients back to follow-up clinic did not give patients the information necessary for making an informed decision. They described how patients received a letter through the post which might not clearly illustrate the intention of the appointment. Some disagreed with the information leaflet being given to patients at CrCU discharge as it was too soon for patients to absorb the information and then recall it when the follow-up clinic invitation letter was sent to them several weeks later. The clinical psychologist mentioned that the way the information was given might lack the necessary detail, especially if conveyed by outreach nurses who were less interested in the follow-up aspects of their role. The clinical psychologist also described scenarios in which patients misconstrued the appointment as indicating that they had a mental illness:

“I know certainly some patients that come to follow-up clinic say they weren’t sure about coming to clinic because they did perceive it perhaps to be more of a mental health appointment or a psychology appointment. So some people will come in saying oh I wonder if you’re going to say I’m potty or not, you know, in their terminology, or certifying me sane or not, so they’re the sort of comments that patients make.” (S06, Psychologist).

Staff suggested that if patients had more insight into what to expect from services it could better inform the way they accessed them and might better meet their needs. The discharge coordinator considered that because their role allowed more one to one contact with complex patients they might visit patients 24 to 48 hours after their transfer to the ward to explain the follow-up appointment. Alternatively, the follow-up clinic nurse suggested that a phone call about the clinic a bit nearer to the appointment time might be more useful for patients.

4.4.5 Psychological needs and support

All staff discussed patients’ needs for psychological support during recovery from critical illness. They related these to the impact of delirium, traumatic memories, PTSD and longer term issues related to personal change, social issues and acceptance of permanent changes to their lives. Some staff described how patients’ psychological needs varied according to their stage of critical illness and recovery. In CrCU, patients were perceived to focus on very immediate concerns relating to their physical state and whether they were going to survive:

"But I think the mind is very good at hibernating, I think, in these circumstances and really, as you said before, it focuses on the physical and really everything else is just put on autopilot, isn't it?" (S07, Consultant in Intensive Care Medicine).

The clinical psychologist felt that inpatients issues centred upon loss of control, symptoms of acute delirium and uncertainty about the future. In contrast, in the outpatient setting, patients' focus had often shifted to the longer-term impact of their critical illness. At this stage patients focussed on how to adapt to the changes they were experiencing, such as new limitations and comparisons with what their lives had been before their illness to what they were like now. Several staff felt that a proportion of patients would have unmet psychological needs during this time, as many patients were not invited to, or did not chose to attend, the CrCU follow-up clinic. GPs and community mental health services were perceived by some staff to lack the adequate understanding of critical illness which was necessary to be able to identify and manage ongoing CrCU related psychological issues. Some staff felt that the provision of more psychological support was needed to identify and meet patients' longer term psychological needs.

Staff also discussed the different levels of psychological support patients needed depending upon their issues. For some patients, talking to staff in hospital who could understand and explain their experiences was felt to provide patients with the emotional support and information they needed:

"I sat and talked to her for about an hour, so just talked through everything that had happened...and she did say that that initial just chance to chat and just tell somebody what had happened had helped quite a lot." (S01, Outreach Sister).

Some staff discussed how patients could also find emotional support through attending the CrCU support group and talking to patients who had been through similar experiences. One CrCU medical consultant suggested that a 'four tier system' of psychological support could be put in place, in which the clinical psychologist should only be a resource for patients who needed more specialised psychological therapy, either in the inpatient or outpatient setting:

"So, you have a kind of four tier system of psychological support, of which one is kind of the bedside stuff, doctors and nurses on the unit, speaking to relatives, all that kind of stuff that we do. Level two is your specialist nurse with support, so that would be the follow-up clinic. Then level three and four, you require a psychological diagnosis that requires a specialist, and it's only

those patients that would see the psychologist.” (S09, Consultant in Intensive Care Medicine).

Many staff felt that improvement was needed in meeting patients’ psychological needs. The clinical psychologist discussed how psychological in-reach for patients on CrCU and the ward consumed an increasingly large proportion of their time as nobody else dealt with patients’ psychological needs. Staff described how any patients displaying emotional or psychological issues tended to be referred to a psychologist, and referred patients could require multiple visits over the course of their hospital stay:

“I’m seeing somebody that’s been in hospital seven months now and I see him twice a week because it’s quite a complex situation so that’s quite a significant proportion of time out of quite a limited resource.” (S06, Psychologist).

Most nursing staff felt that it should be the clinical psychologist who dealt with patients’ psychological issues and did not feel they had a role in providing psychological support beyond identifying the need for help:

“If we have concerns then we’ll escalate that to [clinical psychologist]...if we’ve got any sort of needs with regards to the psychological side of things.” (S02, Outreach Sister).

The CrCU medical consultants felt that physical and psychological issues were linked and that an understanding of what happened to patients on CrCU could inform how staff helped patients to recover from the effects of delirium:

“...there’s obviously a lot of overlap with the psychology and the physical, you know...if you understand the mechanics of what’s going on in the intensive care unit then you can maybe explain where those hallucinations, delirium comes from and that helps the patient, I think, when they realise it’s not just total fabrication, that there is some reality in what they’ve experienced.” (S07, Consultant in Intensive Care Medicine).

The clinical psychologist and the CrCU consultants considered that nursing staff could be trained to deliver low level psychological support and therapeutic interventions at the bedside. Whilst there was a recognition that more psychological training was needed, the clinical psychologist felt there was a reluctance from CrCU staff to adopt any new aspects to their role.

4.4.6 Psychologically oriented questions

Several staff discussed how the identification of patients in need of psychological support required staff to know how to ask psychologically orientated questions. They described how episodes such as delirium on CrCU made patients fear they had mental

health issues. Staff perceived there to be a stigma associated with mental health that made some patients reluctant to readily disclose what they were feeling. It was also suggested that prior responses to their acute delirium from relatives and staff on CrCU made patients feel too ashamed or embarrassed to share their experiences again during recovery:

“...there was a gentleman recently that we saw and he was telling his wife that the staff were spies. And she’d sort of said, “Oh don’t be silly!” so he stopped making comments on some of the things that he believed were happening...And people aren’t sure what to make of delirium experiences, they do think that actually it’s an indicator that they went mad for a while and there’s such a stigma about that isn’t there?” (S06, Psychologist).

There was a perception that many CrCU and ward staff might be reluctant to talk to patients about their psychological issues as they did not know how to manage their conversations with patients who were affected by issues such as delirium. The clinical psychologist felt that staff needed training to deal with the impact of delirium on patients during their recovery from critical illness. Whilst they knew how to involve the family, orientate patients and provide bedside support on CrCU, staff might not know how to effectively explain a patient’s misinterpretation of the stimuli that they had experienced during oral or visual hallucinations:

“Sometimes people think that psychologically orientated conversations are a bit like a Pandora’s box – “So what if I ask them a question and I don’t know what to say?”” (S06, Psychologist).

The clinical psychologist discussed how nurses often kept their conversations with patients light-hearted and superficial, focussing on cheering patients up rather than talking about their concerns, which was only one of the levels of interaction that could be used with patients. The psychologist felt that nurses who had worked in the CrCU follow-up clinic had learned how to pose questions in a way which enabled patients to discuss their experiences and concerns.

In this context, several staff described how patients would often not be willing to share their psychological experiences and needed a lot of probing to encourage them to discuss their concerns. The outreach staff felt there was a fine balance between helping a patient to disclose their concerns and making a comment which closed a conversation down:

“...I always mention the fact that they’ve been through a life changing critical illness and sometimes even that in itself just seems to be a relief for somebody, you know? So we talk about that and then I will offer them, you

know, “It’s perfectly normal to experience feelings of delirium, you may have ongoing recollections, flashbacks sometimes.”” (S02, Outreach Sister).

A sensitive approach was used by the outreach staff to coax patients to share what they were feeling. For example, they might ask the patient about how they were sleeping to ease them into a conversation about nightmares and flashbacks. Staff also discussed how they would describe scenarios involving former patients, which helped patients to identify and share their own experiences.

4.4.7 Normalising experiences

Several staff discussed how patients’ reactions to their critical illness experiences varied. They felt that whilst some patients could attribute their experiences to their critical illness and remain unaffected by them, others felt that their experiences were unique and were disturbed by them:

“And it’s that relationship between what they are experiencing and whether they think that that’s just individual to them or whether that’s related to the experience that they’ve had. And the degree to which it bothers them. It’s very variable. Some people will be very disturbed by it and some people will just say, ‘Oh yeah, that happened.’” (S02, Outreach Sister).

Staff described how patients’ experiences were very typical and widespread following critical illness, yet often patients felt isolated and anxious because they believed their experiences to be unusual and uncommon. When patients were told about the experiences of other patients, they became more open to discussing their own experiences and accepting help and support. Staff described this as ‘normalising experiences,’ a way of reframing and explaining experiences that helped patients’ understand and seek help for their concerns:

“I think the dangerous situation is when you’ve got somebody who thinks I’m the only person this is happening to, I’m the only person who’s felt these kind of things, and that feels extremely isolating... And that acknowledgment that things are common...and that kind of description of what’s normal stops you feeling abnormal.” (S07, Consultant in Intensive Care Medicine).

Another aspect of normalising patient’s experiences was for staff to reassure patients that it was acceptable to feel the way they did. Some staff discussed how patients felt that they should be grateful and feel fortunate to have survived critical illness. This prevented them from admitting to any negative feelings or raising concerns. Staff described how patients felt they needed permission to talk about how they were feeling. When staff acknowledged that it was normal to feel bad, they felt patients were more likely to reach out for help.

4.4.8 Empowerment, control and confidence

Staff discussed how patients relinquished a lot of their autonomy in the CrCU setting, and that healthcare professionals often took over control of patient care. Staff described how healthcare settings were ritualised, with care being delivered according to a schedule rather than discussed and arranged with the patient. They perceived that patients could also bring their own preconceptions, expecting to have everything done for them because they were in hospital, rather than being supported in caring for themselves. Staff discussed how patients experienced a change in how they were perceived and treated by others, which could make it difficult for them to assume control again during recovery:

“And I think these patients have often been looked after for a significant period of time and often the dynamics have changed totally and they’ve gone from being the dominant whatever, patriarch, matriarch or whatever, to suddenly being treated like a baby a lot of the time, and that empowerment, that feeling that it’s – that control aspect of it is quite important.” (S07, Consultant in Intensive Care Medicine).

Staff were felt to misinterpret patients' attempts to regain control of their circumstances, classing such patients as difficult and demanding. The clinical psychologist discussed how such patients could be classed as being non-compliant with care and inappropriately referred for psychological support:

“...there’s usually a reason why people are not engaging, maybe they’re trying to retain some sense of control over their own situation and sometimes saying “no” is the only control people have in a critical care setting.” (S06, Psychologist).

Staff perceived that some of the care and services patients received during recovery delayed their return to independence. They described how patients often felt disempowered in the hospital setting and lacked the confidence to ask staff about their care or to ask for help from staff to meet their needs. Staff discussed how patients felt frustrated about this and had concerns that their recovery would be delayed, but were unable to do anything about it as they felt that circumstances were out of their control:

“And they are happy, well not happy, but resolved to the fact that they just stay quiet and wait...and their confidence and everything is knocked so they don’t question it, do they, because doctors and nurses and professional people like that always know what they are doing and are always right, aren’t they.” (S04, Nurse Consultant).

Staff felt that patients' confidence needed to be rebuilt following critical illness and described the importance of giving patients more control and independence. This could begin in CrCU by increasing the opportunities for them to make decisions and to mobilise, which created an expectation for patients to be engaged and involved. During the recovery process staff perceived that providing patients with adequate information, resources and choices could help patients to help themselves. This was felt to be a way in which patients could re-establish control over aspects of their healthcare and rebuild their confidence.

4.5 Theme 4: Information Provision

Staff discussed the provision of information to educate patients about what to expect following critical illness and signpost the types of help available to them. The major theme 'information provision' is associated with three sub themes: 'information needs and preferences,' talking and listening to patients' and 'using innovation to provide information.'

4.5.1 Information needs and preferences

Staff perceived the amount and quality of information given to both patients and relatives to be inadequate to meet their needs, and described several challenges to the provision of information. These included the format information should take, what the content should be, the type of media it should be provided in, who should provide it, and the timing of information:

"They get provided information but it doesn't seem to be in a format that they can take on board and it often seems to be at the wrong time." (S07, Consultant in Intensive Care Medicine).

Staff felt that patients did not understand what had happened to them in CrCU and were not provided with enough information to help them to make sense of their experiences. Staff felt that appropriate information would improve patients' understanding of their critical illness and facilitate their ability to access advice and follow-up services. Some staff considered it inadvisable to give too much information on transfer out of CrCU, or during the ward stay, as patients would not be recovered enough to process and absorb the information. Others felt that staff needed to give patients honest information about what had happened to them so they would understand the effects they were dealing with during recovery:

"I had one that amazed me...only a young woman, but she'd got out of bed and fallen down. And she hadn't expected it and so she was finding it all

very difficult and she had gaps in her memory and it was all disturbing her quite a lot. So I referred her [patient] to [clinical psychologist] and she came back to me and said... “You’ve just got to tell her what’s happened.” So it’s just be honest with your patients and tell them what’s happened to them and that’s why they’re not well.” (S01, Outreach Sister).

Staff felt that patients had different preferences for the amount of information they wanted about their illness, with some wanting to know very little, and others wanting a detailed account. Staff also felt that patients’ information needs changed over time. They discussed how patients might have unanswered questions about their CrCU experiences because questions could occur to them when they no longer had access to a relevant person to ask:

“And I think the other thing is that that discharge is a moment in time of a continuum, and so the information that patients or relatives need changes over time and that trajectory will change with individual patients.” (S07, Consultant in Intensive Care Medicine).

Staff felt that ward based nurses and allied health professionals who had no previous experience of CrCU might not have enough insight into the impact of critical illness to address patients’ questions. They suggested that when patients found the right person to ask at the appropriate time point, their questions would be addressed but the availability of the right person was not consistent:

“They might be two weeks down the line when they think, ‘What happened then? I remember something about this or I’d had a dream about that,’ and it’s finding the right person to ask the questions of. And if they’re in hospital and they ask the question of the junior nurse at the bed space or the physiotherapist who doesn’t have the insight into what that question might mean then it could fall on stony ground, couldn’t it, and it might not get resolved. It may be dismissed. I think it’s around the awareness of what critical illness means and what it does to people. But then again if they’ve asked the right person, it’s captured and it’s dealt with appropriately.” (S04, Nurse Consultant).

Some staff suggested that providing generic information about CrCU would provide details about usual events that happened in CrCU so that patients could relate this to their own experiences. Another recommendation was to create a package to give to each patient when they were discharged to the ward which could contain a combination of personalised and generic information. The CrCU nurse consultant suggested that an individualised summary letter could be produced, that detailed significant events in the patients’ CrCU stay in lay terms. A letter for relatives could also be included which gave them a short summary about what to expect and some of the things to be aware of

during the patient's recovery. This could be given together with other leaflets relevant to each patient's circumstances and a list of staff contacts for any questions that might arise.

Other staff felt that written information packages were ineffective as patients would find them difficult to read following critical illness, and would not be able to process and absorb written information effectively. A further problem staff mentioned was that patients and relatives were often experiencing overwhelming emotions and many patients wanted to avoid revisiting their CrCU experiences altogether. Staff felt that providing a generic written leaflet might appear to meet the responsibilities of staff, but it would be unlikely to address the concerns of individual patients and relatives.

4.5.2 Talking and listening to patients

Several staff considered that talking and listening to patients was the best way of identifying and addressing their information needs. In this way, any information given to patients could be tailored to meet their individual needs rather than based on staff assumptions of what they might need. Some staff also discussed how it was difficult to predict which patients had issues so it was important ask them. They suggested providing a contact number so that patients and families could ask questions when they needed information, or have information repeated if they had not absorbed it the first time it was given:

“...we make a lot of assumptions without having that opportunity to say, “Well actually, what do you need? What kind of information do you want at the moment?” “Okay, you might not take it all on board but I’ll come and talk to you in another week.” That kind of thing about giving them that point of contact, that touch base that they can ask for that information.” (S07, Consultant in Intensive Care Medicine).

Staff perceived that the delivery of personalised information, either face-to-face, over the telephone, or in the form of individualised letters was the most beneficial approach for patients and families. Their reservations lay in the fact that they did not have the time to provide information in this way for all patients. Staff also raised the issue of being unable to address particular patients' information needs, such as enquiries about financial and social issues:

“Yesterday I spent some time trying to find out how do we get somebody from Citizens Advice or Advocacy in to see that person because I don’t know how to advise him about what to do in the longer term about his financial situation and that’s certainly not my role.” (S06, Psychologist).

4.5.3 Using innovation to provide information

Some staff discussed the possibility of moving away from traditional face-to-face forms of information provision because there were limited resources to provide it:

"I think we sometimes think that we have to cover all bases in one leaflet or one appointment and actually, you know, if we're really going to be effective about what we're doing, we need to think about those kind of non-personnel based interventions, because there's limited resources for that." (S07, Consultant in Intensive Care Medicine).

Instead, they suggested meeting patients' needs in more innovative ways such as the use of technology and web programmes. Staff suggested that educational and instructional resources, for example podcasts about recovery, or relaxation tracks for anxiety, could be provided on the CrCU website or on social media platforms. Providing a range of information in such media was felt to have the potential to inform a large number of patients, relatives and even staff. Staff described many resources already available for patients, such as information websites for patients after critical illness, but felt they did not routinely inform patients about how to access them. Staff felt that the use of media platforms such as Twitter, Facebook and Youtube could be readily accessed by many patients and relatives on their smartphones, computers, e-readers and iPads. They suggested patients needed information that listed resources and links for how to access these media platforms.

4.6 Summary of Staff Findings

This chapter has provided a detailed overview of the key findings from the staff interviews. Staff involved in the care of patients following critical illness discussed their roles and experiences of providing services and care. The subjects they discussed were informed by their experiences of caring for patients in their current and former roles. Four major themes were identified; 'planning for change,' 'continuity,' 'needs and expectations' and 'information provision,' each with a range of sub-themes.

Staff awareness of the issues patients faced was based around their interactions with patients whilst providing services during recovery. They identified a wide range of issues for patients using current services. Staff felt that patients were involved in a series of changes following critical illness and described transitions over boundaries between CrCU, general wards and community settings. Staff perceived that moving from one setting to another during recovery meant a reduction in the intensity of care which made patients feel vulnerable and unsafe. Transitions in care were also a major

concern for staff as they had implications for patients' continued safety and ongoing progress. Staff recognized the need for careful planning to ensure that all ongoing plans and resources for their care were organised. When transfer to the ward was rushed and the patient not optimally prepared for transfer, the patient's safety could be compromised and there was increased risk of deterioration in the patient's condition resulting in potential readmission to CrCU.

Staff considered the challenges to providing continuity of care for patients during recovery. Care was considered to be fragmented between various healthcare settings and professionals and no one member of staff coordinated care for patients throughout their recovery. Staff in different healthcare settings worked in isolation and their expertise was based upon their own specialties. No staff member felt responsible for the entirety of the recovery journey. CrCU staff focused on acute care provision and did not consider the whole continuum of the recovery journey when delivering care. Ward-based staff had little knowledge about common experiences for patients on CrCU, such as delirium. GPs were reported to receive limited relevant information about the CrCU stay and what to anticipate during recovery. This compromised the ability of staff to identify patients' physical and psychological needs and secure appropriate support throughout recovery.

All staff highlighted how their roles in providing services during recovery were only one part of their workload. As their roles were multifaceted, staff had to select which facet of their role they prioritized, and staff considered the recognition and treatment of the acutely ill patient was most important. All staff recognized that the needs of recovering patients were not always met but felt that these were in areas that were outside of their sphere of influence and they did not feel it was their responsibility to change. Staff felt that their workload overwhelmed their capacity which resulted in them selecting the aspects of care during recovery that they believed were most important to address. As a result, staff believed that for some patients, their psychological and rehabilitation needs were potentially unmet.

Staff identified that patients had psychological issues related to their CrCU stay and acceptance of personal change during recovery. They discussed nightmares, traumatic memories and PTSD related to CrCU delirium and identified that patients benefitted from discussing these experiences. Staff considered it was problematic to identify psychological issues outside of the CrCU setting as patients were reluctant to discuss these issues and ward based and community staff were unaware of the issues. When

psychological issues were identified in hospital, patients were usually referred to the CrCU psychologist. Staff felt they did not have appropriate skills to manage patients' issues and the psychologist was better able to address patients' psychological needs. The CrCU follow-up clinic was considered the best place to manage patients' psychological issues, though staff acknowledged that the number of patients invited to clinics was restricted. Staff felt that more patients should be invited to follow-up clinic in order to meet their psychological needs.

Limited resources were considered to constrain both the services provided, and the time staff had available to secure further resources or evaluate and improve current services. Several examples of services needing improvement were discussed, such as the ineffective selection criteria for invitation to follow-up clinic and the underuse of the Call4Concern service for patients following transfer to the ward. Information provision was considered a key development opportunity. Staff considered care for patients and families could be enhanced by providing appropriate information for patients and families, at the optimal time and in the most appropriate format. They also felt that better handover of information about the patient's CrCU history, incorporating important rehabilitation plans and indicating potential problems to anticipate during recovery, would improve continuity of care for patients. Viewing recovery from the vantage point of being a continuum prompted some staff to suggest that, ideally, services should be more flexible and personalised in order to react to patients' varying needs across different time points. The next chapter will describe the patient findings. A summary table of the staff findings can be found in Appendix 7.

5 FINDINGS FROM THE PATIENT INTERVIEWS

5.1 Introduction

In this chapter, findings from the analysis of the patient interview data are drawn together and presented. This study involved video recorded interviews with 10 former critically ill patients. Their routes into CrCU were many and varied, as was the impact of critical illness on their lives, both during and after recovery. The characteristics of the patient participants are presented in the next section, followed by a description of the major themes and subthemes identified from analysis of the interview transcripts.

5.2 Characteristics of the Patient Sample

10 patients were interviewed, six male and four female, between the ages of 34 and 69 years. The types of admission varied, with two being emergency medical, four emergency surgical, three elective surgical and one a major trauma admission. The patients' length of stay also varied considerably, between 24 hours and several months. The patient characteristics and CrCU events are summarized in Table 5.1.

Patient Number	Characteristics	Admission type	Significant critical illness events
P01	60 year old male	Emergency medical admission	Admitted to critical care with a cardiorespiratory illness requiring sedation, mechanical ventilation, and transfer to another hospital for major surgery. He had a very prolonged critical care and hospital stay which was associated with a number of complications including acute renal failure and requirement for a tracheostomy to help him wean from mechanical ventilation.
P02	69 year old male	Emergency medical admission	Admitted to critical care with cardiac illness requiring sedation, mechanical ventilation, and transfer to another hospital for major surgery. Required readmission to critical care due to sepsis and experienced a number of complications including repeated episodes of delirium and acute renal failure.
P03	61 year old male	Planned surgical admission	Admitted to critical care following major gastrointestinal surgery and received routine post op care involving a 4 day stay on the unit. Required readmission to critical care with complications related to surgery and had a prolonged stay on the unit. He experienced repeated episodes of delirium and required a tracheostomy to help him wean from

				mechanical ventilation.
P04	69 year old female	Emergency surgical admission		Admitted to critical care with an invasive soft tissue infection. She underwent repeated surgical treatments requiring a general anaesthetic on several occasions. During her critical care stay she experienced repeated episodes of delirium.
P05	60 year old male	Emergency surgical admission		Admitted to critical care following major emergency cardiothoracic surgery performed whilst the patient was awake as he was unsuitable for general anaesthetic. He had a 24 hour post-operative stay in critical care prior to transfer to the surgical ward.
P06	69 year old female	Planned surgical admission		Admitted following major gastrointestinal surgery which was associated with several complications and required repeated surgeries. During her hospital stay she was readmitted to critical care on numerous occasions and required sedated and mechanical ventilation. She experienced repeated episodes of delirium and other complications.
P07	60 year old male	Planned surgical admission		Admitted following major gastrointestinal surgery for routine post-operative care. Experienced complications and was readmitted with pneumonia requiring sedation and mechanical ventilation. Recalled one episode of delirium on critical care.
P08	50 year old female	Emergency surgical admission		Admitted with respiratory difficulties requiring repeated episodes of sedation and mechanical ventilation. Required transfer from critical care to another hospital for specialised surgery. Experienced small number of delirium episodes.
P09	62 year old female	Emergency surgical admission		Admitted to critical care following acute deterioration on the surgical ward due to sepsis. Required emergency intubation and mechanical ventilation during her critical care stay. Experienced a small number of delirium episodes. .
P10	34 year old male	Emergency major trauma requiring air ambulance transfer to hospital		Admitted to critical care following major trauma and requirement for emergency surgery. Required intubation and mechanical ventilation on critical care and had repeated orthopedic surgical procedures for multiple fractures. Had extensive episodes of delirium and prolonged immobility due to injuries.

Table 5.1 Characteristics of the patient participants

Stories of participants' recoveries were closely interwoven with their experiences of acute critical illness and their time spent in the CrCU unit. All participants experienced physical, psychological and social impacts during their recoveries. The major themes from the patient interviews were described as a 'Recovery Journey' to illustrate the main impacts critical illness had on participants and the ways in which they dealt with

these impacts. ‘Recovery Journey’ encompasses four major themes: ‘surviving,’ ‘towards independence,’ ‘reconstructing reality’ and ‘reshaping identity. Subthemes emerged in relation to all the major themes, as shown in Figure 5.1.

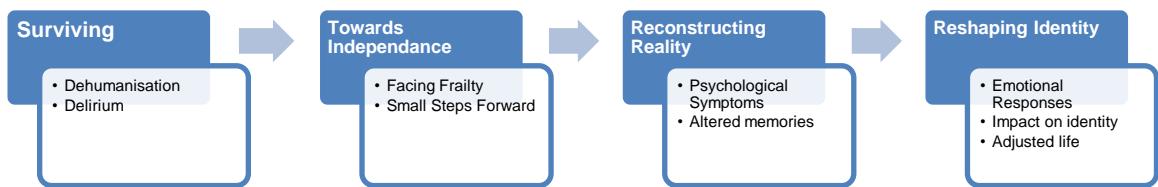


Figure 5-1 Major themes and subthemes from the patient findings

5.3 Theme 1: Surviving

The ‘recovery journey’ begins within the CrCU setting because patients’ CrCU experiences were inextricably bound with their recovery journeys. In CrCU, patients were immersed into a sterile clinical setting, and introduced to a myriad of healthcare staff and unfamiliar hospital routines. Surviving was a major theme to emerge from the patients’ experiences of CrCU. Whilst survival from critical illness was a reality for all the patients in this study, ‘surviving’ encompassed how patients experienced their CrCU stay as an ordeal to be endured. In CrCU, the patients encountered acute changes from their normal lives and social environments. In this setting they diminished as people and changed into passive patients who had to adjust to new norms and adapt to their changed circumstances.

Two sub themes were associated with surviving: dehumanisation and delirium. Dehumanisation describes how participants experienced uncertainty, vulnerability and loss of individuality associated with their critical illness experiences and the CrCU environment. This diminished their agency, leaving patients surrendering control of their circumstances to healthcare professionals and focusing instead on surviving through their CrCU experiences. Delirium describes participants’ experiences of intensive care unit delirium, which affected nine out of the 10 participants in this study. Delirium increased patients’ isolation from reality and was often associated with terrifying hallucinations and nightmares which patients could not control and had to endure during their CrCU stay.

5.3.1 Dehumanisation

Despite being interviewed between one and four years after their CrCU admission, nine out of the 10 participants had vivid recollections of CrCU, which were demonstrated in the language they used to describe their CrCU experience and how they felt in that

setting: “*restricting*,” “*lonely*,” “*boring*,” “*trapped*,” “*imprisoned*,” “*disorientating*,” “*confusing*,” “*painful*,” “*uncertainty*,” “*worry*,” “*fear*,” “*torture*,” “*frustrating*,” “*struggle*,” “*horror*,” “*helpless*,” “*weak*.” The language suggested that at the beginning of the critical illness journey, participants’ experiences were unsettling and challenged their defence mechanisms.

Most participants found CrCU to be an unfamiliar and unpleasant setting, which was far removed from the familiar aspects of normal daily life. The lack of windows and daylight gave the impression of being somewhere ‘*dark and dingy*’ (P01). Limited natural light and varying artificial light levels made it difficult for many participants to differentiate between day and night and participants found the constant environmental noise to be disturbing. In this environment, participants often became sleep deprived which led to disorientation:

“And that was one of my biggest problems, sleeping, critical care especially because it is twenty four-hour noise, you know? Obviously, they’re caring for people twenty-four hours. There’s a lot of things going on, a lot of machinery beeping so it was difficult. And initially when I woke up as well, there were no windows, so you had no concept of time whatsoever.” (P01).

As participants were often lying down, they spent most of their time looking at the ceiling listening to the noises around them which meant that they experienced an incomplete perception of the environment and staff:

“...people would look over you and talk to you but because you were always looking up at them, everybody looked the same. They all looked like dolls.” (P01).

Immersion into the clinical environment, with the anonymisation of staff and the disturbance to sense of time and place, was depersonalising for participants. In addition, feeling drowsy due to lack of sleep and the effect of medications meant that several participants had disturbed cognitive function, and this made them less able to think clearly and to process information about what was happening to them, lessening their autonomy and increasing their dependence on healthcare staff to make decisions and plans on their behalf:

“...if I could think what hell was like, that was getting close to it because I didn’t understand why I was there. And I didn’t understand what was going on.” (P07).

The removal from everyday routines such as dressing and mealtimes further distanced patients from their normal lives. Patients described frustration with being unable to eat, drink or swallow. In addition, monitoring and equipment severely limited movement, requiring toileting and hygiene functions to take place at the bedspace and compromising their privacy and dignity. The impact of this was to make patients feel distanced from their normal individual selves and become more like anonymous patients.

"I mean one of the things that – and this gets a bit personal – but I had to have some suppositories and they had to give me a sample bottle with a pill in so I could attract their attention [by shaking the bottle] because of course I didn't have a buzzer where I was if I needed to use the bedpan. Yeah. So, yeah, there were times when I thought it's not really an environment for somebody who's awake – as awake as I was, you know what I mean." (P08).

The environment precluded the use of mobile phones or internet connectivity for media devices, and many patients had concentration problems, leaving them feeling socially isolated. This was compounded by the bed spaces being far apart which prevented interaction with other patients. Patients could feel further isolated when they were nursed on their own in side-rooms in which they felt unobserved and more vulnerable:

"It must have been about three or four inches of blood in the sink and in the end I pressed the red button a few times but nobody came, so in the end I broke the isolation rules and walked out of the room to call for assistance which was very slow in coming as well because one nurse said, "I don't deal with you," and didn't come." (P02).

For some patients, isolation was associated with psychological consequences such as panic attacks (P02), nightmares (P04) and paranoia (P07). These reactions made patients withdraw more from staff and family which compounded their isolation by creating greater distance between themselves and potential sources of help and support:

"...I felt like I'd been put in a dungeon. And I don't know if you become paranoid when you've been in a place like that." (P07).

Some patients perceived the CrCU environment to be sterile and the care to be depersonalised and non-empathetic. Patients felt ignored by the approach of healthcare staff who focused mainly on the patients' monitoring and electronic records rather than interacting with them personally:

"They're very good but there's not a lot of personal care because the staff tend to just stand at computers and they just watch the monitors constantly and even to attract their attention was quite hard... if they're stood looking at their monitors they don't see you..." (P09).

"I felt on my own... and there were nurses around. There's been people, spoken, obviously came and cared, but I did feel alone a lot. But I don't know what you could do about that because you can't do a one to one with somebody just sat by your bed just to have a chat really." (P08).

In the busy CrCU setting, some patients perceived that personal interaction, including introductions, explanations regarding treatment and rationale for the care being provided, was not a priority for the staff. Patients did not feel very visible as individual people in this setting despite being attached to monitoring equipment and receiving interventions targeted towards their physical recovery:

"A lot of it is fear and wanting to escape when you are in critical care. I know they've got to have a sterile environment and they've got to be quiet and they've got to be able to watch people for things but sometimes I think if there was more communication, even if it was just when someone came up to you they would take your hand and say, 'I'm Dr so and so, now we're just going to look at this because it's not looking very good and we want to make it better,' something like that." (P06).

For many patients, sudden physical illness was an event in their lives over which they felt no control and made them fully reliant on the healthcare team:

"...we all realised at that particular time in our life we had no control of what was going to happen, none whatsoever." (P05).

Patients retold many stories about the events in CrCU, in which they positioned themselves as powerless recipients of treatment with little or no control over their situations. Sometimes CrCU practices, such as ward rounds, actively excluded patients from discussions and decision making about their healthcare plans and treatment. This emphasised the power imbalance between healthcare staff and the patients:

"The doctors used to do the rounds every morning, it was part of the day I used to dread.... you might very often see up to twelve, thirteen people gathered around your bed and you could hear them talking about you but nobody's talking to you...one particular day, the doctor came over to me and said, 'We're going to put DNR above your bed, do you understand what I'm saying?' I said, 'Well, that's do not resuscitate,' and she said, 'Yeah'. And I was in no fit state to kind of argue with her whether I agreed with it going up or not, I just thought I had no choice in it anyway. So, that scared me because I thought I must be in a bad way..." (P01).

Patients were disempowered by their lack of understanding about their condition, their treatment options, or the reasons for the multiple interventions delivered by the healthcare staff in order to treat their illnesses:

"I knew that the only way to get out of there was to do what I was told and listen to what was being asked of me..." (P03).

Some patients felt vulnerable as passive recipients of unpleasant procedures carried out by members of the healthcare team, whilst simultaneously being reliant on other healthcare staff for advocacy and support:

"One thing they did do I remember was they attempted to drain one of my lungs but it had to be done while I was conscious and I couldn't have a lot of sedation because my sats [oxygen saturation levels] were very low...I just remember the horrendous pain of having that done and one of the nurses stood with me and let me hold her hand like and she realised when I couldn't stand any more and she actually stopped them carrying on with the procedure. But by that time, I think they'd more or less done what they needed to do anyway." (P01).

Patients also described how they were uninvolving in decisions regarding their transfer from the CrCU unit back to the ward setting. At the time of transfer to the wards, many patients were becoming aware of how frail they were and their dependency on the healthcare team to meet their needs. They worried that their safety and progress may be compromised by moving to the ward but felt they had no choice in the decision:

"I knew that I needed more time in that recovery, in that cotton wool recovery if you will, where it's more the staff looking after me because I couldn't do it myself. I just felt completely helpless and very, very weak." (P03).

Whilst many patients perceived this transition as a marker of progress in their condition and felt relief at the prospect of leaving the CrCU environment, some patients doubted their readiness for the move and were frustrated that they did not have the opportunity to discuss this with staff or to voice their concerns:

"And I was quite scared of leaving ICU, I was frightened really because I was very well cared for there and I wasn't sure what was going to happen when I left..." (P09).

Patients were anxious about what to expect on the wards and how they would be able to cope without the high level of care and surveillance they had become familiar with on CrCU.

5.3.2 Delirium

Nine out of the 10 patients experienced some incidences of delirium related to their stay in CrCU. Few patients labelled their experiences directly as delirium even though their descriptions of hallucinations, nightmares and unreal memories were definitive characteristics of CrCU delirium. Most patients preferred to reframe their delirium experiences in terms of altered mental states: “*the mind played tricks,*” (P03, P07, P08), “*think silly things,*” (P04), “*in a dark place,*” (P02), “*lose your mind,*” (P06), “*in an alien place,*” (P06), “*weird and freakish,*” (P01), (P07), and “*drift off into gibberish*” (P10).

For many patients, their episodes of delirium were associated with frightening hallucinations and were amongst their worst recollections of CrCU:

“I apparently threw pills. I apparently queried the pills that they were giving me, I used to ask [my daughter] to see what they were. I apparently had a fight with some male nurses. I don’t remember a thing about that, and that’s not me. I apologised profusely on that one because I just can’t believe I did anything like that. I had nightmares of things about my son, about my daughter; I had all sorts of things. And these were preying on my mind even when I came out of whatever delirium I was in, and it was the most horrible experience ever.” (P02).

Other emotional responses described by patients in relation to delirium were: “scary,” (P01), “fear, guilt, embarrassment, horrible feeling, amazement, disbelief,” (P02), “fear I was going to die,” (P04), and “panic” (P10). Common features associated with descriptions of delirium included feeling trapped or imprisoned or being in a different setting entirely such as on a boat or plane:

“I was somewhere else, I was on a pile of pallets. I felt like an asylum seeker trying to get into the country because I was on a ferry on top of a – hiding on top of a pile of pallets. I had to pull this out of my throat and someone was saying, ‘She is pulling the tubes out, pulling her tubes out,’ and they were dragging me across the top of the pallet. But you see I wasn’t seeing them as saving me or helping me, I felt I was in an alien place, that’s the word for it.” (P06).

For some patients’, their experiences of delirium in CrCU were often associated with combative, accusatory, uncooperative or disruptive behaviour:

“Apparently if anything was left around me I used to put it under the pillow. I used to stuff things under the pillow. I don’t know why. But this was perhaps – perhaps I was planning an escape which when you feel that you’re in a confined space and you are being held there.” (P06).

Feelings of paranoia meant that some patients did not share their experiences with staff or family members at the time, which limited their access to rational explanations, support and treatment for their delirium episodes and caused further isolation:

"I thought they were getting ready to take me up there to experiment on me and they were going to kill me. And that was horrible. And my family was coming in and I didn't tell anyone and that was a horrible feeling...I just kept it to myself...I thought I was going to die." (P04).

Lack of understanding of the nature of delirium also meant patients could be too embarrassed to share their experiences longer-term, meaning they did not receive help during their recovery after CrCU:

Interviewer: "Did you tell anybody about seeing Elton John?"

Participant: "No, did I heck. You know?"

Interviewer: "Have you ever told anyone?"

Participant: "No. No"

Interviewer: "So, why haven't you told anyone?"

Participant: "Embarrassment I suppose, you know, I don't know. It seems just freakish. Weird." (P07).

When patients shared their experiences of delirium episodes with their family, they found them to be a source of comfort and support and also helpful in reorienting them to what was real by correcting them when they were '*mixed up*' (P10):

Participant: "I phoned my dad up in absolute tears at eleven thirty at night."

Interviewer: "What did your dad do?"

Participant: "He was just talking to me and I had my head under the covers and it was just...he was trying to calm me down and after about 30 minutes he managed to calm me down enough." (P10).

Delirium was a significant experience for patients that occurred during their critical illness and treatment. Patients were unable to comprehend or control their episodes of delirium. Instead, delirium added to the unpleasant aspects of CrCU that patients had to endure. Even a single episode of delirium could disrupt patients' sense of normality and added to the dehumanising features of critical illness by further distancing them from family and staff. When patients experienced prolonged episodes of delirium, in which they acted in uncharacteristic ways, this distanced them even more from reality and was associated with unreal memories and memory gaps during recovery.

5.4 Theme 2: Towards Independence

This section describes how patients came to terms with the immediate aftermath of critical illness. Most patients experienced their CrCU stay as a ‘*bit of a blur*’ (P05) in which they often had periods of altered consciousness. Following survival from critical illness, ‘Towards Independence’ describes how patients were left facing unexpected frailty and physical changes and were heavily dependent on others to meet their everyday needs. For all patients, this was the beginning of a prolonged battle to rebuild their strength, recover their autonomy and regain their independence. Sub themes associated with ‘Towards Independence’ were ‘facing frailty’ and ‘small steps forward.’

5.4.1 Facing frailty

All patients experienced frailty resulting from their critical illnesses. Frailty was associated with extreme physical weakness, weight and muscle loss, setbacks in their condition and sleep disturbance. Patients experienced weakness even if their stay in CrCU was short. For those with longer stays and prolonged inactivity, their physical weakness was more profound and their recovery period extended. Physical weakness made patients feel helpless, vulnerable and disheartened:

“I couldn’t get out of bed so I was so weak. I think that was another part of the illness you don’t realise but I’ve always been a strong person but I just couldn’t do anything I was so weak...it felt awful because I’ve always been independent...” (P04).

Patients described feelings of uncertainty and fear about whether their physical weakness would be a permanent consequence of their illness, leading to chronic disability:

“I’ve often spoken to people whose life has been dramatically changed by an illness or disability or an accident and I know what consequences that can have. So, yeah, it was frightening in that respect.” (P08).

“Eventually I got stood up, and I thought, ‘I’m never going to walk again’...I just felt that a big part of my life was gone. (P07).

All patients experienced some weight loss in CrCU and for some this was extreme and associated with loss of muscle mass, compounding their physical weakness. This made them feel “shattered” (P03), and “old” (P02), and played a large part in their ongoing frailty during recovery from critical illness:

“When I came out of hospital after my heart surgery, I was sixty nine kilogrammes so I’d gone from being overweight to being underweight. But at

that point, I'd no definition of muscles in my legs and arms and everything. I was just literally skin and bone.” (P01).

“I was fifteen stone, I’m now down to ten and a half stone and I’m struggling to walk up and down corridors...” (P03).

Some patients talked about how appetite changes complicated their attempts to gain weight and build up their strength and many found themselves in the unfamiliar position of having to force themselves to eat:

“I was very slow in getting better because I wasn’t eating and I didn’t like the food, I felt sick all the time.” (P02).

Most patients experienced sleep disruption and described this as an impediment to their recovery efforts. Many patients, unable to lie in their familiar and preferred position for sleep, were forced to sleep supine due to equipment such as intravenous lines and pumps, and treatments such as arm and leg braces. This was uncomfortable and disrupted their sleep. In hospital, all patients referred to the high noise levels and continual disturbance during both day and nighttime:

“...the second night I was transferred at like three thirty am, four am in the morning to another ward. I understand why these things happen but it’s not conducive to a peaceful, restful recovery.” (P08).

“And the lights I think were supposed to go off at ten but quite often it was eleven and then it wouldn’t be very long before the lady in the next bed would start. So I mean she was elderly, she had dementia as well so that didn’t help.” (P09).

Physical conditions and medications could frequently disrupt patients' sleep patterns, even on returning home. This caused persistent lethargy that disrupted patients' efforts to rebuild strength and resume activity:

“I’m tired all the time, you know, and I have a lot of catnaps and feel that I want a lot of catnaps.” (P03).

“I couldn’t sleep at night. It was three am and then I’d go to sleep...” (P02).

Several patients also woke up abruptly due to nightmares about CrCU, which interrupted their sleep and in some cases prevented them from going back to sleep for fear of experiencing further unpleasant dreams:

“I had been having some very bad dreams...all I can remember they were vivid and they were very scary, very scary. I do remember one night, I don’t think I slept more than about ten minutes, because I was frightened to go back to sleep.” (P05).

All patients felt shocked about the extent of their physical weakness and, for some, how suddenly this had happened to them. Most patients had incomplete memories of their CrCU stay and did not recall how sick and incapacitated they had been. This meant that they were unprepared for the weakness that followed. Other patients compared their circumstances to past experiences, such as prior illnesses, procedures and surgeries, which influenced their recovery expectations:

"I did not expect to be so incapacitated as I was ...and I compared it when I had a quadruple bypass and it was very similar but by the third and fourth day I was walking the length of the ward, but I couldn't with this." (P05).

Some of the patients who had planned admissions to CrCU described how the preparation for their treatment and CrCU admission was misleading, leaving them unprepared for the nature of the events which unfolded and the impact these would have on them. These patients based their expectations upon the standard pre-operative verbal and written information which outlined the typical surgical pathway and excluded explanations about the likelihood and impact of complications:

"Before I was ill, I was supposed to go in hospital, be out in five days, back on my feet and away. Up and running. And that sounded brilliant to me, you know?...Never, ever dreaming that I was going to come out of hospital in this condition." (P07).

"Well I'd read all the leaflets and I thought, oh well, a couple of weeks, I'll get over this and then I can carry on with my life. Well unfortunately that didn't happen... I certainly didn't expect complications." (P06).

All patients were dependent on others to some extent to meet their personal care needs and families often provided very practical help. In hospital, families supplemented the care given by staff and they often continued this care when the patients returned home. Sometimes family members took ownership of aspects of the patients recovery process, such as preventing them from doing too much too soon, ensuring they ate healthy meals and that patients took exercise, even joining them in healthy activities:

"And I read this booklet and they says walk a lamppost a night, and I have a wife who, when she's told to do something she does it, which then passes on to me. So, we were walking a lamppost a night." (P02).

The patients acknowledged both ward-based and community-based physiotherapists as important to their recovery due to their efforts and perseverance in helping patients

to rebuild strength and mobility. In particular, physiotherapists were perceived to be encouraging and enabling of patients' self-efforts:

And there was a young lad there, a young physiotherapist and he was brilliant. Like a drill sergeant. He got me a pair of crutches and he marched me up and down that passageway and there were no saying, "I'm not doing it." And that started me road to recovery because from thinking, "I'm not going to walk again" to actually walking with crutches, it's a big step." (P07).

Whilst patients experienced immobility and dependency on staff and family as a result of critical illness, rebuilding strength and regaining independence required them to adopt a more active role during their recoveries.

5.4.2 Small steps forwards

For all patients, physical weakness persisted for weeks to months after hospital discharge, which exacerbated their efforts to regain their independence. Most patients felt completely unprepared for the length of time and amount of effort it would take them to regain their strength. Ongoing frailty continued to affect most activities of daily living once they returned home:

"Well, I was actually in bed I would say for about a month when I went home off and on, more in bed than out of bed...it was the weakness that I couldn't do anything, I couldn't take a top off a bottle, I had no strength at all..." (P04).

Even when patients had regained some mobility prior to hospital discharge, this could itself create a false sense of their own strength and abilities and it could be difficult for them to understand how weak they remained in comparison to their pre-hospital fitness:

"I didn't realise how weak I was until I had to walk out the hospital and walk to the car and it was exhausting...I didn't realise that, you know, because I hadn't really walked anywhere for weeks." (P09).

'I felt very weak. I was hoping to walk out but my wife said no way, the sister said no way, you are going in a wheelchair...So my wife wheeled me up the corridor in a wheelchair, I think that dented my pride a little bit but I thought I'll live with this. I remember her words were, 'Be quiet, you're alive', so that ended that argument.' (P05).

For most patients, frailty and physical weakness meant that rebuilding strength and regaining independence was a gradual process which required sustained efforts:

"I just saw it as stepping-stones of, "Right, do this, do this, do this and right, what's next? What's the next focus?" (P10).

Most patients experienced a sense of reward, elation and renewed self-confidence as their strength grew. For some, physical improvement in their condition, their strength and their mobility marked the beginning of their recovery:

"One of the carers...said, 'Come on, we're going to get you outside today'. And we walked outside in the fresh air and that was the first time I'd done that....So, that was the start of the recovery and I knew that things were gradually getting better." (P01).

"By the fourth and fifth day I was walking down the ward doors and back unaided...So my spirits were really starting to jump up and down by then; I thought I'm getting there now." (P05).

As patients became stronger, they were motivated to embrace more activities for themselves and took greater personal responsibility for healthy actions that promoted their recovery. Most patients set small, incremental goals towards self-directed targets. Whilst patients were striving towards different end goals, in the early stages they all focused on regaining more independence and reclaiming some of the activities associated with their normal lives:

"The first target was the clinic and I'd walk backwards and forwards to there. Then round a small block and we bought a dog.... I felt pretty confident that I'd be able to make these targets. I felt – I know you can't feel recovery like that, but I felt different every day...It came to a stage where suddenly I felt, well, I'm getting better all the time." (P02).

Setting small goals helped patients recognise the progress they had made and provided considerable motivation to keep going. They also boosted patients' confidence that they could achieve the targets they set, encouraging them to set more ambitious goals. Goal setting was an important aspect of the recovery process that helped patients to move from self-care to more progressive targets, such as doing the shopping, walking for a set distance, driving the car and taking a holiday. In this way, goal setting moved them towards independence and helped to regain some normality in their lives.

5.5 Theme 3: Reconstructing Reality

In this section, the third stage of the participant recovery journey, 'Reconstructing Reality' is presented. Patients described ongoing psychological issues in relation to their episodes of delirium in CrCU and their unreal and partial memories of what happened during critical illness. 'Reconstructing Reality' is associated with two sub themes, 'psychological symptoms' and 'altered memories'.

5.5.1 Psychological symptoms

Patients reported a range of psychological symptoms following critical illness and the impact these had during recovery. The symptoms they reported are associated with PTSD which is a recognised complication of critical illness, known to occur clinically or sub-clinically in patients during recovery.

A common experience was for patients to experience dreams and nightmares about CrCU that woke them up in a panic or prevented them from going back to sleep. Patients also reported intrusive thoughts and scary flashbacks of CrCU which made them feel they were back in the CrCU setting:

“...sometimes there are medical programmes, dramas on, someone is in hospital in the programme, and there’s all the beeping and the carry on that you get in critical care and that takes you back.” (P06).

“And I used to wake up in a sweat and then think oh you’re not there [critical care] anymore, you know?...I used to have weeks that if something would trigger and I’d think about that room [on critical care] and about that feeling I had and all of that and I used to cry, I used to sit and cry.” (P04).

One patient reported feeling a fear of the dark, and another described panic attacks, in both cases they attributed this to the CrCU unit:

“...for what seems like a year I had a nightlight on in my bedroom at home. And I put it down to ICU [critical care unit] because I’d never ever been frightened of dark before.” (P07).

“When I had some visitors, the phone rang and somebody else wanted to visit and I said, “Yeah, come after dinner,” or “come tomorrow,” or something, and then I had to grab hold of [wife’s name] because I was having a panic attack saying, “No, I don’t want them to come.” (P02).

Nearly all patients referred to these psychological symptoms in a non-medicalised language. Before their episode of critical illness, most of the patients had not had any prior experience of having psychological problems. Most patients considered it to be completely out of character for them to experience psychological problems and they had difficulty accepting they were happening:

“I just can’t believe I’m talking about these, because I didn’t think I’d have anything like this happen to me....” (P02).

“My mind isn’t broken but it’s telling me all these weird things.” (P10).

These patients had a reluctance to share their experiences with other people, especially if they were strange experiences related to delirium. Patients reported not

wanting to be thought of as having mental health problems, suggesting that this is a stigmatised issue:

“Because I’m not soft, well I don’t think I am, anyway. I said, “This isn’t me. I’m not stupid.” (P02).

“It didn’t matter that they saw what was wrong with me [physically] because that will get better, that will heal up...but when it’s in your head people can’t see it and I think if they hear what you are talking about it might give them the impression that you’re not a full shilling². ” (P06).

In patients who had previously experienced psychological issues, critical illness could exacerbate pre-existing mental health conditions. One patient had previously been diagnosed with PTSD following military service and immediately recognised the potential for this to reoccur due to the traumatic nature of his critical illness. What started as nightmares and feeling withdrawn whilst in hospital, escalated to fears of becoming depressed once he had returned home:

“I know I got very withdrawn because my wife was getting annoyed that I was pushing her away. And I think I had an outburst of bad temper, no control. I knew this was a sign of trouble. I didn’t really want to do anything...I could feel the pressure biting at my ankles...that’s when I knew that the depression, the psychological side was a possibility because I felt I’m not coping well with these thoughts.” (P05).

Many patients associated their perceived psychological symptoms with having had a life-threatening condition and traumatic memories of CrCU. This was further complicated by patients’ recall of events which occurred on CrCU. Patients discussed both real and unreal events on CrCU and their significant memory gaps which affected their ability to reconstruct a cohesive narrative about their critical illness.

5.5.2 Altered memories

All patients had incomplete memories of their CrCU stay and some had very little or no recall at all. For many, their recollections, and their retelling of events during interview, were jumbled and confused:

“Yes, very little small snippets, but it all gets mixed up in to a, “What’s real? What’s not real?” and again, less at the time but more afterwards, as you talk to people you can start joining the dots up.” (P10).

² “Not a full shilling” is an informal British saying which means ‘of unsound mind.’ wordhippo.com

Patients had an accurate recall of events up to a specific point in the illness pathway, such as clinical deterioration on the general ward (P09) or emergency department (P01, P02), or emergency roadside care prior to being air lifted to hospital (P10). Beyond this point, their memories became mixed up or missing altogether for several days or weeks before the patients next concrete memories of waking up on CrCU, or on the ward following CrCU discharge:

"I can't remember loads of stuff, you know? I mean, my wife will tell me things and I'll say "No idea, no idea. Can't remember." (P03).

Patients' incidences of delirium on CrCU further distanced them from an awareness of what was really happening around them. During recovery, these unreal events were often more readily recalled and were more vivid and real to them than the true events that had occurred on CrCU:

Participant: "I've got photos of me in ICU, my face mask on and I was still chatting away and all the rest of it...I remember seeing this man was flying under [the bed] and I remember seeing a big metallic spider and it was tapping on the top of the roof in a cubicle."

Interviewer: "Were you aware at the time that it wasn't real?"

Participant: "No, it was."

Interviewer: "It seemed completely real?"

Participant: "Yes." (P10).

The impact of altered or gaps in their memories varied between patients. Some were untroubled by their loss of memory and did not feel the need to have more information about the events on CrCU:

"What I don't know isn't bothering me. If something comes back to me then okay. But I'm not bothered about what I don't know. In fact, if I learnt anymore I'd probably be more embarrassed by the sound of it." (P02).

"I've moved on, you've got to move on, you can't keep these things and worry about them or how long were you there, and it doesn't really matter. What's done is done." (P03).

Other patients were upset that they were unable to remember what happened to them during their illness. They wanted to know factual information about their critical illness, when it happened, how it was treated, where it was treated and who was involved. Filling in memory gaps helped patients to understand the finer details and piece together a more accurate picture of events in CrCU. This information gave patients some context to their experiences and helped them to move forward in their recovery.

Family members played a very large role in filling in the memory gaps patients had about their CrCU stay:

“...it was so important for me to find out how it had happened and why...that was part of my healing process because I needed to know what had happened even down to seeing my arm the way it was...so it was all put into context.” (P04).

“A lot of the information has come from my daughters especially and my sister but there’s one or two other family members as well.” (P01).

For some patients, unreal memories did not have any impact, even though the delusions themselves had in some circumstances been frightening and distressing at the time. One unreal memory even appeared to be comforting as it resolved their fear of dying:

“This was not like the hallucinations. This was absolutely clear. It was a white light. It was very warm. It was very comforting. There was a voice that I recognised but I can’t tell you who it was. Yeah. And it made me feel happy and I wasn’t frightened in any way, shape or form.” (P03).

For other patients, unreal memories were distressing as they continued to invade their thoughts in the form of flashbacks and nightmares during recovery. Some patients had more difficulty processing their unreal memories and during recovery were unsure of what had been real and what had not:

“...it’s like what was real and what wasn’t, do you know what I mean? I mean talking about it now and obviously because of the whole experience I can get quite emotional but it’s something that happened and thankfully I’m alright, you know; I need to go forward really.” (P08).

Reconstructed memories could also be distressing for patients when family members shared details of the combative, uncooperative or disruptive behaviours which accompanied their delirious episodes. Whilst patients could rationalise these events and were even reassured that they were normal reactions, this did not appear to completely resolve their lingering emotions:

“It bothers me that I misbehaved like that but it obviously wasn’t me as such. It bothers me that if I was coming out with foul language or anything like that. When people ask me actually, well, I was just in a dark place really, I just cast it aside...but I’m not bothered about it now except my feeling of embarrassment that I did things which I would not have normally done.” (P02).

For some patients, psychological symptoms and altered memories were something that they were able to resolve themselves and which they described as having little impact

on their recoveries. Other patients needed help from CrCU services to meet their psychological needs. Some patients discussed the importance of visits by the CrCU clinical psychologist while in hospital. The clinical psychologist helped them to deal with their fears associated with their CrCU stay and to rationalise some of their unreal memories related to their delirium episodes:

“Seeing the clinical psychologist helped...those visits were very important...being given the time to relate your experiences to someone who knows how to take this information on board...Although we did seem to go over things again and again, each time it seemed as though I was letting go a bit more of the fear and perhaps the memory...I said ‘Well we’re just going over the same ground.’ She said, ‘Yeah, but a little bit more comes out,’ which I felt did unburden my experience onto someone else...I was giving that memory to someone else to think about.” (P06).

Other patients were helped by attending the CrCU follow-up clinic, an outpatient clinic held at the hospital and managed by a CrCU clinical psychologist and a nursing sister from the CrCU unit. Where patients had memory gaps about the details of their critical illness or subsequent physical issues which arose, the clinic appointment enabled them to ask questions and provided explanations which allowed them to put their physical state into context:

“...I could go and see a photograph of my arm...I mean it isn’t very nice but I wanted to see what it was like, what it had done to me...and I could see why they couldn’t stitch my arm up and why I had to have the skin graft because the wound was so wide, so big, so it was all put into context, yeah, it was good.” (P04).

“She [nursing sister] explained clinically what had happened and why this had happened so I was able to understand that then and I was able to set that at rest... I had my own idea that’s what it was but somebody sat there, looked at my notes and said, “That’s why.” So that I was able to come to terms with that.” (P05).

At the CrCU follow-up clinic, patients were also asked about any perceived ongoing psychological issues associated with their critical illness or CrCU stays:

“I had to fill a questionnaire in before I got there...she [clinical psychologist] showed me the score and she said, ‘You’re just on the borderline, but I’ve watched you during the interview [discussion between patient and psychologist during the clinic session]...little nuances were coming out from my body language and how I was actually speaking that things weren’t quite right...things weren’t this big, rosy-coloured garden that I was trying to paint.” (P05).

Three patients also took the opportunity to revisit the CrCU unit, which was offered at follow-up clinic or support group meetings. One participant felt the revisit was not beneficial as they had had a relatively short stay in CrCU. Conversely, for two of the patients the revisit was important in reconstructing their memories and resolving ongoing psychological symptoms such as nightmares:

"I used to close my eyes at night and think, "Oh that room," but once I saw it I thought, "Oh blimey it's just a room in a ward," and that went away." (P04).

"I saw some of the equipment that had been used on me which I found helped a lot because a lot of what had happened I wasn't sure whether I had dreamt it or it was hallucinations due to all the drugs I was on. But when I came face to face with some of the equipment...that put things in context and gave me some sort of reassurance that I wasn't going mad and this wasn't just in my head, it really did happen." (P06).

Not all patients in this study chose to attend the CrCU follow-up clinic or to revisit the CrCU setting. One participant with profound memory gaps about his CrCU stay had not wanted to revisit the CrCU unit. This participant stated that his incomplete memories about his CrCU stay did not affect him though he remained embarrassed about his behaviour towards staff during his delirium episodes on CrCU.

The impact of unreal memories or memory gaps on patients during recovery varied. Some patients were ashamed of the way they behaved during their critical illness, even though they had no recollection of this. For other patients, filling in the details gave context, helping them to understand the nature and consequences of their illness such as frailty and psychological issues. In contrast, a few patients with memory disturbances were unconcerned and did not feel the need for more information or detail.

5.6 Theme 4: Reshaping Identity

Critical illness effected patients far beyond the physical and psychological impact already described. Patients also experienced changes to personal identity, roles, relationships and socioeconomic status. The pre-critical illness health status of the patients in this study varied, as did the events and experiences during critical illness. This meant that patients embarked on their recovery journeys from different starting points. Patients who experienced the biggest physical and psychological impact not only faced a more demanding recovery journey, but also encountered the biggest challenge in terms of adaptation to changes in their identity. Sub themes associated with reshaping identity were 'emotional response' and 'impact on identity.'

5.6.1 Emotional response

The sudden shock of critical illness, surviving the CrCU ordeal, enduring setbacks and complications, and facing profound physical debility had an emotional impact on patients. All patients in this study experienced the events leading up to or during their critical illness as a huge shock:

"I think it was such a shock in my life, it was like a bolt out of the blue." (P04).

"I was quite active and everything, and this knocked the stuffing out of me. It was a big blow to my whole body, not just physically because you lose all your strength and everything, but you feel you lose your mind as well..." (P06).

Patients described being shaken by the CrCU experience, feeling upset and vulnerable in relation to their weakness, disempowered and helpless as a patient in the healthcare setting or due to their dependency on healthcare teams and family. Patients were especially impacted by the continual cycle of setbacks and complications which prolonged their CrCU and hospital stay:

"I've got emotional a few times...I understand now because it could be a reaction to all sorts of things, feeling sorry for yourself, vulnerable, tablets, there's three reasons. Not being able to do things. Feeling frustrated. There's another couple. There are reasons for it. I can appreciate that it happens it's happened to me." (P02).

"I was not strong enough; I was ill all the time; I kept getting infections...that was the time when sometimes I got really depressed about it because I kept thinking every time I'm better I come down with something new, you know? There was... I remember at least three times just- there were points when I just became sick all the time, you know?" (P01).

Patients also faced uncertainty about whether their new physical status would be a permanent one, and feared long-term changes to their lives:

"At first, yeah, I was weepy, very weepy...when you're used to doing everything for yourself and you're used to being so independent and when you can't do those things...I wasn't strong enough and then you get, you know, am I ever going to be strong enough?" (P04).

Another emotional response to surviving critical illness was guilt. Guilt was a multifaceted emotion. One participant reported feeling guilty about having survived yet having difficulty in coping afterwards:

"I was feeling guilty. And I thought here's me, this big, macho man feeling guilty that I've survived a life and death experience and I can't get my head

round it...people said, "Oh you are so rubbish, you should be so grateful"... and I think that started to get to me in the end." (P05).

Guilt was also associated with the stress that patients' illness placed on families and the support families provided during critical illness and recovery. This was especially so if patients felt responsible for their situation and the impact this had on their family and friends:

"And it must have been hell of a traumatic time for him [patient's son]; six times they called him. He lives over Manchester way and six times critical care called him to the hospital to say goodbye. It was that touch and go on a few occasions with the sepsis and the bleeding and everything." (P06).

"I have guilt around the accident in the sense of it was my decision to buy the bike...it was my decision, instead of sitting in the traffic, I decided to pull out and just go steadily past things...So, I see it that I had done it to myself..."This is my fault" is how I look at it, but it wasn't theirs [family], yet they've ended up having to pick up a lot of the pieces about it and you have to deal with the consequences of that." (P10).

Some patients found it difficult to adjust to the physical and mental impact of their critical illness or were preoccupied by the all-consuming efforts needed to recover independence. In this scenario, patients could feel overwhelmed and distanced from others, trying to ignore their fears or feeling unable to speak out about them:

"...when I was on the ward I was laughing and joking and jovial because if you do that then you don't have to deal with anything else." (P10).

"I think the patient has to get over the initial shock of being on the ward....when you've got time to start to think about what's just happened to you...it raises other problems that perhaps weren't there initially because you are trying to get this coping mechanism going then...Perhaps if somebody had spoken they'd have realised that inside I was screaming out...This is the problem. Busy ward, a lot of sick people, very easy to miss something when you are dealing with other things that are far more at a higher priority." (P05).

When emotional reactions remained unresolved in the hospital setting it could become more difficult to face up to them later in their recovery trajectory:

"I push it in to a little box and hide it. If you don't bring it up then it doesn't matter." (P10).

"Well I didn't go to the first one [support group meeting], I bottled out of it. I said to my wife, 'No I'm going to get myself through this, I don't need any help, I'm not that bad'. But it never really went away." (P05).

For some patients, their overwhelming emotions could cause them to become withdrawn and socially isolated. Physical incapacity prevented patients from taking part

in many activities which brought social connection and this sometimes placed a strain on relationships. Some patients described this as like being isolated from the world:

"Well you become impatient as well with people that complain, "Oh I've got a bad back" "My leg's aching." I don't care...my wife said I became very selfish and I became for a long time - the only way to describe it is - in a little bubble and that was for a good year, where you just try and keep everything away and, in the protection, you still survive And the best way I can describe it is that I survived for a year, year and a half; I didn't live." (P10).

"You find that for a while you've got people all around you but you're in this box that it's a lonely box, you know, they're all milling round, they're all doing things, they're either hoovering, plumping cushions, you know? Cleaning, making me a butty and me thinking, "Oh, bugger off," you know? "I want to be on my own."... You feel like you're isolated from the world. It feels like all hope has gone." (P07).

Families often took on responsibility for providing emotional support to patients during their recoveries. This could take the form of listening to patients' concerns, encouraging their efforts in regaining strength and mobility, and at times administering some, 'tough love' to promote the participant's wellbeing:

"I think the secret then is a person that you trust the most to say, "I'm not having a very good day at the moment, I just need to run something by you." (P05).

"Well the first thing was my son played hell with me. I was sat at home in my chair looking miserable. I shan't use the words he used but it was along the lines of, "You're going to die in that chair, get your backside up and get yourself moving." (P07).

Patients also found peer support helpful in dealing with their emotional responses, either by talking to other patients in the ward setting, or, for one patient, the CrCU support group. Talking to people who had been through similar experiences helped patients to learn from others how they dealt with their issues. Patients found it helpful to understand that they were not alone and that the way they felt was common. The CrCU support group was considered to be a safe environment to vent emotions to people who had experienced critical illness:

"I went to it [support group] and that opened and closed the door. I came back from there like the world had been taken off my shoulders because I met people that had gone through similar experiences...we were encouraged to speak to each other and there were facilitators there to help us...I actually felt in a very safe environment..." (P05).

Some patients valued their interactions with members of staff on the wards who chatted to them about things which were happening outside of the hospital and which made patients feel better connected to the outside world. Building relationships with staff and being able to laugh and joke with them improved patients' motivation and mood during recovery, and lessened their feelings of being a burden:

"...the nursing side of it and the personal touch was the great... you got to know the nurses in the sense of that they'd have a bit of fun, they'd come up and chat to you, just to generally chat...it perks you up and keeps you going and you build those relationships..." (P10).

A few patients described how they were visited by a clinical psychologist to help them with their emotional state whilst they were in hospital. In hospital, the emphasis was on fixing physical issues and improving mobility, and some patients found it a relief to have someone to talk to who gave them the space to discuss other issues such as their 'normal' lives and families and how they were feeling:

"She [critical care clinical psychologist] talked about things that the medical people probably wouldn't talk about... just asking about what I did and about the family. Just kind of non-medical things about your health and how you're doing." (P01).

"It was again someone different; it was someone professional to talk to who didn't have an emotional tie in it. Sometimes you just need to empty your head out to somebody...I can't remember talking about my delusions but it was more about my anxiety that was worrying me more." (P10).

Talking to a non-family member and someone independent from the direct care team freed patients from the worry of being a burden and helped them to process their experiences and feelings. It also provided a connection back to the real world and helped them to re-identify with their self as a normal person rather than a patient.

5.6.2 Impact on identity

Identity is associated with the individuality of each participant prior to their illness, which includes their personality, their resilience and their role in society. Whilst critical illness brought about biological changes, it also resulted in unfamiliar emotional responses and a socially altered state. Finding themselves in the unfamiliar CrCU setting, patients lost the ability to control their own lives, and most faced uncertainty about their survival or unpredictability about their prospects for recovery. During recovery, patients experienced both temporary and permanent impacts of their illness on their working, family and social lives. Whilst these scenarios brought about considerable challenges for patients, impacting their self-esteem and self-confidence,

they also brought patients' resilience to the fore, evoking coping mechanisms that helped patients to endure and, in some cases, to thrive.

In the hospital setting, patients became immersed in new mini socio-cultural settings, 'the wards,' and were faced with adjusting to the new norms of each of these settings, such as the medical surveillance of their health and the routines and roles associated with ward life. Most patients perceived the wards to be very busy and several patients described how they felt reluctant to ask for help from the ward nurses who they felt were always under pressure. They described having to wait a long time for attention from the nurses, and felt they had to wait to be mobilised, attain pain relief or sleep medication and other medically prescribed care and treatments:

"Because the workload that they're under I thought was quite intensive...this was a ward that was busy and the staff were working pretty much flat out." (P03).

Patients learnt how to adapt in the ward setting to ensure that their needs would be met. One way was to minimise the amount of demand they placed on the nursing staff. Patients were keen not to appear to be a nuisance and kept their requests to what they considered the essentials they needed:

"I'd like to say I tried to be the best patient that I could. I tried not to ask them for anything unless I felt it was necessary..." (P03).

"You can think yourself into sitting there and letting everybody run around after you. Or you can think yourself into saying, "I'm going to do as much as I can for myself, and then anything else people will see I'm trying to help myself and they won't think I'm a burden, and if I do need a bit of a lift, they'll give us a lift"." (P07).

It was common for patients to compare themselves with the patients around them and to forego their own needs for the benefit of other patients who they considered to be more acutely ill or dependent than they were. Comparing themselves with other patients who were in a worse condition made them feel better about their own situation and feel inspired to keep going. Patients discussed how they felt reassured by these comparisons as they perceived that their own circumstances could have been worse:

"...when you are laying on a ward with people on a lot of life support systems which you're not on, you realise that you're not quite as bad as other people." (P05).

"And one thing that did inspire me was when they decided I had to have a leg brace...I saw some marvellous people there. There were lads there who had lost their legs in the military. Laughing and joking about one leg being shorter

than the other...and I thought, "Well you've got both your legs, it's just one that's not working proper. Just knock yourself together, you bloody idiot." (P07).

In the ward setting, patients appreciated being able to interact with other patients, sharing their illness experiences and often finding humour in their circumstances. Patients 'looked out for each other,' shared ways of coping with their situations and helped each other cope with their situations:

"I think having people on a ward, on a small ward like that, is a good thing if you get the mix right and we did, and we had a bit of a laugh." (P05).

Patients also coped by making comparisons between their current circumstances and worse possible outcomes. For some, this was the knowledge that they had narrowly escaped death which made them appreciate their lives and feel grateful. Others coped by measuring the symptoms of their illness against potentially more severe and debilitating effects:

"I was told that maybe this fasciitis could go on my face, I could have got it anywhere and, you know, where I got it was very fortunate because I can hide it. But I think if it was actually visible I think that the recovery would have been a lot worse for me personally." (P04).

Whilst their altered physical appearances, reduced mobility and inability to perform everyday activities had been demoralising for patients, small successes in resuming self-care activities rebuilt their self-confidence and self-esteem:

"And I think once I had showered myself properly, top to bottom, and was able to get out and towel myself down...my confidence grew again. It was this thing of convincing my body that physically I wasn't this weakling anymore, I was getting back to normal." (P05).

For most patients, leaving behind the sick-role meant a change of outlook from that of the patient to one of a person and member of a wider social community. Whilst this was a welcome transition, it reintroduced some worry and vulnerability. Patients were eager to regain some normality in their lives, whilst being worried about leaving the safety of the healthcare setting in case their condition deteriorated and no one would notice and act on their behalf:

"I got back in my home which is a comfort zone but I suddenly felt so vulnerable it was frightening...I missed the bubble of the ward and the routine, and there was always someone to check that you are okay. It wasn't that my wife wouldn't have done this, I just couldn't get it in my head that I was safe...I think it took 48 hours before I started to feel okay." (P05).

Some patients discussed a point in their recovery from which they felt they had turned a corner from being a sick patient to one in which they felt human again, and were returning to their normal selves. The turning points were self-specified, and did not always coincide with services or physical location, such as transfer from one setting to another. Many discussed reducing their dependence on others and being able to resume some 'normal' activities as key turning points:

"I suppose you're still like a patient even though I was at home. Yeah, I was having a lot of care... And I suppose once I started cooking and things as well, you just feel like you're normal again...I think probably the first time I went to the shops...I was like "Oh. I'm out and about. I'm with normal people." (laughs) "Not people in uniforms or lying in beds." So it's just being back in the world really that was great...And going back to work I suppose was a milestone, "I am normal now." (P09).

"I went to the shop...when I got home I remember shutting the door and I just broke down, I just had the biggest cry and it was relief, relief that I was going to be alright...day by day I was doing more things, and I was thinking, "Oh yeah, you are getting better." (P04).

Many patients discussed how, during the long recovery process, they learned ways to adapt to their circumstances. Several shared experiences which highlighted how they coped with the changes to their identities and approached the process of rebuilding their lives. These included actions that boosted their self-confidence and self-esteem, ways in which they strengthened their relationships with family and friends and how they secured lives that had purpose and meaning to them:

"I'd lost my place in life...I lost my position of being the one that helped to being the one that needed help. And that's partly what made me decide to be more positive in my life and try and get back some of the mobility and some of the positive thoughts rather than the negative thoughts." (P07).

Patients discussed how they took personal responsibility for healthy actions that promoted their recovery. These included ensuring they ate well, performed exercises and practiced mobilisation. When patients approached recovery by setting small goals that they could achieve, they felt more aware they were making progress and experienced a sense of achievement from achieving more independence:

"When I had the bathroom done I moved on and found, well, you can walk now, so there's nothing to stop you getting one of them little trolleys, going to the kitchen, making yourself a sandwich and a cup of tea. You don't have to sit there waiting for somebody else to do it. And then I found that ... there was other things that I could do to get myself independent." (P07).

Many patients reported that returning to work a key stage in regaining their former identity. On returning to work some patients found it to be a welcome distraction from their illness and they valued the social interaction and appreciated the new routine. Some patients described feeling pressure to return to work. They perceived their families, friends and employers expected them resume work and further absence threatened their job security.

"So you have the pressure of your friends, you have the pressure of what you think your boss is thinking, if your staff see you –but at the same time, I needed to go back because I needed something to – in some ways occupy my time but also make me have to get up." (P10).

All patients had times during their recoveries where they faced challenges and had to persevere with recovery efforts despite obstacles and setbacks. They also had to persist with all the hard work required, even when progress was slow or had plateaued altogether. Patients demonstrated a dogged determination to get better and return to some form of meaningful life. Many of the patients described themselves as stubborn, single minded, strong and determined:

"... it was a gradual process. Nothing miraculous happened, there was no miracles. It was more like an endurance run than a sprint." (P07).

I always think that my stubbornness or daftness or whichever way you want to think of it and the refusal to accept is what's got me as far as quickly...that single-mindedness of, "Actually, I will fix it." (P10).

Many patients adopted an optimistic and hopeful approach towards their recoveries. In the CrCU setting some found focussing on the positives helped them endure their ordeal. In the context of the longer-term recovery process this approach could also be helpful when patients were able to evaluate their lives from the perspective of the positive aspects that remained:

"...you've not got to look at what you've lost, you've got to look at what you've got. And ... I've two grandkids, I've three kids, I have a home, you know? So, basically, I had a word with myself, you know?"(P07)

Other patients struggled to adopt an optimistic mindset, especially those whose lives had changed most dramatically and who were left with long-term chronic health problems. Struggling with negative emotionality and finding it difficult to accept their changed realities made it more difficult to recognise any positives:

"I mean I'm absolutely battered, I don't think it should be quite like that...it's come too early for me because I think that I've still got a lot to offer and I feel that's been pulled away from me, the rug's been pulled away..." (P03).

When patients focussed more on the condition they had been in prior to their illness, this placed them under an additional burden of expectation for recovery. These patients had little regard for their incremental successes, instead focusing on how far away they were from their pre-illness state. This made their perceptions of the recovery journey to be a longer, more arduous and demoralising one:

"Right I'm in a condition now where I can live and be quite happy at home living but I want to do that 10k assault course that I said I was going to do before I had my accident so right, what can I do to do it?" (P10).

"It's a real struggle because from having a life of action man where, for want of a better expression you feel as though you can run through a brick wall, I'm now wrapped in cotton wool and I have a rollercoaster ride in terms of my feelings – every day, every week, every month. I try and put in as much positivity as I can but in actual fact life stinks ..." (P03).

One participant always focussed on what he had to achieve next rather than appreciating the successes he had already achieved. The perceived slowness of progress and the inability to resume normal activities was emotionally draining and associated with frustration and low mood:

"I'd got to a point where I'd had enough of not progressing and the slowness of the progression and the frustrations of not being able to work and gradually your visitors tail off...And it was getting to the point where I struggled to get out of bed and that's when I broke and went [to the GP] and said, "I need something."'" (P10).

Serious illness placed patients in a position of unpredictability about their future, and exposed patients to physical changes, limitations, restrictions and emotional responses to these changes. Recovery efforts meant overcoming the sick-role and rebuilding their identities in the social context. Patients adapted to a series of transitions and changes, using their own resilience and any help they could secure to support their efforts.

5.6.3 Adjusted life

Critical illness forced patients into a world with dramatically shrunken boundaries. Hospital and home formed the outer limits of their existences for several weeks to months and many patients found illness to be socially isolating. During the long recovery process, away from normal life and routines, patients adapted to several changes in their circumstances and learned to accept new realities.

Most patients in this study suffered from long-term fatigue which made activities they had previously taken for granted become more tiring. As a result, some patients became less active than they had been pre-illness:

“...so much as I’d like to sort of carry in couches and wardrobes I can’t do it.” (P03).

“I would say about two years after it happened, up to about two years, my energy levels were not good. I was having to go to bed earlier; I couldn’t do the things that I used to do...” (P04).

Fatigue became a new fact of life that patients had to factor into planning activities and excursions:

“You have to plan your day to actually, “Right if I do this, I do this then I’m going to be shattered and then I’m going to end up nagged [harassed by wife].” So, most nights I am now in bed at eight thirty pm because I’ll take myself out in the day time and I get to the point I just go, “I’m going to bed.” (P10).

Other physical changes patients reported were chronic pain (P03), sexual dysfunction (P05), femoral nerve damage requiring a leg brace to enable walking (P07), skin thinning and excess mucus production (P03), vocal changes (P08) and concentration issues (P10). Some physical changes had only a limited impact on patients’ lives, particularly if they were single issues, but when patients experienced multiple chronic physical changes, these were more debilitating and clouded patients’ enjoyment of life:

“I want to get as much out of my life – what’s left of it – as I can. You know? And I want to able to play with my grandchildren and still do these things. It’s restricting at the moment because of the prednisolone that I’m taking; the steroids have a terrible effect on my skin, and breathing problems.” (P03).

Some changes, such as cognitive deficits, impacted many activities that were normally taken for granted and required some patients to make adaptations to the way they planned and carried out activities:

“I still struggle remembering everything day to day...and it’s frustrating that I will go off on random tangents and then I forget what we were talking about...I find I have to make notes...I find driving harder...even my day to day job, my staff have been very good with me and they know that I forget things.” (P10).

Two patients made big life changes following their illness, deciding to retire from work altogether:

“I had to retire...I couldn’t go back because I wasn’t myself so I didn’t feel as if I wanted to go back.” (P04).

I mean I went back to work...I was only back a couple of months and then I finished...I was glad to finish, yeah...My husband’s retired as well now...I

think it's frightened him so much...I mean being ill...having it twice in 18 months does kind of force you to rethink your life a bit." (P09).

For some patients, their life-threatening experiences meant they worried less about small matters, experienced less stress and had a renewed appreciation for life:

"You appreciate everything. Just on a sunny day, I can top up my tan. I just sit out all the time...I do spend a lot of time outdoors because I didn't see any outdoors last year." (P01).

Patients also experienced closer connections with family and friends and increased empathy towards others. Some experienced increased social connectedness with the wider community. Patients expressed their gratitude to families and friends who supported them in so many ways throughout their illness and recovery. In addition to providing care and support, families could be helpful in finding different ways to help patients contribute to family life once again:

"I've started joining one or two groups and doing things with them. I was involved in a march the other day and that was like you know I wouldn't have even been able to do that a couple of years ago." (P01).

"My daughter's a master at it because when my grandson were looking for colleges to go to, normally she would have took time off work, but she let me take him. Gave me a purpose. You know? You're not that useless old bugger that's sat at home doing nothing, you're out helping the family, which I've done all my life, you know, so it's giving me something to do back, and that gives back to them." (P07).

Not all life changes were so positive. Some patients experienced difficulty in adjusting to the loss of their former place or role in life:

"I'm not able to work because of what's happened to me. And to me, it's had a devastating effect because my life has been about sport...I'm just unable to do it. I'm not able to run like I used to, you know, I find walking any distance a problem..." (P03).

Some had unwelcome identity changes such as loss of confidence as a result of critical illness, which restricted social interaction:

"I'm now struggling when I go into social environments. I tend to be very quiet. Where I'm not as confident...you just don't feel as comfortable, I'm not the same person, I'm not the same physical person as I used to be..." (P03).

"I've lost a lot of confidence. I'm not as outgoing...I just lack the confidence that I had before." (P06).

Having experienced the tenuous nature of their health, some patients also described becoming more cautious, wary of the possibility that illness could reappear without warning at any moment:

"I think when you're sat on your own but you're not watching telly or something and it's quiet and you do start thinking about what you've been through and you know will it happen again and stuff like that." (P01).

For many patients, critical illness introduced new experiences of vulnerability, uncertainty and unpredictability which altered their outlook on life, causing a re-evaluation of their attitudes, values and beliefs.

5.7 Summary of Patient Findings

This chapter has provided a detailed overview of the key findings from the patient interviews. Recovery from critical illness was experienced as a journey which began with the critical illness experience and ended with the adjustment to a new life. Four major themes were described under the overarching theme of the 'recovery journey.' These were 'surviving,' 'struggling for independence,' 'reconstructing reality' and 'reshaping identity.'

Patients' experiences of recovery from critical illness were intricately interwoven with the events they experienced in the CrCU setting. Recovery did not start where critical illness ended. The transition from being a critically ill patient to recovering on a ward was an unpredictable frame of reference as many patients experienced cycles of setbacks in their conditions and some were even readmitted onto CrCU. For patients, the start of recovery was associated with feeling well enough to face the consequences of their illness and begin efforts to deal with these consequences.

Patients descriptions of their episodes in CrCU were amongst the most distressing experiences they recounted in their interviews. Patients found the setting to be a dark and unwelcoming environment in which they lost their individuality, their agency and their grasp on reality. Replacing these were social isolation, unpleasant interventions and terrifying hallucinations and nightmares. These experiences placed further burden on patients, who had to recover from both their critical illness itself, and the impact of their CrCU stay.

Critical illness had a major impact on patients, both in the extent of the early weight loss and muscle weakness to the fatigue that endured over the following months and years. Patients were surprised at their newfound fragility which left them feeling

vulnerable and disheartened at their loss of independence. Early recovery efforts focused on building up strength and regaining the ability to perform self-care needs to reduce their dependency on others. Patients used incremental goal setting to work towards recovery targets that increased their mobility and activity towards independence.

Patients had incomplete recollections of their stay in CrCU and unreal memories and psychological issues during their recoveries. Periods of unconsciousness, disorientation and delirium left patients struggling to understand which CrCU experiences were real and which were unreal. Some patients wanted to understand what had happened to them in CrCU, and others did not. Family members provided patients with most of the information they received about their CrCU stay. Some patients also filled in their memory gaps by revisiting the CrCU unit or talking to staff. Patients experienced anxiety, panic attacks, nightmares, and intrusive thoughts following critical illness, which for some continued for months and years. Whilst they could be reluctant to admit to these, patients found that discussing these experiences with the CrCU psychologist helped them to make sense of their experiences and learn how to cope with unwelcome psychological issues during recovery.

The impact of critical illness extended beyond physical and psychological effects during recovery. The uncertainty of illness, the unpredictability of recovery and the loss of agency in the healthcare arena had an emotional impact. Patients described a range of emotions such as feeling low, becoming tearful and crying, feeling anxious and feeling guilty. Patients were often surprised by their emotional responses and frustrated that they had little control over them. Chatting to family and other patients helped them to understand their reactions and come to terms with them.

Critical illness abruptly removed patients from their familiar lives and social settings, together with their normal roles and routines, and plunged them instead into a series of healthcare settings. During recovery, patients underwent a series of transitions through different socio-cultural environments and had to learn to adapt to, and navigate each to secure the help and support they needed. Patients relied on resilience and a range of coping mechanisms to help themselves overcome adversity during recovery. These included learning from other patients, adopting an optimistic attitude, focusing on the positives and setting achievable targets that moved them back towards their normal lives. These processes boosted patients' self-esteem and self-confidence and motivated them towards more ambitious goals. However, patients faced with long-term

physical changes experienced a bigger impact on their emotions and identity. This necessitated more support with adapting to the changes and acceptance of a new 'normal.'

The patients in this study did continue their lives where they left them before their illness happened. The journey of recovery following such illness required that patients repair broken bodies, rebuild emotional defences and reclaim their identities within their families and society. They all experienced some degree of permanent change to their identities, attitudes and lifestyles. For some this meant making life-changing alterations such as retirement. For others it required them to make small adjustments to how they approached their daily lives and amend their priorities and values. The next chapter presents the patient feedback event and the joint patient and staff event. A summary of the patient findings is shown in Appendix 8.

6 THE PATIENT AND JOINT PATIENT AND STAFF EVENTS

6.1 Introduction

EBCD methodology uses partnership between patients, families and staff to transform health services. To achieve this objective, the approach recommends that events are held in which patients, relatives/carers and staff members can share their experiences in order to identify which events of their illness and healthcare matter most to patients and staff. This information is then used to shape future services. In this chapter the patient and joint patient and staff events are presented, in which patients, families and staff met together with the intention of deciding on priorities for service improvement. The chapter is arranged into two sections. The first section describes the two events. The second section provides an overview of the data and analysis of the findings.

6.2 Venue

The events were arranged at a hospital Trust in the North West of England, the host institution for the study. This enabled the researcher to provide free parking, arrange catering and ensure suitable facilities for patients with ongoing mobility issues. It was also more convenient for staff to take time out from their shifts by attending an extended lunch session and being able to return to their shift following the event. The Education Centre at the Trust was chosen for the venue as it had specially designed meeting rooms that facilitated interactive group sessions. A large multifunction room allowed both small and large group workshop activities to be organised as the tables and chairs had wheels to facilitate easy changes to the layout depending on the planned activity. The layout is shown in Figure 6.1.



Figure 6-1 The multifunction meeting room

Free parking for attendees was arranged immediately outside the venue and refreshments arranged for when patients first arrived, to be followed by lunch when the staff joined the meeting. Tea, coffee, cold drinks and pastries were available throughout the meeting.

6.3 Attendees

Initially, the patients who had been interviewed were contacted to update them on the progress of the study and to inform them about the upcoming event that was being planned. All the patients remained engaged with the study and expressed a wish to attend the event.

The patient participants were sent a written invitation to attend the event. Nine out of the 10 patients confirmed that they could attend and some said that they might bring a family member on the day if they were available. One patient declined as she was scheduled to be on holiday overseas on the date of the event, but expressed a wish to be invited to any further events. The patient feedback event was attended by seven patients and three relatives/friends (one partner, one son and one family friend) together with four facilitators. Two patients sent apologies just prior to the event as one had a rescheduled appointment and one had to attend a funeral.

It was desirable to have an approximately equal number of patients/family members and staff at the meeting to allow an adequate mix for smaller group activities and to promote patient confidence in sharing their experiences with staff. It was also important to invite staff members who could influence recovery care for patients. Eleven members of staff were invited, six of whom had been interviewed as part of the study. Some members of staff had changed role since their interviews and staff members who had taken on those roles were invited in their place. The eleven staff members initially invited were:

1. CrCU medical consultant and clinical director for CrCU
2. CrCU medical consultant and lead for follow-up services
3. CrCU nurse manager
4. Medical ward matron (former CrCU outreach nurse)
5. CrCU nurse consultant
6. Former consultant nurse and current lecturer for undergraduate nurses
7. CrCU clinical psychologist
8. CrCU outreach nurse

9. CrCU follow-up clinic and support group lead nurse
10. CrCU follow-up clinic nurse
11. CrCU rehabilitation physiotherapist

Seven staff members confirmed attendance. Four were unable to attend. The clinical director was on leave, and the clinical psychologist, CrCU outreach nurse and CrCU follow-up nurse were on clinical duties at a different hospital site. Four additional staff members agreed to attend in their places; a CrCU outreach nurse, a CrCU follow-up clinic nurse, a CrCU staff nurse and the CrCU ward clerk who provides a CrCU support group with administrative support. On the day, the ward matron was unable to attend as the Care Quality Commission had made an unannounced visit.

Three people were invited to join the researcher in facilitating the event; the researcher's PhD supervisor, a CrCU research nurse at the site and an education technician to organise the technical aspects of an interactive quiz and audio recording.

6.4 Schedule of Events

Plans for the event had originally involved holding a two hour patient feedback event in the morning and a two hour joint patient and staff session in the afternoon with a lunch break in-between. Consultation with some of the patients during the planning stage suggested this was too long a session for patients to attend and remain focused, particularly as some were still struggling with chronic pain and mobility issues. The patients suggested that the event should be shorter or held on more than one occasion. In consideration of patients' needs, it was decided to hold one event with a one hour patient feedback event immediately prior to a two-hour combined patient and staff event. Lunch was arranged to be served immediately after the first session, once the staff had joined the patients and a round of introductions had been made. In this way, lunch could be eaten during viewing of the patient experience film to maximise the use of time and make it easier for all patients and staff to attend the whole meeting.

6.5 The Patient Feedback Event

The patient feedback event was an hour long meeting for patients and family members. The EBCD methodology provides guidance on the activities and conduct of the patient and family session (Bate and Robert, 2006) and is summarised below:

- A patient feedback event is held to give patients and their carers the opportunity to meet and become acquainted prior to the co-design meeting. Patients and family

view the edited film and can share their reflections and feedback, and comment on the content (Bate and Robert, 2006). Various design techniques and exercises are facilitated, which, together with a scheduled group discussion, lead towards the development of an emotional map associated with the highs and lows of patient care (Bate and Robert, 2006).

- A long sheet of paper incorporating the key stages of the patient journey is placed on the wall and the touchpoints were added.
- Patients moved the touchpoints up and down on a high/low scale on the wall to visually represent what are the best and worst parts of their experience. This generated an ‘emotional rollercoaster’ of the patient journey.
- A patient experience map was created as patients recorded on post it notes the emotions they felt at each touchpoint.
- The co-design approach was discussed and patients are then divided into smaller groups to identify key priorities for service improvement.
- After the event the touchpoints were confirmed and validated, the emotional impact recorded and patients’ priorities for change were identified.

6.5.1 Preparation for the emotional mapping exercise

For the purposes of this event, the emotional mapping exercise was recreated as an interactive quiz in which the patient/family ratings of each touchpoint and the emotions associated with them could be captured in the one hour timeframe of the patient and family session. The quiz required careful planning beforehand to optimise the use of the time and to meet both objectives of the emotional mapping exercise; for patients and families to share the emotions they felt at significant touchpoints, and, to rate these touchpoints to determine the highs and lows of patients’ interactions with services. In order to use this interactive system, it was firstly necessary to decide what the key touchpoints of the recovery journey were. The touchpoints needed to be representative of the patient journey and comprehensible for the patients when presented as quiz questions. The key touchpoints, shown in Figure 6.2, were identified from the analysis of the data taken from the five main stages of the patient recovery journey described in Chapter 5.

ADMISSION TO CRITICAL CARE	CRITICAL CARE ENVIRONMENT	DAILY ROUTINES AND INTERACTIONS ON CRITICAL CARE	LOSING YOUR MIND	LEAVING CRITICAL CARE
<ul style="list-style-type: none"> First experiences of critical care 	<ul style="list-style-type: none"> Being in a strange world Separation from familiar people and normal routine Knowing what is going on 	<ul style="list-style-type: none"> Treatment and care Interactions with staff Information and explanations 	<ul style="list-style-type: none"> ICU delirium Disorientation * 	<ul style="list-style-type: none"> Anticipation of change in care/being able to cope Moving to a new environment
BEING A PATIENT ON THE WARD	GETTING BACK ON YOUR FEET	MEMORY GAPS	EMOTIONAL / PSYCHOLOGICAL RESPONSES	LEAVING HOSPITAL
<ul style="list-style-type: none"> Relying on others Relationships with staff Recovering in the ward setting 	<ul style="list-style-type: none"> Feeling weak Efforts to regain strength and start moving Encountering setbacks 	<ul style="list-style-type: none"> Loss of memory about critical care events Receiving explanations and answers Help from staff 	<ul style="list-style-type: none"> Feeling emotional Psychological reactions Rollercoaster of emotions 	<ul style="list-style-type: none"> Preparing to leave hospital The discharge process Information for recovery
BEING A PATIENT AT HOME	STRUGGLING FOR INDEPENDENCE	GETTING BACK TO NORMAL	Critical Care Recovery Services	LIFE AFTER CRITICAL ILLNESS
<ul style="list-style-type: none"> Adjusting to being at home Receiving care outside the hospital setting Being dependent on family and others 	<ul style="list-style-type: none"> Doing more for yourself Marathon not sprint Goal setting Marking progress Plateaus 	<ul style="list-style-type: none"> Getting out and about Being part of the real world Resuming normal activities Being a person not a patient Planning for the future 	<ul style="list-style-type: none"> Access to critical care follow up clinic Critical care follow up clinic Talking to a psychologist Resolving questions and memory gaps Revisit to critical care Peer support - critical care support group 	<ul style="list-style-type: none"> Adapting to lasting physical and mental effects Living with chronic illness Fatigue Personality and emotional changes

Figure 6-2 Key experiences and main touchpoints

The second stage of this process was to reframe the touchpoints as questions to allow the patients to rate their experiences in a range from positive to negative. For example, the touchpoint ‘admission to critical care’ was reframed as the question, ‘how did you feel about your admission to critical care?’ A maximum of thirty questions was chosen to fit in with the one hour timeframe. This allowed up to two minutes for each question to be answered and for the patients to verbalise any emotions they associated with that touchpoint. A PowerPoint presentation was designed, which posed the questions, as shown in Table 6.1.

What are you feelings about.....	
Your first experiences of critical care?	Disorientation in critical care?
Communication with staff on critical care?	Being a patient on critical care?
Feeling out of control?	Hallucinations and nightmares in critical care?
The critical care environment	Leaving critical care?
Being a patient on the ward?	Being physically weak?
Being in the ward environment?	Efforts to get back on your feet?
Having setbacks in your recovery?	Not remembering what has happened?

Finding out what has happened?	Experiencing uncertainty, anxiety, fears and tears?
Getting emotional support?	Leaving hospital?
Being a patient at home?	Expectations about recovery?
Being unable to do things for yourself?	Achieving goals?
Getting back some normality?	Low mood, scary memories and flashbacks during recovery?
The critical care follow-up clinic?	Talking to the critical care psychologist?
Revisiting critical care?	Attending the critical care support group?
How your life has changed after illness?	How you have changed after critical illness?

Table 6.1 The patient interactive quiz

An emotion grid was also developed to help patients to identify some of the emotions they had felt at each of these touchpoints. The emotions included in the grid were used by the patients themselves during the patient interviews (Chapter 5). Patients were also invited to add any other emotions or key words that they felt were important. The emotional grid is shown in Table 6.2.

AFRAID SCARED	ANXIOUS PANICKED	TEARFUL UPSET	UNCOMFORTABLE	UNCERTAIN WORRIED	ISOLATED LONELY
FRUSTRATED IMPATIENT	SHOCKED SURPRISED	ELATED EUPHORIC	RELIEVED	CONFIDENT	ANGRY
DISBELIEF	NUMB	STRANGE WEIRD	ASHAMED EMBARASSED	GUILTY	CONFUSED MUDDLED
RELAXED CALM	RESIGNED HELPLESS	PROUD	BORED	DISAPPOINTED	DEVASTATED
INDEBTED	OVERWHELMED PRESSURED	WEARY	PLEASED GLAD	REASSURED	SAD LOW
TRAPPED RESTRICTED	GRATEFUL	MOTIVATED INSPIRED	VULNERABLE	DEMOTIVATED	DEMEANED

HORRIFIED	INDEBTED	STUPID SILLY	IGNORED	HUMBLE	PARANOID
NO EMOTION	UNCONCERNED				

Table 6.2 Emotional grid

The recovery map and emotional grid were posted to patients prior to the patient feedback event together with an explanatory letter providing details about the quiz, encouraging patients to begin thinking about their experiences once again prior to the event.

6.5.2 The Interactive Quiz

The interactive quiz was set up by the technical team at the Education Centre. Questions were read aloud by the researcher from a PowerPoint display and answered individually by each member of the group. Patients and family members were given hand-held remote control devices, which they pressed to give a numerical score in response to each question. Patients were asked to rate each touchpoint on an 11 point scale ranging from minus five as the most negative experience to plus five as the most positive experience. A score of zero was considered a neutral response with no strong feelings. If a touchpoint was not considered relevant then participants did not have to vote on that individual point. Family members who accompanied patients could also vote using a handset. The system was set up to distinguish between responses from patients and family members. The individual scores were automatically collated and combined to give an overall rating for each touchpoint.

Once voting on a question was complete, the group were then asked to verbalise any emotional or key words associated with that touchpoint and a brief discussion allowed context to be given for some of their responses. The responses were written on post-it notes and placed around the relevant touchpoint by one of the facilitators. During the emotional mapping exercise, keeping to time became an issue as several participants wanted to debate the issues around each touchpoint. The facilitators managed this by reminding the group that later activities would allow them ample time for debate.

The emotional mapping activity resulted in an abundant and comprehensive display of emotions associated with each touchpoint, completing the first objective of the exercise. The second objective of using the overall scores for each question to move

the touchpoints up or down the wall to illustrate the highs and lows of the recovery journey was not possible due to a technical issue which meant that the scores were irrevocably lost. As the scores were unavailable for the meeting, the patient journey in touchpoints was made highly visible from all aspects of the room by displaying it horizontally across the wall with the associated emotions scattered around each



Figure 6-3 The emotional map

touchpoint, as illustrated in Figure 6.3.

6.6 The Patient and Staff Combined Session

The second part of the event involved a two hour long session in which the patients and families were joined by the members of staff in a combined patient and staff session. The aim was to engender partnership between the patients, family members and staff in order to identify the key patient experiences that required transformation. The first part of the patient and staff event was focused around the patient experience film. The second part of the combined session centred upon the emotional map displayed on the wall.

6.6.1 The patient experience film

The patient experience film provided an illustration of the recovery journey and demonstrated the key touchpoints for patients during critical illness and recovery. As no staff members were responsible for providing care for patients throughout the whole

care pathway, the film provided an opportunity to show them the whole recovery journey, and to give context for the combined patient and staff activities that followed.

The film followed a loosely chronological order, in that touchpoints were interwoven around critical illness and CrCU, early recovery and the ward setting and longer term recovery following hospital discharge. The framework used to structure the film was based on the major touchpoints experienced by all patients as follows:

- Surviving – this tells the story of patients' CrCU experiences.
- Struggling for independence – this describes the shock of patients discovering their own frailty and weakness and the ways in which they struggled to rebuild their strength, mobility and activities of daily living.
- Psychological and emotional issues – this demonstrates the psychological and emotional impact of critical illness on patients in the weeks, months and years of recovery.
- Returning to normal – this section shows how patients strive for 'normality' and to progress from being a patient to being a person once again, and how their lives have changed following critical illness.

The film can be viewed at <https://youtu.be/YgpTxcemjF4> or on the accompanying pen stick.

A 30 minute timeframe was chosen to allow all the major touchpoints of critical illness and recovery to be illustrated without being overly long and thereby losing the audience's attention. The film was also edited to capture both positive and negative experiences and provide a balanced overview for staff.

The patient experience film was viewed by patients, family members and staff in the first part of the joint patient and staff event, whilst lunch was served. A mixture of staff and patients/family members were sat at each table, as shown in Figure 6.4. Viewing the film appeared to have a strong emotional impact on all the patients and family members with some overtly crying and, at one point, most, if not all patients had tears in their eyes. One family member also appeared quite angry when she saw her husband describe the offhand attitude of staff who had turned down his request to see a psychologist. Staff described viewing the film as an emotional experience. Some felt that even though they thought they were providing a good follow-up service to patients, it was clear to them that their care was failing to meet some of the patients' needs in some areas. One staff member shared:

“As nurses, we do our best to look after people, but the film shows that this is not always good enough because some people are still struggling with their experiences.” (Current CrCU nurse consultant)



Figure 6-4 The patient film

For several staff, the film provided new insight into what patients were experiencing in CrCU and what was actually happening to them during recovery.

The film was perceived by patients and staff to clearly illustrate the patients' experiences of critical illness and recovery. Staff and patients felt that healthcare teams in and out of hospital needed educating about the patient recovery journey. Several staff members felt that the film would be a very useful asset for training staff on the ward about patients' experiences in CrCU. Another staff member suggested that all staff at the hospital Trust should see the film to gain an insight into the patient experience and that it should be a mandatory part of the training programme.

6.6.2 Small discussion groups

When the film was over, the attendees split up into three groups with a mixture of patients/family and staff, together with a facilitator, to discuss their reactions to the film, making written notes on their discussions based on what they had viewed. After 30

minutes, a member of each group fed back to the larger group the key points they had discussed. This feedback session was audio recorded to augment the written notes with further detail and context. The small group discussions are shown in Figure 6.5.



Figure 6-5 Small discussion groups

6.6.3 Large group discussion

The final activity of the combined patient, family and staff session involved a large group discussion based upon the emotional map displayed on the wall, as shown in Figure 6.6. The objective was to determine priorities for service improvement. Patients, family members and staff were invited to look at the wall and discuss any touchpoints that were most poignant or important. This session was audio recorded and notes were also written on a flipchart by a facilitator.



Figure 6-6 Large discussion group

Following the large group discussion, the event ended with a summary of the next steps for the research study and everyone was thanked for their attendance and contribution.

6.7 Postscript to the Event

In the week following the event, the IT department at the Trust was unable to locate the file with the responses to the quiz. As the rating exercise was one of the two objectives of the emotional mapping exercise, it was felt to be important to try and recapture the scores to complete the data collection and inform the subsequent analysis. Therefore, a paper version of the quiz was produced and the patients who had attended the event were sent a postal copy to complete. They were asked to answer the questions as they had responded on the day if possible. Whilst the data captured on this occasion may have slightly differed to that captured on the day, the paper copy was quickly posted to the patients in an attempt to collect their responses whilst they were still fresh in the patients' memories. The postal questionnaire gave patients the opportunity to provide additional comments to those expressed at the event and was returned by all the patients who had attended the event.

6.8 Findings from the Patient and Joint Patient and Staff Events

The joint patient and staff event was held to bring together patients, family members and staff to explore priorities for improving services for patients following critical illness. The event was the first time that the various patients had met each other and the first time they had met together with staff members. This opportunity for patients to speak out as a group of peers with staff members naturally focussed discussions on the issues that patients considered to be most important. The trigger film illustrated the whole of the recovery journey, and the patient experience wall identified key emotions for patients associated with each touchpoint of that journey. Patients and staff were free to discuss whatever stood out to them from the entirety of the recovery journey and the associated emotions without being directed towards topics selected by the facilitators. Unfortunately, the rollercoaster nature of the recovery journey was not visually displayed on the experience map at the event due to IT problems following the interactive quiz. However, there was considerable overlap of the touchpoints which patients and staff chose to focus upon in the small group sessions, and some of these were further deliberated during the large group discussion. These have formed the

foundation of what matters most to patients and staff and have been used to identify the priorities for service improvement.

6.8.1 Data Collection

The data from the event was captured in a combination of written information by the facilitators and participants on post it notes and flip charts, and an audio recording of the feedback from the small group sessions and the whole group discussion around the experience map.

Emotions and keywords associated with the touchpoints were captured on post it notes and displayed on the wall as a patient experience map. The touchpoints and keywords associated with each touchpoint were collated and are shown in Table 6.3

First Experiences of Critical Care	Numb	Dark	Scared	Strange
	<i>"Dismissed by professionals as just another drunk."</i>			
	<i>"Didn't realise situation"</i>			
Critical Care Environment	Humbled	No natural light	Dark	
	<i>Positive (safe environment)</i>			
Communication With Staff On Critical Care	Kind	Angry	Well informed	
Being a patient on critical care	<i>No comments</i>			
Being Out Of Control	Safe	Comfortable	Helpless	
	Reassuring		Useless	
Disorientation in Critical Care	Unnerving	Afraid		
Hallucinations And Nightmares In Critical Care	Strange	Drugged	Confused	Scared
	Frustrated	Terrified	Frightened	
	<i>Preconceptions</i>			
	<i>Pleasant memories (travels)</i>			
Leaving Critical Care	Happy	Frightened	Isolated	
	Vulnerable		Positive	Too soon
Being A Patient On The Ward	Encouraged	Vulnerable	Disturbing	
	<i>Helpful (outreach)</i>			
Being Physically Weak	Strange	Frustrated	Determined	
	<i>Worried</i>			
The Ward Environment	Lack of sleep	Banter	Bored	
	<i>Well informed</i>			
Efforts To Get Back On Your Feet	Determined	Supported		Sad
	<i>Relative motivation</i>			

Having setbacks in your recovery	Frustrated	Devastated		
	<i>"Rebound from ward to critical care"</i>			
Not Remembering What Has Happened	Glad			
Finding Out What Has Happened	Elated	Weird	Disbelief	Surprising
Experiencing Uncertainty, Anxiety, Fears And Tears	<i>Upsetting (other people's memories of events)</i>			
	Dread	Anxiety	Fearful	Uncertainty
	Emotional	<i>Memory recall</i>		
Getting Emotional Support	<i>Unusual (changes in family dynamics)</i>			
	<i>"Felt like a burden"</i>			
	<i>"Don't want to hear, "you're lucky to be alive."</i> "			
Leaving Hospital	Reassuring	Family supportive		
	<i>Faced hallucinations and dreams</i>			
	<i>Psychological support helpful</i>			
	<i>Reassuring that it is normal</i>			
	<i>Felt like a nuclear bomb</i>			
	<i>Families need more psychological support</i>			
Being a patient at home	Ill-informed (not enough written info)			
	Pushed out (rushed)	Chaotic	Frustrated	
	forgotten	Alone	Isolated	Dismissive
	Happy	Uncertain	Poorly coordinated	
Expectations About Recovery	Frustrated	Angry	Supported	Let down
	<i>Uncertainty about the future</i>			
Being Unable To Do Things For Yourself	Inconvenienced	Low		
	Sad			
	Pleased (done better than expected)			
Achieving goals	Angry	Frustrated	Confident (as recovering)	
Getting Back Some Normality	<i>Loss Of control/routine (not done the way I do it)</i>			
Emotional/Psychological Responses Low Mood, Scary Memories And Flashbacks During Recovery	Loss of identity	<i>Overwhelmed and frustrated</i>		
Being Invited To Critical Care Follow-up Clinic	Striving	Coming to terms	Not met	
Talking to the critical care psychologist	Grateful	Happy	Uncertain	
Revisiting critical care	<i>Adjusting to new normal</i>			
	Helpless	Paranoid	Terrified	
	<i>Horrified</i>			
	Helpful	Reassuring	Indebted	
	Helpful			
	Reassuring			
	<i>Helpful to see it in a different light</i>			
	<i>Embarrassed seeing other sick people (didn't feel worthy)</i>			

Attending the critical care support group	Positive	Helpful
How Your Life Has Changed After Illness	Difficult	Different attitude to life
How You Have Changed After Critical Illness	Impatient Didn't realise how ill had been	Less tolerant

Table 6.3 Emotions and keywords associated with touchpoints

The key points from the small group discussions which followed the film were captured on post it notes. Each small group summarised their discussions and shared these with the larger group. This part of the discussion was also audio recorded and written notes were taken from the transcript. This information was summarised into key points raised by patients, family members and staff, collated into categories and is displayed in Table 6.4.

CRITICAL CARE ENVIRONMENT		
Patient	Family	Staff
Patients don't understand what has happened and why.	Family members felt well informed about what was happening to the patients.	Sometimes interventions need to happen rapidly so explanations have to wait.
Staff should explain events, processes and procedures.		Staff trained to always provide explanations. Patients do not retain information. Information needs regular repetition.
Events can be overwhelming and patients experience 'information overload.'		
On ward rounds staff should address the patient.		
Staff stare at monitors and computers and don't interact with patients.		
Staff and were too busy to talk to patients.		
No windows or natural daylight.		Pet therapy and visiting musicians have been introduced.
Subdued or stark bright lighting.		Setting in the basement to be adjacent to the operating theatres.
Large analogue clocks needed, positioned where clearly visible to patients.		Setting not designed for purposes of a critical care unit.

Patient	Family	Staff
Pictures of nature on walls.		
Videos and photographs of patient during critical care and recovery – helpful to put experiences in perspective, in particular delirium experiences.		Needs careful consideration due to risk of retraumatising patient.
Relative's room dismal, gloomy and depressing.	Family members received peer support by talking with other families in waiting room.	
	The waiting room needs to be comfortable and relaxing to promote more interaction.	

CONTINUITY OF CARE

Transfer to ward frightening as number of staff much lower and less observation.		Patients and families need to be involved in planning of transfer to ward.
Prepare patients in advance about what to expect on transfer.		Staff should discuss patient's expectations with patients and the family.
Lack of long-term care		
Patients still not back to normal and have poor quality of life for several years after illness.		No long-term plan three to four years down the line. Patients have limited exercise tolerance, not returning to work, no long-term plan or support.
No support available for patients with ongoing, longer-term issues.		Support group helpful but needs psychologist there to help patients adjust and adapt to limitations.
Follow-up clinic at 3 months is not practical for patients with longer term needs.		
Emotional Care		
After transfer to wards patients can get that low mood and anxiety and think what's on earth's going on.	Visit from someone who speaks to patients and asks some general wellbeing questions. If patients or relatives want support at that stage it	Staff focus is on physical, not emotional issues.

Patient	Family	Staff
Staff offer inappropriate emotional support such as, “You look so well!” leaving me thinking “Well why do I feel like this?”	could be arranged.	Welfare visit as early intervention after transfer. Should it be nurse, doctor, psychologist, liaison person from critical care?
		Could use psychological screening tool to identify psychological issues.

INFORMATION

Provide families with enough information about who to turn to if patients start to suffer from emotional and psychological issues at home.	More information for patients and families after critical illness and once patient is back home.	
Patients should be made aware of how to access the support group and follow-up clinic much earlier, and the fact that they can be accompanied by their partners.	Who to contact for more information and support.	
Should have this information sooner to prevent problems building up.		
If you are only in critical care for a short period you do not meet the criteria for follow-up and if you do not have an obvious problem you do not meet the criteria for psychological support.		
The nature of admission affects how you adjust to your illness.		

TRAINING AND EDUCATION

Outside of critical care healthcare do not understand what experiences patients and families have been through and why these patients have different issues.		Training and education of staff in hospital and community services about the critical care experience – could be part of their mandatory training.
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Patient	Family	Staff
		Specialist care on the critical care unit but wards each have their own speciality and they're not aware of what it means to have had a critical illness.
		Need to educate staff that patients do have more just one problem but have this critical illness are quite unique and special patients.
		The healthcare team needs educating about the whole patient recovery journey so they are informed and can offer patients realistic advice and support.
		Outreach team are actually teaching staff now about what a stay in intensive care is like for patients. Its part of the rolling teaching program. Would be great to show staff the film.

COMMUNITY BASED CARE

Age appropriate rehabilitation for young trauma patients rather than nursing homes.		Rehabilitation that is appropriate for patients who were previously fit and healthy with focus on recovery and return to work and social life.
Rehabilitation that supports a patient's motivation to work hard to recover.		
Equipment and other resources available as soon as needed so patients avoid unnecessary difficulties.		
Lots of small problems were inconvenient to recovery, e.g. no wheelchair to get from ambulance to rehabilitation centre, picking up niggling infections in nursing		

Patient	Family	Staff
home.		
Needed to be self-motivated to drive own rehabilitation progress		

Table 6.4 Summary of small group discussions

The whole group discussion based on the emotional map on the wall was captured as summary points on flip chart paper by the facilitator and notes taken from the audio recording, and this information is summarised in Table 6.5.

Patient	Family	Staff
PERSONALISED CARE		
Short staffing and agency staffing challenges the ability to provide individualised care.	Variety of emotional and keywords on wall suggests that patients have different needs Speak to both patients and their families to understand what patients' needs.	In critical care there the number of agency staff per shift is restricted.
	Knowing the patient as individual is important to understand their history and their needs.	Individualism is important – previous experiences can 'bubble up' at times of stress.
	On handovers, take on board what is being said about the patients and what the your patients are saying.	I think for nurses it is important to know your patients, know that family, know that history. Get to know their background.
		Staff so busy they don't think of the things sometimes, often we don't get time and you're in a rush to the next patient.
REHABILITATION VERSUS FOLLOW-UP		
Three patients attended cardiopulmonary rehabilitation programmes and rated these highly.		Nurse-led follow-up clinic is the best they can offer as there is no psychologist or physiotherapist available.
Patients perceived rehab programmes provide information, ongoing advice and peer support.		They acknowledge that a move to a more rehabilitation based service would be desirable

Patient	Family	Staff
Attending rehab programmes with same group of patients builds up trust and opportunity to be more open to sharing experiences.		Resources for follow-up clinic and support group are currently prioritised over rehab programmes
A lot of which services you receive depends on what happened to you. At the moment it is just pot luck if you get services or not.		Some patients are reluctant to attend follow-up clinic.

EBCD METHODOLOGY

EBCD methodology provides a good way to capture a lot of information from patients, families and staff about services in a short space of time.		
Recommended to use this approach on a regular basis.		
Process therapeutic for several patients and some signposted to further resources as a result.		

CONTINUITY OF CARE

GPs not helpful. They do not understand the critical care treatments and patient's critical care experiences.		Discharge from hospital chaotic and rushed.
GPs do not appreciate the impact of critical illness on patient's emotional state.		Discharge is a time of anxiety, dread and frustration.
GPs don't know patient's complex medical histories and patients frustrated with having to provide explanations repeatedly.		Staff willing to listen to patient recommendations.
GPs fob patients off with inappropriate treatment or advice.		
Patients don't get the information and		

Patient	Family	Staff
reassurance they need from GPs or MDTs.		
Patients discussed how they had to visit various departments for different health issues.		
Patients have to search out information from a number of sources and are passed back and forth between MDTs and specialities when trying to find answers to their queries.		
The opportunities for patients to get information are intermittent and based on attending scheduled appointments at set intervals.		
Follow-up clinic was not a practical way to get answers and signpost patients to appropriate sources of support as it was only offered at three months following hospital discharge.		

EMOTIONAL VERSUS PSYCHOLOGICAL

Patients perceive that emotional issues are mislabelled as psychological problems.	How people cope with adversity depends upon their past experiences	
Patients reluctant to mention emotional issues for fear of being labelled with mental health problems and unfit to be going about their normal lives.		
Patients feel healthcare professionals misunderstand the reasons for their emotional issues and rather than exploring the reasons behind their issues they assume it is due to the illness they have been through.		
Men find it more difficult to admit to having		

Patient	Family	Staff
emotional problems and are not accustomed to talking to each other about emotional issues.		
Men are used to being the patriarch and to admit to emotional problems is seen as a failure on their part.		

Table 6.5 Summary of the large group discussion

All the information collected from the events were analysed to identify priorities for service improvement.

6.8.2 Data Analysis

Data analysis involved a progressive process which began with listing all the information summed up on post it notes during the smaller group sessions and the information captured on the flip charts from the larger group discussion. Similar points were clustered together and categorised into the key topics that were discussed. The audio recording was transcribed by the researcher and written notes taken from the transcript to add more detail to the written information captured during the activities. This information was used as the basis for identifying what patients and staff considered to be priorities for service improvement.

Once the priorities for service improvement had been determined, using the findings from the events, the information collected from the postal version of the interactive quiz were analysed. This helped to corroborate the choice of priorities by revealing what patients rated as their most negative experiences during critical illness and recovery. The comments made by patients also provided further clarity and context to each of the priorities identified.

6.9 Priorities for Service Improvement

Four priorities were identified from analysis of the information from the patient and the joint patient and staff events; improving the CrCU experience for patients; addressing patients' emotional and psychological needs; positioning patients at the centre of services; and, developing a supportive framework to promote the recovery process. In this section these priorities for service improvement event are discussed.

6.9.1 Priority One: Improving the Critical Care Experience for Patients

Improving the CrCU experience for patients was a key priority that patients identified during the small group discussions. The particular touchpoints related to CrCU also evoked very strong and negative key words and emotions during the emotional mapping exercise. Patients experienced CrCU as a dark and depressing environment, associated with unpleasant recollections of disorientation and lack of control. For many patients, their experiences of hallucinations and nightmares, and their lack of understanding of what was real and imaginary added to their unpleasant experiences, and these lingered well into recovery as patients struggled to understand what was real and unreal.

Patients and family members felt grateful for, and reassured by, the skills and expertise of the staff and recognised that providing acute care and treatment was a priority in saving patients' lives. However, in this setting, patients did not fully understand what was happening to them or why. They did not feel well informed about the multiple interventions and procedures they received and they felt isolated and detached from the people and the activity surrounding them. Patients wanted more explanations from staff about their treatment and care and also more non-medical conversations. However, some patients also felt that their capacity to absorb and comprehend information could be impacted on CrCU where they were often overwhelmed by the unrelenting events that were happening whilst simultaneously feeling acutely unwell. Patients felt staff focussed their attention on computers and monitors and were too busy to interact with patients. They highlighted the need for staff to spend more time talking to patients and getting to know them so that they would be able to provide more personalised care and explanations to meet patients' individual needs. Some staff explained that a recent initiative in CrCU was to put posters at the bedside to give CrCU staff individualised information about the patient and their relatives, highlighting their likes and dislikes and background. This was with the aim of promoting conversations with patients that could be personalised to each patient's situation. The poster could accompany the patient throughout their hospital stay so that ward based staff would also be able to continue to personalise care. They admitted this was only happening for a select few of the longer-stay patients rather than a routine practice for all patients.

Staff reacted to patients' candid exchanges about their CrCU experiences with acknowledgement of the issues they raised about the setting, though with less appreciation for patients' experiences of being uninformed and isolated. There was a general readiness amongst staff to associate the CrCU setting with patients'

disorientation, hallucinations and nightmares. Staff were eager to share recent initiatives such as pet therapy and visiting musicians that had been introduced to improve the CrCU experience for patients. There was less agreement from staff that patients received limited explanations of interventions and procedures or that this could be associated with patients' disorientation and feeling a lack of control. Staff felt they were trained to provide explanations to patients every time they delivered care and believed this happened, except in emergency situations where interventions needed to be delivered immediately. They felt that patients were unable to recall explanations as they had poor retention of information. They discussed the need to regularly repeat explanations to patients and suggested reinforcing these explanations with patients and families following their CrCU stay. Both patients and staff felt that the timing of explanations was an important consideration as well as a need to understand what explanations were meaningful to patients. This may help patients to cope with the CrCU experience whilst avoiding the provision of unnecessary or unhelpful information.

6.9.2 Priority Two: Addressing Patients' Emotional/Psychological Needs

Addressing patients' emotional and psychological needs was a priority identified in both the small and large group discussions. Several issues were associated with addressing emotional and psychological needs, with one of these being the awareness that the two terms relate to different responses that patients experienced as a result of critical illness or their stay in CrCU. Patients described becoming emotional following critical illness, which was associated with their responses to the life-threatening nature of critical illness, uncertainty about recovery, vulnerability associated with physical weakness and dependency and the prolonged timeframe of recovery. Patients' described emotional responses as low mood and depression, being tearful and upset, anxiety and feeling guilty. Patients also discussed ongoing psychological symptoms such as hallucinations, nightmares and flashbacks that related to their CrCU stay. These symptoms could happen unprovoked and were ongoing for many patients, even several years after their illness. Patients were wary of the triggers that might provoke such symptoms such as television programs with a hospital or CrCU theme.

Being aware of patients' emotional and psychological responses was an important skill that staff required in order to address these needs. Both patients and staff agreed that outside of CrCU there was a lack of knowledge of the psychological reactions that were related to a patient's CrCU stay, even though these occurred frequently in this population. In the hospital setting, patients often returned to very acute ward areas

where the focus was treating acute physical conditions and staff were not trained or motivated to assess and care for emotional and psychological needs. Ward staff were perceived as too busy dealing with emergencies and other priorities and reluctant to address emotional topics with patients for fear of upsetting them. There was an agreement that professional healthcare staff should be trained to recognise when a patient was behaving abnormally and that staff focus on discharging patients in the best physical and mental condition to avoid the need for psychological help at a later date.

Patients discussed misdiagnosis by healthcare professionals in the community setting when they experienced low mood in response to long-term disabilities, lifestyle and role changes. Patients reported that GPs routinely presumed patients' low mood was an expected effect of their illness and offered antidepressants, whereas patients wanted help in adjusting to their changed circumstances. In contrast, several patients considered their family members to have provided the most significant emotional care. Family members suggested that helpful resources and information should be provided to help them support the patient.

A further issue in addressing patients' emotional and psychological needs was the variation in patients' acknowledgment of their needs and acceptance of support. Patients could be reluctant to admit to having emotional or psychological needs due to the stigma they perceived to be associated with issues surrounding mental health. Male patients raised a range of barriers to admitting emotional or psychological needs such as pride, dissonance with their patriarchal role, aversion to showing weakness, feeling like a failure as a man and lack of prior experience in coping with, or discussing, their emotions. In some circumstances suppressing their emotional needs meant that patients avoided having to face up to them, though this posed an obstacle for staff and family members who were offering support.

Addressing patients' emotional and psychological needs highlighted the challenge of designing a service that was both sensitive to these needs and flexible enough to provide support when patients needed it. Timing of support was considered important. In the turmoil of the CrCU setting, patients experienced many competing pressures. When events settled, patients were often in the ward setting with no further contact with CrCU staff who had the knowledge to address the emotional and psychological issues that emerged. Staff proposed the idea of a CrCU staff member offering a welfare visit to the patient and family once the patient had been on the ward for a few days. The

welfare visit could be performed by healthcare staff such as a nurse, physiotherapist, occupational therapist or psychologist and would have a focus on the patient's general wellbeing. Staff recommended using a psychological screening tool to help assess the patient's mental state and refer them to a clinical psychologist if appropriate. In contrast, a family member suggested the importance of a gentle approach that built rapport with the patient and provided time for them to have a conversation about how they were feeling. If the patient did not want any help at this stage, they could be given information on who to contact if they needed to talk to someone in future, including contact details for supportive services.

6.9.3 Priority Three: Position Patients at the Centre of Services

A third priority identified from the events was the need to position patients and families at the centre of service provision. Patients had to fit into the current healthcare services, which were not ideally positioned to meet their specialised needs during recovery from critical illness. In the hospital setting, patients were transferred from CrCU into speciality based care, such as respiratory, surgery or medicine, where staff provided specialist care in their specific area of expertise. In these settings, patients' CrCU related issues were easily overlooked as care and treatment had a narrower focus. As critical care did not classify as a speciality outside of the CrCU, in contrast to, for example, neurosurgery or respiratory medicine, staff acknowledged there was no critical care-specific programme of care. The CrCU outreach team typically only provided follow-up of patients transferred from CrCU in the first 24 hours, and had a physiological focus. However, the recent addition of a CrCU rehabilitation physiotherapist to the outreach team offered the potential to provide more specialised and prolonged care for some patients during their ward based stay.

Services for patients who were discharged from hospital into the community setting were also perceived to be unsuitable by patients. Patients who did not live with family were often discharged from hospital into rehabilitation or nursing homes, or had a home carer package arranged. Several patients considered the types of community services to be misaligned to their requirements. Rehabilitation homes for elderly patients recovering from joint replacement surgery were unsuitable for young patients rehabilitating following major trauma. Nursing homes for the elderly lacked staff with the skills or experience to manage patients with complicated dressings or treatment regimes. In these settings, patients had experienced setbacks such as recurrent infections and severe sepsis, requiring emergency readmission to CrCU. Patients had

limited choice about the care they received following hospital discharge and experienced variability in the quality of care provided to them.

Through viewing the film and talking to patients, staff learned about the long-term impact of critical illness, as patients shared their stories of the problems they experienced, even several years after their illness. Staff heard about the impact of poor exercise tolerance and ongoing limitations which left patients unable to work and assume their pre-illness roles and activities. Some patients felt they still needed physical, social and psychological support years after their illness. Both staff and patients acknowledged the lack of any long-term services or plan to manage patients' ongoing problems months and years after their critical illness.

In discussions about follow-up services, staff and patients agreed that the CrCU follow-up clinic did not support the needs of patients with longer-term issues. One appointment with a nurse three months after CrCU discharge could not address the issues of patients with ongoing disability, emotional issues and reduced quality of life several months and years after critical illness. The service was felt to be exclusionary as invitations were based on inclusion criteria set by staff rather than consideration of each patient's individual circumstances. The service was considered unreactive to the different circumstances of patients who were still in hospital or rehabilitation at three months, or who developed issues after this timeframe.

Staff acknowledged the limitations of the service and admitted that the criteria excluded some patients from attending the clinic. Two patients in the group considered that the cardiopulmonary rehabilitation programmes that they attended dramatically improved their health and fitness by providing eight weeks of physical training and educational classes. Some patients and staff felt that this could be a useful model to adopt for post-CrCU patients. Patients felt that going through the programme with a group of other patients gave them the opportunity to develop trust with other patients. This meant that by the time they had a discussion group, people were far more open with each other than they would have been at the start of the programme and were able to benefit from sharing a wide range of issues. Staff acknowledged the advantages of offering a group programme rather than one to one sessions at follow-up clinic. They highlighted that the service was delivered in the best way they could manage currently with the resources available, but agreed that the reconfiguration of services to provide group rehabilitation was a goal for the future.

6.9.4 Priority Four: A Supportive Framework to Promote Recovery Process

The final priority identified from the patient feedback event concerned the coordination of services to provide continuity of care during recovery. The recovery experience map and the small and large group discussions illustrated many time points during recovery at which patients' encountered obstacles and adversity. These led them to experience anxiety and frustrations that made it difficult to progress with their recoveries. This priority focuses on the need to improve transitions in care, provide helpful and supportive information and provide a more seamless recovery service.

Transitions from one area of care to another evoked stress, worry and frustration for patients. Whilst seen as a positive indication of progress, several patients were apprehensive about transitions and how they would cope in the new settings, build relationships with new staff and adjust to unfamiliar routines. The first major transition for patients was transfer from CrCU to the ward. The adjustment from having an individual allocated nurse on CrCU to having to share a nurse with multiple other patients on a ward was described as frightening. Patients also felt uninformed in the planning process for transfer to the ward and wanted to be involved in the decision-making process. Patients felt that discussions about transfer should include the patient and their relatives so that staff could inform them about the next stages of their care and provide realistic expectations of what to expect on the ward.

Another major transition was hospital discharge. Emotions on the recovery experience map such as 'chaos,' 'pushed out,' 'rushed,' 'dread,' 'anxiety' and 'frustrated' highlighted the need to improve this experience for patients. Patients felt mixed emotions about leaving hospital, which was viewed as a sign of progress, but tempered with uncertainty about how they would cope in a different environment. For some, hospital was a 'safety blanket' and patients were worried about suffering from setbacks in their recovery once they left. Several patients felt that, despite planning from healthcare professionals such as social workers, their hospital discharge was very poorly coordinated. Equipment and other resources were not available when they needed them so patients had to endure unnecessary difficulties.

Following discharge from hospital, many patients experienced care that was even more fragmented. Patients discussed how they had to attend various hospital follow-up appointments with different specialities for different health issues. They found that if they wanted advice or reassurance about a new issue, they had difficulty identifying someone who could answer their questions. Instead they would be told that their issue was a 'surgical' or 'medical' concern and would be passed around from department to

department. Patients also described how they saw a different GP on every visit so no one GP became familiar with a patients' complex medical history. This made patients frustrated by having to repeat their history to each new GP they visited, who did not have time to read their lengthy medical histories.

Patients experienced difficulties in accessing information and explanations that empowered them to make progress with recovery and access services when they needed them. Patients and families often spent large amounts of time and effort searching sources such as the internet to find answers to their questions and determining how to secure resources. They wanted practical information following discharge from CrCU which contained names and contact numbers of staff they could contact if they had a specific need, and practical information about accessing services they could use during their recovery. Some patients at the joint patient and staff event did not know about the follow-up clinic and support group. Others only heard about them by accident. Families also felt they should be aware of who to contact should the patient develop any emotional or psychological issues following hospital discharge. Staff felt that this had been partly addressed, with all patients now being given a regionally developed booklet about recovery, though this was quite impersonal, containing generic information about recovery rather than access to local CrCU staff or services. In the community setting, some patients felt that GPs did not provide helpful advice or information as they did not understand the CrCU treatments and patient's CrCU experiences. Some felt that they were 'fobbed off,' with inappropriate treatment or advice as GPs did not recognise the help they needed and could not arrange appropriate support.

6.10 Findings from the Interactive Quiz

Following the patient and joint patient and staff events, the postal versions of the interactive quiz were completed by the seven patients who attended on the day. The scores and the emotional words and comments from the quiz were collated and analysed to provide further insight and clarity around the priorities identified at the event. The scores from the quiz were collated and calculated as means. These have been ranked in order of lowest to highest mean and have been presented in Table 6.6 together with the comments patients made about each touchpoint.

Touchpoint	Score	Comments
Hallucinations and nightmares in critical care	-3.5	"Frightened of dark." "Environment with no windows or clock so unable to accept reality from nightmare situations."

		<p>"Terrifying. Couldn't differentiate between what was real and what was imaginary."</p> <p>"Not in critical care but back on the ward."</p> <p>"Terrifying. Felt extremely real. Couldn't make them stop."</p> <p>"Strange."</p> <p>"Drugged."</p> <p>"Confused."</p> <p>"Scared."</p>
Being out of control	-3.29	<p>"I normally live totally independently so hit me hard."</p> <p>"Lost."</p> <p>"Alien environment."</p> <p>"Frustrated."</p>
Being physically weak	-3.14	<p>"Embarrassed, shocked; previously very independent, able and relatively fit."</p> <p>"Worried; could not walk."</p> <p>"Very frightened."</p> <p>"Frustrated; lack of independence."</p> <p>"Didn't realise how weak I was till it was time to go home."</p> <p>"Didn't realise how weak I was"</p>
Disorientation in critical care	-3.00	<p>"Analogue clock meant you couldn't tell if it was 3am or 3pm."</p> <p>"It was the drugs; drifting."</p> <p>"Felt isolated and removed from reality."</p> <p>"Felt lost, in a different place. e.g. on a channel ferry or in a hotel."</p> <p>"Terrified; lack of control. Felt I was in a different environment."</p>
Having setbacks in your recovery	-3.00	<p>"Ups and downs were horrible. Uncertainty lasted throughout."</p> <p>"Tried to run before I could walk."</p> <p>"Angry; scared."</p> <p>"I was in hospital for three weeks after intensive care and had a few setbacks. Thought I was never going to get out."</p> <p>"Not again. Annoyed, down, depressed."</p>
Low mood, scary memories and flashbacks during recovery	-2.86	<p>"I think it was mostly low mood with me. Have occasional flashbacks but I think these make me appreciate where I am now."</p> <p>"Had a sulk for a while (my son cured that.)"</p> <p>"Initially unable to comprehend that I was still alive."</p> <p>"Still struggling with flashbacks and low mood."</p> <p>"I did have flashbacks for a long time but just put them to one side."</p> <p>"Still occasionally have nightmares."</p>
Being unable to do things for yourself	-2.71	<p>"Frustrating but remained positive. When I realised I no longer needed oxygen I felt confident I'd be able to do anything."</p> <p>"Annoyed."</p> <p>"Very frustrated and intolerant."</p> <p>"Frustrated; angry." "Burden to family/wife. Frustrated."</p>
Critical care environment	-2.43	<p>"Whilst feeling safe with the staff, expertise and equipment, the environment was horrible and dark."</p> <p>"Tomb. Locked up."</p> <p>"No windows or any concept of time."</p> <p>"Isolated. Lost in time and space. Unfamiliar surroundings."</p> <p>"Isolated."</p>
Experiencing uncertainty, anxiety, fears and tears	-2.43	<p>"I tend not to show emotions but there were some horrible times there. Thankfully my mental health helped me fight."</p> <p>"Why? I ask myself."</p> <p>"Initially found it very hard emotionally, it almost raised my former PTSD from events in the Falklands war."</p> <p>"Don't want to hear, "You're lucky to be alive. ""</p> <p>"I hid my depression for a long time once I left hospital. Thinking about what I went through still gets me emotional, even four years on."</p>
First experiences of critical care	-1.43	<p>"Dismissed by professionals just another drunk."</p> <p>"I'm afraid I don't remember anything for a week as I was in a coma."</p> <p>"Confusion."</p> <p>"Very frightened and anxious."</p> <p>"Wasn't aware that I was in critical care."</p> <p>"Scared. Dependant. Burden."</p>

Communication with staff on critical care	-0.71	"Difficult with tracheostomy. Once out fine." "Staff very busy." "Very little remembered about the communication." "Not enough explanation about procedures." "Difficult whilst intubated." "Could have done with a pen and paper. Otherwise staff were lovely."
Leaving critical care	-0.67	"Thank God." "Hoped to recover without any lasting effects." "Pleased to go to a ward where things seemed more normal." "Worried about going back to a ward as I had been sent home with sepsis. I was worried it could happen again." "How will I cope? Am I ready?"
Critical care follow-up clinic	-0.40	"Never had one. I remained in Preston and Manchester hospitals for four months. Never had follow-up." "Felt it was good to participate." "Can't remember a follow-up clinic." "Made me feel normal."
Finding out what has happened	-0.33	"Frightened but hopeful of a positive outcome." "Still not sure." "Hard to comprehend and deal with what had happened." "Remembered almost everything." "Shocked; worried. It took months to find out what had been done." "Shocked." "Reassured."
Not remembering what has happened	-0.14	"I remember most of it apart from seven days in a coma." "Confused." "I needed clarification of memories." "Not really bothered. It happened. That's all there is to it." "After visiting the unit I would score a three as I realised a lot that I was experiencing was normal."
Being a patient on critical care	-0.14	"Couldn't have been in a safer place." "Dependent." "Lack of any info about being on the unit other than what was initially stated on admission." "Strange environment; scary."
Being a patient at home	0.29	"Initial care was OK. Better from family. Nice to be home in charge again." "District nurses pleased themselves." "Initially I was not the best type of patient, because I wanted to run before I could walk and emotionally I was a wreck." "I feel more independent but still a bit vulnerable and low at times." "I was very lucky as I had hospital at home for six weeks. The staff were excellent but it was intrusive at times as they came three times a day (but so much better than being in hospital)." "Glad to be home. Not normal, and a burden. Lonely."
The ward environment	0.57	"An improvement on daylight, but less staff so felt insecure at times." "Much better (than critical care)." "My recovery was underway." "Happy to see the sky and changes in weather." "Felt cared for, looked after." "The intensive care ward was quite lonely. Couldn't communicate with other patients."
Attending the critical care support group	0.67	"Fantastic group of people, staff and former patients and family. Only found out about it by searching the internet. Departing patients need to be made aware of its existence." "Wasn't told there was a support group." "Haven't been involved with it." "Didn't attend."
Leaving hospital	1.00	"Mostly positive; hopeful; uncertain; frightened." "Home sweet home." "I felt brilliant, but worried about leaving the comfort and safety blanket of the hospital." "Glad to be leaving but didn't go home so felt vulnerable in the nursing home." "Mixed. Happy to be going home but worried about having a relapse." "Scared; fear; how will I cope? Disorganised. Went badly due to"

		<i>issues with transfers to rehab unit and initial facilities at the rehab unit, but was useful to push me forwards.</i>
<i>How your life has changed after illness</i>	1.00	<p><i>"After two years fantastic rehab support from pulmonary rehab with NHS physios and a continuation of this with ABL health, I am now working again doing a very physical Tesco.com van delivery driver."</i></p> <p><i>"I'm almost normal once again, and you realise that you only get one go at life so make the most of it."</i></p> <p><i>"Less independent, unsure of the future. Lost confidence in myself."</i></p> <p><i>"It puts things into perspective. Life is very short and should not be wasted."</i></p> <p><i>"Still can't do what I did before. Still get tired and have to be measured in my expectations and approach. Have to do things a little slower and take a little longer."</i></p>
<i>How you have changed after critical illness</i>	1.14	<p><i>"Oh yes. I have a totally different outlook on life. I appreciate my life far more. Unbelievably I'm also a fitter, stronger 63 ½ year old."</i></p> <p><i>"Many changes in my life, some good, some bad, but that's life."</i></p> <p><i>"I can still be moody and withdrawn and my wife has helped again and again to bring me back up. I still struggle to come to terms that I survived."</i></p> <p><i>"Frustrated that physically I'm not as strong as I was. Angry that I look different. Ashamed of my body image."</i></p> <p><i>"I went back to work after six months but was offered severance so retired. My husband was working abroad but also retired. So our lives totally changed. We now make the most of our time with holidays, trips out and looking after our grandson. Unfortunately now I have been diagnosed with a blood cancer but the chemo and aspirin are sorting it out."</i></p> <p><i>"I worry less. I have become less tolerant. I actively give opinions. Felt detached from emotions for a long time."</i></p>
<i>Getting emotional support</i>	1.67	<p><i>"I couldn't have had better emotional support from staff and family and friends, even if at times I was stubborn and didn't want it."</i></p> <p><i>"Family got me through."</i></p> <p><i>"My wife was my rock and my saviour. These words are not written lightly. Nobody could have brought me back to deal with my experience."</i></p> <p><i>"I got some support which was helpful."</i></p> <p><i>"Not necessary."</i></p> <p><i>"The psychologist who visited me on the ward was useful and helpful. I wish I had sought help sooner."</i></p>
<i>Getting back some normality</i>	1.71	<p><i>"Mostly very positive but just that thing at the back of your mind that nudges you to think it might happen again."</i></p> <p><i>"What is normal?"</i></p> <p><i>"Give it my best."</i></p> <p><i>"I feel I've come as far as I can. There will always be restrictions. I've just got to accept things will never be normal."</i></p> <p><i>"Each day felt like a small milestone to getting better."</i></p> <p><i>"Took a long time, felt pressured to get back to work."</i></p>
<i>Revisiting critical care</i>	1.83	<p><i>"It didn't phase me at all. It was a delight to meet staff who cared for me, enjoyed their faces when I walked in. Environment didn't phase me."</i></p> <p><i>"Too hard."</i></p> <p><i>"Scared initially. Reassured when I recognised equipment and the areas I was treated in."</i></p> <p><i>"Was offered but didn't feel it was necessary."</i></p> <p><i>"Less scary than I remembered."</i></p>
<i>Efforts to get back on your feet</i>	1.86	<p><i>"The physios tried their best with me. They were so lovely and I always felt I was letting them down, but I couldn't do what they wanted."</i></p> <p><i>"Physios were great."</i></p> <p><i>"Would give it my best effort."</i></p> <p><i>"Tiring, painful, pressured."</i></p> <p><i>"Brilliant. Couldn't wait to get out and about."</i></p> <p><i>"Very determined. Had a goal in mind to walk, didn't want to wait. I was prepared to push myself even to the point of doing too much."</i></p>
<i>Expectations about recovery</i>	2.14	<p><i>"They've definitely been exceeded. Once home and off oxygen I became very positive. I think four years on, the results show I was</i></p>

		<i>right.”</i> “Got to be positive “Now fully recovered.” “I felt disappointed that my recovery was delayed again and again due to complications.” “I got further than I thought I would.” (positive with support and patience)
Talking to the critical care psychologist	2.5	“I was adamant I was fine and didn’t need one. I was persuaded and the critical care psychologist was brilliant.” “This needs to be done on the ward for some patients, as I became very withdrawn, not eating or talking, and only my wife noticed this.” “I felt the chats with the psychologist very helpful. Getting things off my chest and putting things in perspective.”
Being a patient on the ward	2.57	“Hopeful; I’m out of critical care so there is some hope, even if at the time it was uncertain.” “Well looked after.” “Hope that I would fit in and not be a burden.” “Quite happy. Staff were very good. Felt human again. Very busy even at night.” “The staff were excellent. Well looked after. Didn’t want to be a nuisance.”
Achieving goals	3.14	“It was hard at times but I’m a fighter and I’ve achieved much more than could be expected.” “Mountains getting smaller.” “Not quite able to achieve all, which sometimes leaves me annoyed and frustrated.” “I feel I’ve achieved some goals giving me more independence. e.g. dealing with T.P.N. but some things are beyond reach.”

Table 6.6 Scores and touchpoint comments from the interactive quiz

The mean scores from the quiz have also been used to illustrate the rollercoaster nature of recovery from critical illness, as shown in Figure 6.7.

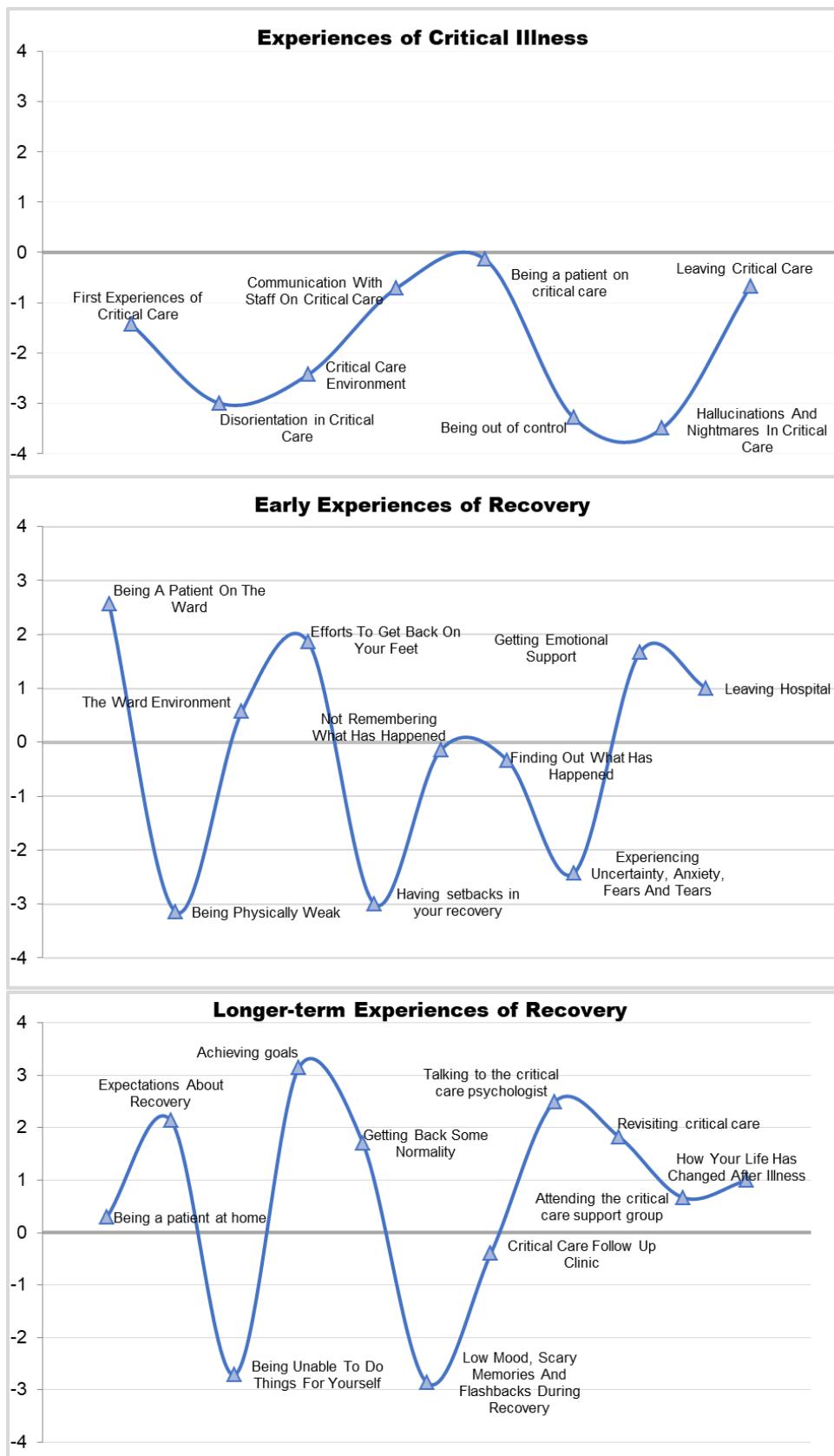


Figure 6-7 The recovery journey experience map

Figure 6.7 clearly illustrates that every touchpoint associated with the CrCU experience received a negative score and why improving the patient experience of CrCU, out of the whole recovery journey, was identified as a priority for service improvement. Patients felt defenceless against hallucinations and nightmares, which they were unable to control and were extremely distressing experiences during critical illness. Scary memories and flashbacks were still having an undesirable impact on some patients, though over time they appeared to be less disturbing and patients were better able to cope with the impact. Patients' scores and comments also endorsed their distressing experiences of the CrCU environment.

The interactive quiz demonstrates that patients experienced a stark contrast to their negative experiences of CrCU, once they returned to the ward setting. In the ward setting, patients were beginning to recover from their acute illness and therefore feeling better and optimistic of recovery. Patients scored the care they received in the ward settings very highly as they had felt well cared for and valued building relationships with the staff and chatting to other patients on the ward, in contrast to the isolation they felt in the CrCU setting. Whilst patients were initially apprehensive about moving from an area where they were closely observed by many staff, patients adjusted by making efforts to do more for themselves so they would not be a burden to staff in ward areas where nurse-to patient ratios were approx 1:5 rather than the 1:1 ratios that they experience in CrCU. Serendipitously the reduced nurse to patient ratios in ward areas acted as a stimulus for rehabilitation. In the ward setting, patients became more involved in their own care, particularly with the physiotherapists, who supported their efforts and goals to become stronger, more mobile and more independent. These were amongst the highest rated touchpoints of the recovery journey.

Figure 6.7 illustrates that low mood, scary memories and flashbacks, and experiencing uncertainty, anxiety, tears and fears were amongst the most negative touchpoints on the recovery journey. This corroborates the findings from the events and endorses the importance of addressing patients' emotional and psychological needs. Comparing this with the most positive experiences, 'talking to the CrCU psychologist' was rated as amongst the best experiences of the recovery journey for those patients who had received this care. Patients felt that their discussions with the psychologist were helpful, giving them the opportunity to unburden themselves and helping them to see their circumstances in perspective. On a similar theme, 'getting emotional support' was rated highly by five out of the seven patients. Patients valued emotional support from

family members and found it helpful to learn that their emotions were a normal response to illness.

6.11 Summary

This chapter has described the patient feedback event, and the patient and staff event, giving an overview of the organisation of the events, the activities undertaken and the analysis of the findings. This was the final stage of the activities for this current study, resulting in four recommendations for service improvement that introduced recommendations based upon prevention of some issues, early identification of others, and supporting patients in meeting their longer-term needs. The joint patient and staff event represented the first time that patients had been directly involved in any service improvement in this CrCU setting and successfully demonstrated the participatory intentions of the EBCD methodology. The creation and use of a patient “trigger” film and its use in a joint patient and staff event was outlined along with the process of emotional mapping of key touchpoints along the recovery journey. This joint patient and staff event gave the patients a voice to raise issues with their care and the provision of services and challenged the assumptions of staff about the recovery process. Whilst it was difficult to accept some aspects of care had negatively impacted patients, staff appreciated the opportunity to listen to what patients had to say and were motivated to use the event as a platform from which to improve future care and services. A summary of the event findings is shown in Appendix 9.

7 DISCUSSION

7.1 Introduction

This chapter presents a discussion of the key findings from this research which brought together former critically ill patients, their family members and staff who cared for them, with the aim of improving service provision for patients following critical illness. The aims and objectives of the research were achieved and included; capturing patient experiences of recovering from critical illness to understand what shapes their expectations of the recovery process; exploring patient experiences of hospital based care and wider support in the community setting following an episode of critical illness; exploring and describing the experiences of the staff who care for patients following discharge from CrCU; mapping the emotional touchpoints for patients and identifying patient/carer and staff priorities for improving patient experiences of hospital based care and support in the community.

The study started out with individual patients and staff telling their stories and culminated in a collaborative event involving patients, families and staff. At each stage of the research process, themes were identified that addressed the research objectives and, in turn, informed the next stages of the study. Patient interviews captured how patients' experiences of CrCU impacted upon their lives during recovery and generated a film, revealing the momentous impact of critical illness and the journey to recover physical, emotional and psychological health and wellbeing. In contrast, staff interviews primarily focussed on co-ordination of care following critical illness based upon their perceptions of patients' needs. The patient feedback event allowed patients to clearly describe the emotional impact of the touchpoints comprising the recovery journey. The collaborative process of the patient and staff event culminated in the identification of patient focussed priorities for service improvement, namely; improving the critical care experience for patients; addressing patients' emotional and psychological needs during recovery; positioning patients at the centre of services; and, developing a supportive framework to promote recovery.

This study generated multiple and rich sources of data from the various interviews and events. Translating all these findings into a meaningful whole was enabled by using an EBCD approach, itself a form of participatory action research. As such, the meaning and relevance of this study has been developing alongside the individual processes

involved. The findings have consistently revealed the ways in which patients had to navigate the recovery process by adapting their needs and expectations following critical illness to fit in with the remit of current care delivery and service provision. This highlights a key all-encompassing message behind this EBCD study, that improving patient experiences of NHS services requires a person-centred approach to care which recognises that each patient is different and provides individualised care centred around their needs rather than the needs of the service.

In an international review of the concepts of person-centred³ practice, Louw et al. (2017) identified the key common principles as:

“...a holistic perspective of patients and their illness experience, a therapeutic alliance between the patient and clinician as well as respectful, enabling collaboration with the patient.” (Louw et al., 2017)

In the UK, the Health Foundation ("The Health Foundation," 2016) captures these principles within their framework for person-centred care. The framework outlines personalised, coordinated and enabling care as the three main principles, with an overarching fourth principle of treating people with dignity, compassion and respect as shown in Figure 7.1.



Figure 7-1 The four principles of person-centred care

³ The terms person-centred and patient-centred are used interchangeably in the literature to describe care, practice and services (Jakimowicz and Perry, 2015, Paparella, 2016, Louw, Marcus and Hugo, 2017).

The four principles of person-centred care are closely interwoven with the findings from this study and the priorities identified for service improvement and they form the framework around which this discussion is structured. The first section is about improving experiences in critical care by humanising care to enable patients to embark on the recovery journey from the best position possible. The second section addresses patients' emotional and psychological needs in the context of personalised care, which moves beyond the illness per se, to recognise the needs of a person with an illness. The third section considers the coordination and continuity of care and services to meet the individual and evolving needs of patients over the course of recovery. Finally, the fourth section completes the circle, reflecting on how promoting care that is humanised, personalised and coordinated restores patients' independence and enables them to take a proactive role in their recovery journey.

7.2 “First Do No Harm”: Improving Experiences in Critical Care

This section considers dehumanisation in CrCU as characterised by behaviours which obscure the person who is the patient and focus instead on clinical parameters and conditions. The study identified that patients' experiences' in CrCU sent shockwaves through their worlds which reverberated on every aspect of their lives during recovery. Although the focus of this study was on experiences *following* discharge from CrCU, one of the most poignant findings was the extent to which patients were affected by their experiences *during* the CrCU stay. A major theme from the patient findings identified the dehumanisation patients experienced during their CrCU stays and improving patients' experiences of CrCU was a key recommendation for service improvement. Interpretation of these findings requires understanding of the concepts surrounding the humanisation of healthcare, which involves treating people with compassion, respect and dignity. This is a unifying principle of person-centred and patient-centred care and is discussed in this section in relation to the critical care arena.

7.2.1 “I am not a number”: Understanding dehumanisation in critical care

Haslam (2006) describes dehumanisation as denial of human nature and human attributes, which can lead to perceptions of individuals either as objects/machines, or as animal-like. According to Haslam (2006), dehumanisation is characterised by impersonal care-giving that lacks emotional support, touch and warmth and overlooks individual agency and autonomy. Leyens, Demoulin, Vaes, Gaunt, & Paladino, (2007) propose an alternative model, infra-humanisation, which describes how members of a

particular group (the in-group) tend to assign to themselves more positive and uniquely human emotions (compassion, fondness) than those outside their group (the out-group) who they perceive as having more primitive and negative emotions (pain, anger). In relation to healthcare, infra-humanisation occurs when healthcare professionals consider patients as outside of their own group and deny that patients have uniquely human emotions such as compassion, fondness, contempt and disillusionment (Galvin, Leitch, Gill, Poser, & McKeown, 2018).

A consistent finding across the patient interviews in the current study was the distressing emotions that patients associated with recollections of CrCU, and an emerging realisation that the way care was structured and delivered had a prominent role in this process. Patients used very negative language when describing their CrCU experiences, such as '*trapped*', '*uncertainty*', '*torture*', '*struggle*', '*horror*', '*helpless*' and '*weak*.' This language and the associated experiences uncovered the theme of dehumanisation in care on critical care. Indeed, the first part of the recovery journey is named 'surviving' as this encompasses how patients felt out of control and that they just had to "weather the storm" on CrCU. Findings from this study suggest that it is not only critical illness, but the CrCU environment, treatments and care regimes per se, which are associated with impacts such as reduced agency and self-determination that continue to affect patients during their recovery.

The concept of dehumanisation in CrCU is a relatively new aspect to consider in improving the care of the critically ill patient. Wilson et al. (2019) describe depersonalisation of CrCU patients as a 'devastating loss of personal identity.' The authors provide the following list of characteristics of dehumanisation:

- Loss of identity (and appearance)
- Loss of ability to communicate
- Loss of ability to advocate for one's self
- Loss of family presence
- Loss of control
- Loss of modesty/privacy
- Purposeful shaming/mockery
- Purposeful exploitation (e.g. for research)

Several findings from this current research study align with the characteristics described by Wilson et al. (2019). The patients participating in this study were

interviewed between one and four years after their CrCU admission, yet the isolation, vulnerability and helplessness they had felt in CrCU continued to evoke distress, and in some cases, horror. In fact, patients' experiences in CrCU were amongst the most distressing and debilitating they experienced throughout the whole of their critical illness and stayed with them throughout their recovery journeys. The patient interviews revealed many issues around loss of identity, with one patient actually defining recovery as '*feeling like a human being again*,' (P09). Many patients recalled the frustration of being unable to speak to staff or family due to endotracheal intubation or a tracheostomy tube. At the joint patient and staff event, one patient described how their dignity '*went out the window*' and another discussed their discomfort with regard to the lack of privacy when talking to the clinical psychologist with just the curtains to separate them from the other patients and staff. In this current study, there were many environmental factors, such as unnatural lighting, noise and unfamiliar and unpleasant routines, which dissociated them from normality. In addition, several patients recounted individual experiences relating to impersonal care, lack of involvement in, or understanding of, their care and treatment. Restrictive visiting policies on the CrCU also separated patients from the familiarity and support of their family and friends. Figure 7.2 summarises the findings from the patient interviews which are associated with dehumanisation. The ongoing burden segment is shown slightly separated from the others to reflect the impact from dehumanisation which can affect patients after CrCU and impact on their wellbeing during recovery.

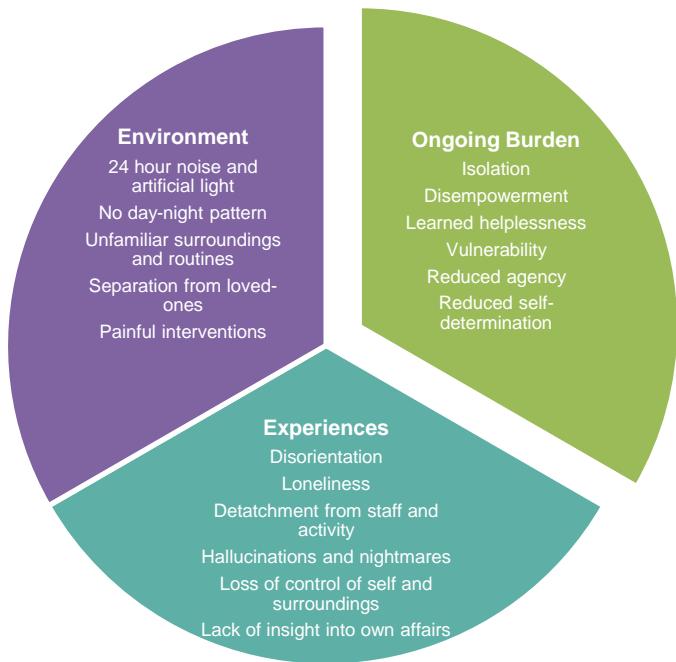


Figure 7-2 The CrCU environment, patient experiences and ongoing burden

Brown et al. (2018, p. 1390) describe CrCU as '*loci of dehumanisation*', suggesting that patients are susceptible to dehumanisation as they often lack typical human qualities such as consciousness, agency and self-determination, and acquire learned helplessness, the sense that they are unable to exert any control. These opinions are endorsed by Galvin et al. (2018) who also apply the concept of infra-humanisation to critical care. The authors explain how patients become de-individualised by connection to life-saving technology, and changes in physical appearance (e.g. generalised oedema, wounds, facial distortion due to equipment like the endotracheal tube) and loss of the ability to interact or make eye contact (Galvin et al., 2018). In such circumstances, CrCU staff may unintentionally perceive patients as less like themselves and therefore less human (Galvin et al., 2018). In contrast, in the current study, one patient described how the staff '*all looked the same*', which potentially added to the sense of depersonalisation.

This current study adds evidence which endorses the descriptions of dehumanisation by Brown et al. (2018). Several patients described events in CrCU that had made them feel powerless, helpless and not in control. All the patients had episodes of altered consciousness and/or CrCU related delirium which left them disoriented and unaware of what was happening around them, using descriptions such as '*I didn't understand*

'what was going on,' (P07). Patients also described situations in which they were unable to influence events or decisions which were being made about their care, without their involvement, *'I was in no fit state to argue...I had no choice in it anyway'* (P01). One patient succinctly captures the loss of self-determination and agency:

"...we all realised at that particular time in our life we had no control of what was going to happen, none whatsoever." (P05).

Brown et al. (2018) suggest that dehumanisation and loss of dignity have essentially the same meaning, the loss of human qualities. The authors define dignity as the essential value of a human being. In addition, respect is regarded as the conduct that honours and recognises a person's dignity which allows observable identification and measurement of respectful and disrespectful care (Brown et al., 2018). The authors suggest that dehumanisation can be characterised as loss of dignity and respect, which are more readily accessible constructs to understand and to measure.

A group of clinicians and academics at John Hopkin's University present the most comprehensive understanding of respect and dignity in CrCU through a number of qualitative and observational studies. The group have investigated respect and dignity from the perspective of patients and relatives (Beach et al., 2015), healthcare professionals (Geller et al., 2015) and using direct observation within the clinical setting (Carrese et al., 2015). The patient and relative study identified a number of elements that characterised respectful behaviours:

- Treated as a person/human being
- Being treated the way you would want to be treated yourself
- Being acknowledged or given attention
- Treated as a family member or friend
- Treated as an individual
- Treated as important or valuable
- Treated as an equal

These elements of respect and dignity are a vivid contrast to the dehumanising care described in this current study. They also help to illustrate the ways in which the care described by patients in the current study could be considered as dehumanising. When patients could not gain the attention of staff, when patients felt alone and unacknowledged in a crowded unit, when patients felt unable to challenge decisions made by staff, it becomes clear why they did not feel respected as human beings.

Respectful care gives patients a sense of worth and importance rather than reducing them to a condition or even a set of numbers on a monitor (Beach et al., 2015). Patients in this current study gave several illustrations of disrespectful and rather paternalistic communications with staff. One patient described being ‘told’ that their clinical condition no longer required a CrCU level of care and that they were being transferred to the ward. There was no consultation about whether they felt ready for the transfer or opportunity to address any issues about how they would cope. Another patient described being ‘...*in for a talking to*’ (P01) by a consultant when he [the patient] was reluctant to undergo surgery. Patients appreciated participating in this research study, which suggests that the introduction of some EBCD methods as part of a continuous improvement process would enable staff to demonstrate respect for patients whilst offering the opportunity to improve respectful care.

Haslam (2006) suggests that in healthcare systems, patients are expected to be passive recipients of interventions in a system which values technology and technologically derived information rather than patient individuality and subjective experiences. In this current study, the accessibility of patient records, investigations, imaging and live monitoring on computers and central consoles throughout the unit meant that healthcare providers were able to observe, diagnose and make treatment decisions remotely. This could remove patient interaction and involvement in the process altogether. One patient described how ‘*the staff just stand at computers and they just watch the monitors constantly*’ (P09). Miles and Asbridge (2014) argue that in an era of advancing technology, there is a need for highly technical skills to be delivered with an understanding of the patient as a person who is suffering from an illness.

CrCU is perhaps the most technologically driven environment in the hospital setting, and more sophisticated monitoring and complex treatments are continually being introduced. In the host study location, a consistent shortage of staff has led to new staffing policies which allow newly qualified nurses to be recruited onto CrCU. These new recruits will now have less experience of systems outside of CrCU. Traditional recruitment policies mandated nurses to work in the ward settings for a number of years in order to gain general experience of nursing before being recruited onto CrCU. Now newly qualified nurses must rapidly gain a daunting number of highly technical competencies immediately after qualification. It is possible that this may compromise some of the more interpersonal aspects of the nursing role. Critical care nurses can find it challenging to give patients their full attention amongst the competing demands

of technology (Price, 2013). Staff need to learn multiple highly technical skills and training is focused around gaining technical competencies and credence is given to gaining these competences (Price, 2013). Nurses depend on the machinery which helps them to feel safe and in control (Crilly, Dowling, Delaunois, Flavin, & Biesty, 2019). In this current study, the staff interviews endorse these findings, with suggestions that continual monitoring makes it easier for CrCU staff to do their jobs. One staff member explained that CrCU nurses tended to unnecessarily maintain continual monitoring of patients right up until their transfer to the ward. This has been associated with transfer anxiety in patients following discharge to the ward, who fear unnoticed deterioration due to the lack of close scrutiny (Salmond et al., 2011).

7.2.2 “Patients are people too”: Humanising critical care

The increasing awareness of dehumanisation in CrCU, and in healthcare more generally, has recently led some groups of CrCU practitioners to explore ways in which to care for critically ill patients with more humanity. Wilson et al. (2019) stress the need for staff to refocus on what the patient in CrCU is experiencing and treat patients as humans in order to mitigate consequences for patients’ wellbeing both during critical illness and recovery. However, the findings from this current study indicate that there are significant differences between staff and patient perceptions of how patients experienced CrCU. Staff thought that patients perceived the CrCU to be an unpleasant physical environment but did not realise that the way care was delivered was a factor in patients’ negative experiences. Indeed, at the joint patient and staff event, staff were keen to share with patients a number of changes to improve the CrCU environment for patients, such as the introduction of visiting musicians and the ‘pat-dog,’ shown in Figure 7.3.



Figure 7-3 The pat dog on the local CrCU

Whilst interventions, such as enabling a dog to sit with the patient on CrCU, have been proposed to ease the suffering and build motivation for recovery (Hosey, Jaskulski, Wegener, Chlan, & Needham, 2018) these are environmental improvements that do not deal with the wider issues regarding the way care is delivered. In their interviews, staff did not discuss the dehumanising impact of CrCU, or suggest this was something patients needed to recover from. Even at the joint patient and staff event, when patients mentioned specific episodes of care that had left them feeling helpless or disempowered, such as the daily exclusion from the ward round or the DNR order that was put in place without consulting the patient, staff did not obviously link this with dehumanisation. Whilst they were aware that a CrCU admission had psychological consequences for patients during recovery, staff largely discussed this in relation to the effects of delirium.

In this current study, the staff findings indicated an underlying assumption that patients preferred to be in the CrCU setting rather than on the general wards due to the one-to-one nursing. Staff attributed any deficiencies in care to care after CrCU, and it was difficult to penetrate the tacit impression that the care provided on CrCU was of a superior quality compared with care in other areas. The quality of care on the wards has been explored in the critical care literature, with patients experiencing episodes of poor care and negative interactions with staff (Field et al., 2008, Ramsey et al., 2013). Field et al. (2008) describe ways in patients perceived that ward-based care did not meet their expectations or needs as there were too few staff and staff were too busy.

Patients also discussed negative interactions with indifferent and insensitive staff, who made them feel lazy, or lacked understanding of their CrCU related physical debility. Staff varied in their compassion and responsiveness and patients often relied on their families for basic care (Ramsey et al., 2013). Interestingly, Ramsey et al. (2013) found that patients felt the power imbalance between themselves and nurses and would not share their concerns due to fear of compromised care, which suggested that nurses perhaps did not know about the episodes of poor care experienced by patients.

The original use of the EBCD methodology in this current study, to explore the whole of the recovery journey rather than a specific pathway or individual service, enabled patients to reflect back on their journey as a whole. This enabled patients to compare one experience with another and they considered their CrCU experiences as extremely negative and, on the whole, their ward-based experiences as very positive. It is possible that the negative aspects of ward-based care were offset by the more positive ones, such as building friendly relationships with staff and other patients, help with becoming more independent, and generally feeling less ill than on CrCU. Building more positive experiences into a patient's CrCU stay could possibly alleviate some of their more distressing memories, but ultimately this does not remove the need to address the dehumanising aspects of care.

The use of the EBCD methodology afforded a unique insight into why dehumanisation is a hidden harm. Bringing patients, families and staff together at the event revealed interactions in which patients discussed unsatisfactory care experiences and some staff appeared to be unconvinced that this had happened and attempted to rationalise these events. For example, one patient described how staff carried out painful interventions without explanation or even warning the patient. Some staff could not accept that this was an accurate recollection as staff were trained to provide explanations prior to interventions. Another staff member qualified such incidents by explaining that in emergency scenarios, explanations may be waived. The event demonstrated that staff perceptions of the quality of the care they deliver are both deeply embedded and often based on assumptions rather than accurate measurement or feedback. In fact, the only regular form of feedback received in the CrCU is the thank you cards expressing gratitude to the staff for the excellent care that saved their lives. This indicates a way in which staff may, inaccurately, misinterpret gratitude from patients and families as a validation of the way care is delivered, which in itself could be maintaining the unintentional dehumanising behaviours and practices. However, the joint patient and staff event demonstrated that whilst patients wanted to express their

gratitude to the staff for professional care that had saved their lives, they were even more compelled to share their experiences of how the interpersonal aspects of care needed to be improved. This highlights the importance of collecting patient experiences to capture a ‘truer’ picture of what patients’ value in relation to care delivery. The use of the EBCD methodology as an approach to continuous improvement could help staff to capture which aspects of care patients appreciated most in order to promote the delivery of these aspects into everyday practice.

In CrCU, where it is essential for staff to focus on life saving care and treatments, the patient experience may be viewed as a lesser priority. In this current study, the traditional approach to improving patient experience is to intermittently collect satisfaction surveys from patients and families or feedback from the follow-up clinic on an ad hoc basis. However, a novel approach to humanising CrCU was taken in a large inner-city teaching hospital in Scotland (Connelly et al., 2019). Connelley et al. (2019) conducted a quality improvement programme to enhance patient experience and care by finding out what was important to patients and delivering small and practical measures to make improvements in care. The approach originated from the Institute for Healthcare Improvement in the US and involves staff asking patients ‘what matters to you?’ (<http://www.ihi.org/Topics/WhatMatters/Pages/default.aspx>) which is intended to provide more personalised care to patients. CrCU patients were asked by a staff member on a daily basis, “what matters to you today?” Within their own setting very practical actions were highlighted, such as ensuring a patient’s mobile phone was well charged to enable contact with family or arranging discussion with the surgeon about their treatment. The authors suggest that this approach could improve care on CrCU and has the potential to enhance long-term outcomes for patients. It is interesting that practical suggestions from patients were also captured at the joint patient and staff event which provides another potential mechanism by which to collate recommendations and advice that might enhance care in the CrCU.

An alternative approach to humanising CrCU is introduced by Sokol-Hessner, Folcarelli and Sands (2015). Discussing the primary focus on safety in healthcare, which associates definitions of harm with physical injuries, the authors propose the routine measurement of preventable emotional harm. Sokol-Hessner et al. (2015) suggest that damage to a patient’s dignity happens when staff fail to respect the patient as a person, and that these harms matter more to patients than actual physical ones, which appears to be endorsed by the findings of this current study. The authors recommend that healthcare services need to be accountable for defining, delivering and measuring

established standards of respect in the same way that the safety culture has been established over the past 20 years (Sokol-Hessner et al., 2015). For example, the incidence of readmission to CrCU is considered as a quality marker for CrCU and safety measures such as the outreach team follow-up visits were developed around this measure. Brown et al. (2018) warn that there may be reluctance by clinicians to recognize that disrespectful events are patient harms in a culture where even physical harms are underreported. Findings from this current study also highlight that before staff perceive disrespectful events as harms, they need first to be able to recognise and acknowledge that disrespectful events are taking place.

Framing dehumanisation in terms of failures in respect and dignity could offer a more practical way to inform staff of how to provide humanistic care. The John Hopkins group have validated an ICU Direct Observation Tool (Carrese et al., 2015) and an ICU-RESPECT Index (Geller et al., 2016). The observational tool examines staff interactions with patients and relatives and gives a practical assessment of respectful and dignified care. Components of the tool are based around staff conduct and demeanour. Domains of staff conduct include how the staff greeted the patient, protected their modesty, explained activities, talked to them at eye level, and responded to their needs. Domains of demeanour include the extent to which staff were not distant, but were compassionate and supportive, and behaved in a positive and pleasant way. The ICU-RESPECT Index is a 21-item questionnaire for patients and families. It includes a wide range of practical measures such as whether staff explained what actions were being undertaken in an understandable way and made an effort to know the patient as a unique individual. These 21 items illustrate practical ways in which patients and families can be treated with humanity. Both tools have the potential to improve care in the local setting by emphasising the elements of humane care and measuring them in practice.

Whilst the measurement and identification of failings in respect and dignity is important, the engagement of CrCU staff is central to the process of improving patient experiences. Efforts to improve patients experiences in CrCU need to take into account the impact of working in CrCU. CrCU is a pressured and chaotic workplace, and staff have a high exposure to acutely unstable patients, distressed families and death. In such circumstances staff may routinely construct barriers between themselves and patients and their families to protect themselves from excessive emotional distress. As a means of defensive dehumanisation, nurses have been shown to consider patients in less than human terms (e.g. rational and moral beings) and in more primitive terms

(e.g. instinctive or impulsive beings) as a coping mechanism to protect themselves against stress (Trifiletti, Di Bernardo, Falvo, & Capozza, 2014). Similarly, attributing patients as not fully human by perceiving them to have only primitive emotions (e.g. fear, anger, distress) rather than more human emotions (e.g. sorrow, remorse, optimism) has been shown to protect nurses against burnout (Vaes & Muratore, 2013).

Several authors have explored the impact on staff of working in a CrCU setting, describing high rates of burnout syndrome and compassion fatigue (Costa & Moss, 2018; Embriaco, Papazian, Kentish-Barnes, Pochard, & Azoulay, 2007; Quenot et al., 2012). Burnout syndrome manifests as exhaustion, depersonalisation and reduced personal accomplishment as a response to work-related stressors whereas compassion fatigue is characterised by failure to get involved in caring relationships with patients (Moss, Good, Gozal, Kleinpell, & Sessler, 2016; Van Mol, Kompanje, Benoit, Bakker, & Nijkamp, 2015). Both depersonalisation and decreased compassion in CrCU are considered to have a negative impact on patient-related outcomes during recovery (Moss et al., 2016, Van Mol et al., 2015, Embriaco et al., 2007). If the impact on staff of working in CrCU is not addressed, it is perhaps unrealistic to expect measures to provide more humanistic care for patients to be successful.

Research in the area of dehumanisation, dignity and respect on CrCU is limited and there are very few studies that have related patient experiences to this construct. This current study has added valuable insight into how patients experience dehumanisation on CrCU. This study also proposes an original suggestion that the emotional harm from dehumanisation may even delay patients' recoveries. During interview, some patients discussed experiences such as being reluctant to make decisions about their healthcare, reliance on family members to take charge of their care at home, lacking confidence in areas they previously felt strong, and, their avoidance of interacting with healthcare services. For example, one patient remained on the ward for weeks as he could not make the decision about whether to consent to heart surgery or not. Another patient discussed their avoidance of anything associated with hospitals, and now sets time boundaries around any new admissions that are recommended. One patient asked for details about the next scheduled peer support group but then lacked the confidence [*"I bottled out,"* (P05)] to attend the meeting. Patients also discussed how they had a lingering fear of readmission and how they restricted their activities or delayed holidays even though doctors had advised them they were physically back to normal. It is not possible to determine from this study the degree to which dehumanisation may have contributed to these impacts, though the findings suggest

that further research in this area is needed to explore the potential impact that humanising CrCU care could have on recovery.

In summary, the potential impact of dehumanisation in CrCU is beginning to raise concerns about care delivery in selected critical care organisations, though this area has yet to be the subject of widespread research. Dehumanisation sees the person fade into the background as staff take over and the CrCU machine ‘kicks into gear.’ Dehumanisation is an emotional harm, creating a learned helplessness and loss of confidence and self-direction that needs to be restored in order for patients to fully engage with the recovery process post CrCU. Dehumanisation in CrCU has been associated with failure of dignity and respect, with patients repeatedly subjected to assaults on their dignity, privacy, control, self-advocacy and interaction. As such, it is essential to challenge dehumanising behaviours and practices in order to deliver truly patient-centred care that affords people dignity and respect.

7.3 A person with an illness: Addressing Emotional and Psychological Needs

This section addresses patients’ emotional and psychological needs in the context of personalised care and considers the need to recognise what matters to patients is more than just the physical impact of their illness. Miles et al. (2014) argue that the measurement of objective parameters has replaced the patient’s individuality and the treatment of biological dysfunctions has diminished the importance of patients’ subjective experiences of illness (Miles et al., 2014). The touchpoints of the recovery journey generated in this study demonstrated that the key events and emotions experienced by patients was not limited to physical illness alone. This discussion focusses on the need to embrace the whole needs of a person who has an illness by addressing their wider emotional and psychological needs.

7.3.1 “My mind isn’t broken but...”: Emotional and psychological responses

A key finding from this study was that patients’ emotional and psychological needs were often misunderstood, and, grouped together under the umbrella of psychological problems. Emotional and psychological issues are multifaceted and interwoven, and, the terms are used interchangeably within the literature. However, this study identified that it is useful to unravel some differences between psychological and emotional issues when considering how best to address patients’ needs, in order to arrange the most appropriate support. Patients’ descriptions of becoming emotional following

critical illness can be differentiated from the more overt psychological symptoms such as nightmares, unreal memories, flashbacks, intrusive thoughts and depression that often become apparent in the months following critical illness. Reports of psychological problems in the form of nightmares, hallucinations, delusional memories and flashbacks following critical illness have been widely reported in the literature (Pattison et al., 2007, Minton & Carryer, 2005). Storli et al. (2009) identified that these issues were associated with anxiety and panic attacks for some patients. Findings from this current study complement the literature, with many patients discussing often vivid and frightening psychological symptoms which intruded into their lives during recovery.

Whilst more obvious psychological symptoms associated with critical illness have been widely reported in the literature, the emotional impact of critical illness has received less attention or has been grouped together with psychological problems. However, for patients in this current study their emotional responses such as tearfulness, panic, stress and anxiety appeared to reflect, at least in part, the wider personal impact of critical illness. All patients in this current study suffered from physical weakness and many from cycles of setbacks during early recovery and these experiences were associated with negative emotions. Patients felt shock, distress, vulnerability and uncertainty, associated with their physical weakness, which has been widely reported in the literature (Gardner et al., 2005; Lee, Herridge, Matte, & Cameron, 2009, Salmond et al., 2011). Shock is a common response from patients upon discovering their physical weakness, and dependency on staff and family to provide personal care has been reported as demoralising (Minton et al., 2005; Ramsey et al., 2013, Cox et al., 2013). However, findings from this current study suggest that what also matters to patients about losing their independence goes beyond the loss of function or activity or dependency on others. Loss of independence also appears to have a negative impact upon patients' sense of self and self-confidence, which could make patients more cautious, risk averse and less likely to challenge themselves during recovery for fear of failure or setbacks.

Whilst patients' physical needs associated with their weakness appeared to be recognised in the hospital setting, the huge emotional impact this had upon them was largely overlooked in care provision during early recovery. Recent research by Corner et al., (2019) suggests that when patients become fully conscious following critical illness, they expect their physical capabilities to be as they were prior to critical illness. It comes as a huge shock to discover their weakness and this appears to cause emotional distress and vulnerability. The authors suggest that patients need time to

'recalibrate' to their new situation, and recommend that staff help patients to do this. Recalibration is the way in which patients shift their viewpoint from who they were before CrCU admission to who they are when they awaken following critical illness and this new viewpoint becomes the benchmark for recovery efforts (Corner et al., 2019). Failure to recalibrate could partly explain why some patients approach recovery with unrealistic expectations of what they can achieve and how long this will take. Corner et al. (2019) suggest recalibration is an important early stage in enabling patients to form practical ambitions and goals for recovery.

7.3.2 Redressing the balance: Addressing emotional and psychological needs

Findings from this study indicate patients' emotional needs are not normally discussed by the staff that patients routinely encounter during their hospital stay. Some of the CrCU outreach nurses who visited with the patients the day after their CrCU discharge encouraged patients to talk about their psychological and emotional problems, although this tended to be in relation to the impact of delirium, and, was only done if time allowed and the individual nurse was interested in this particular aspect of care. Significantly, when patients are asked about issues such as mood, sleep and family, staff are demonstrating that these are normal responses to illness, especially in situations in which patients experience recurrent setbacks and have unpredictable outcomes (Buckley, 2008, p. 65-66). If staff initiate a conversation with patients around their wider personal issues, this acknowledges these are important and patients learn that their responses to illness are normal and not an indication of weakness, and that someone is willing to talk about them. In this study the timing of the outreach visit, the first 24 hours following transfer from CrCU, may have coincided with patients feeling overwhelmed by their newfound physical incapacity and the adjustments to the ward setting following transfer from CrCU. At this timepoint, patients may not yet have had the time to recalibrate or even understood their emotional needs. The wider literature has identified that patients feel an urgency to recover their independence, and early recovery is characterised by a focussed effort to rebuild strength in order to regain mobility (Gardner et al., 2005; Lee et al., 2009, Ågård et al., 2012; Maddox et al., 2001).

Another patient perceived that regaining independence would address their emotional issues and focussed entirely on fixing their physical problems and '*blocking everything else out*' (P10) [see *patient film*]. Significantly, Buckley (2008, p. 78) stresses that patients may not raise these issues with staff unless asked, no matter how worrying they are, which corresponds with the findings of this current study. In the current study

patients identified issues such as stigma, feeling 'soft,' feelings of failure, unwillingness to burden families and feeling ungrateful for being alive which made them reluctant to raise emotional issues.

Patients found that obtaining support for their emotional and psychological issues was a rather ad hoc process throughout recovery which led to disparity in the support patients received. Whilst CrCU follow-up clinics and psychological in-reach was highly valued by the patients who attended, only a minority of the patients in this study had access to these services. In contrast to the care provided for physical recovery, psychological and emotional needs were often unrecognised, misinterpreted or unsupported. Patients and staff in this study reported experiences of CrCU staff who referred all emotional and psychological issues to a psychologist, ward staff who did not recognise or dismissed any psychological issues and GPs who reportedly misinterpreted patients' issues as low mood states and prescribed antidepressants. Some CrCU staff presumed that CrCU follow-up clinics would address patients' psychological problems after hospital discharge, releasing them from any responsibility of care. This unfounded presumption is problematic as only a small proportion of patients attended the follow-up clinic in the current study. In addition, psychologists are only able to provide consultations to a restricted number of in-patients. The tendency for CrCU staff to refer all emotional and psychological issues to a psychologist places further demands on an already pressured service and has repercussions on the availability and priorities of the CrCU psychologist for patients who need specialised management.

The lack of acknowledgement regarding psychological and emotional issues reflects the lack of a whole person approach to care delivery in this current study. This finding is endorsed within the wider literature, with NICE guidance for improving patients' experiences of NHS services (NICE, 2012, 2019) highlighting that the acknowledgement that patients may need psychological and emotional support is an essential requirement of care. In essence, this guidance advocates that patients should be viewed as individuals who have an illness. Staff are urged to recognise that patients' needs are not constrained to treatment of their illness alone, but require discussion, information and support for any psychological, spiritual, social and financial support needs they have (NICE, 2012, 2019).

Rana Awdish (2019), a consultant in intensive care medicine, who also became a CrCU patient due to a life-threatening illness, emphasises how the act of just being

'seen' as a person is therapeutic for patients. Discussing how healthcare professionals are achievement orientated in an effort to fix things, she suggests that it can be a difficult ethical process for a doctor to put aside their own agenda in order to respect the patients' values, yet this is necessary to truly co-create a plan of care that is centred upon the patients' goals. Findings from this current study indicated that sometimes patients do not comply with treatment as they feel this is the only way they are able to exert any control over their circumstances when they feel disempowered by healthcare staff and regimes. At other times patients have clinical reasons that render them unable to comply with care or pre-prescribed physical therapy goals, such as cycles of setbacks that may not always be physically obvious. The Health Foundation (2014) warns that standardised approaches to care delivery may ultimately damage patients' quality of life and recovery process by limiting their capabilities of managing their conditions well. Instead, individualised services are proposed as a means to promote independence and drive care towards patients' personal wants and needs.

By talking with patients about both their emotional responses and psychological symptoms, staff can provide empathy, compassion and provide reassurance that their responses will improve over time. Patients and families in this current study felt that recognising emotional needs should be an essential element of care that any healthcare professional should practice. For staff to consider this to be unimportant or not part of their role is erroneous as many patients in this study became demonstrably emotional when recalling their critical illness experiences, despite years having elapsed. Staff may feel that they have no way to address patients' emotional responses, yet many patients found that the opportunity just to talk about their experiences in this study was therapeutic. This suggests that encouraging patients to discuss their emotional responses during critical illness and early recovery may help them to understand and resolve emotional issues and move forwards.

A further benefit of staff routinely talking about wider issues with patients would be to differentiate between emotional and more specific psychological symptoms associated with delirium and unreal memories, so that appropriate support could be arranged or highlighted as a potential future requirement. Meeting emotional and psychological needs requires hospital staff to be aware of the issues that patients experience, be sensitive to patients' concerns and understand the criteria and process of referral. Findings from this study identified some inconsistencies across these areas and many patients had unmet psychological and emotional issues as inpatients that remained unresolved at hospital discharge. More importantly, patients did not know how to find

appropriate support for their issues following hospital discharge and only a minority of patients attended the follow-up clinic or peer support group. This is an important issue to address during the early stages of recovery as patients' unmet needs can escalate over time (King et al., 2019) and psychological problems are linked to early hospital readmission for former CrCU patients (Donaghy et al.). At the patient staff event, the idea of welfare visits was developed, involving visits to former CrCU patients and families on the ward by a member of the CrCU team to talk to patients about their wider issues. Staff suggested that assessment could also be made of the patients' wellbeing, for example, by using validated tools to measure and highlight psychological concerns. This appears to be a person-centred approach, which may improve many patients' identified needs and has the potential to reduce ongoing distress and curtail the development of future issues.

Several patients in this current study suggested that some support needs should be addressed earlier than the three month follow-up clinic timepoint, particularly for emotional and psychological issues. If follow-up services were redesigned to enable assessment of predictable issues prior to hospital discharge, this could help with earlier identification of needs and allow for appropriate support and resources to be arranged for all patients who had been in CrCU. This was recently demonstrated for physical fitness by the use of the 'activity measure for post-acute care inpatient mobility short form' by ward nurses to measure how much assistance post-acute care patients needed to complete mobility tasks prior to discharge home (Hoyer et al., 2019). Tools to measure emotional and psychological health, which are used at the study location in CrCU follow-up clinics, could be administered prior to hospital discharge to identify support needs. Both the wider literature, and this current study, indicate that many patients are not invited to attend follow-up clinics so fail to have their support needs identified and met. Assessment on the wards could increase patient and family contact with CrCU staff following transfer to the ward, allowing discussions around patients' needs and goals for recovery and providing the opportunity to arrange individualised information and resources according to patients' needs.

In summary, findings from this current study suggest that clinical practice within the study setting is broadly driven by the identification and treatment of clinical conditions and, as a result, important individualised person-centred issues such as psychological, social and practical needs are often overlooked. For a small number of patients in this study, their access to psychological services or peer support was felt to be an important aspect of their recovery care. For many patients, their emotional and

psychological issues were not addressed either in hospital or by follow-up services, and some discussed ongoing issues even at the time of interview for this study.

7.4 Minding The Gaps: Coordinating Care to Enhance Recovery

This section considers the coordination and continuity of care and services to meet the individual and evolving needs of patients over the course of recovery. In a paper advocating person-centred clinical practice, Miles et al. (2014) discuss how medicine has become increasingly reductive and services have become highly specialised. This creates a challenge for CrCU patients who often cross multiple specialities and many healthcare boundaries during their treatment and recovery. Appropriate care delivery needs to be maintained across transitions for patients to receive maximum benefits from healthcare services. Providing coordination of care becomes increasingly important for CrCU patients who have multiple evolving healthcare needs during recovery.

7.4.1 “Passed from pillar to post”: Providing continuity of care

Issues with continuity of care following critical illness have been consistently highlighted in the literature (Deacon, 2012, Laplum et al., 2011, Lee et al., 2005, Prinjha et al., 2009). In this current study, continuity of care was a key theme amongst staff. Staff acknowledged the fragmentation between care settings, with each tending to focus on their own specialities and having little interaction with CrCU. This created silos of knowledge within each speciality, and beyond the CrCU environment. For example, awareness of PICS was restricted to CrCU follow-up services. If ward-based staff have little awareness of CrCU treatments and care or the patients' issues following critical illness, it becomes more difficult for them to interpret handover information from CrCU. It is possible that more technical aspects of care are the main focus of handovers as CrCU staff focus on patient safety. Staff discussed how the handover of information from CrCU to ward staff could became diluted or lost with subsequent transitions between care settings, creating problems for staff responsible for the next stages of care. Patients also described repeatedly telling their story to different healthcare professionals as information did not travel with them across the various services they used. These issues create particular problems for patients following critical illness as they experience many transitions between healthcare departments and settings during recovery.

Improving transitions in care both within and between healthcare settings is a key aspect in delivering continuity of care and, in this current study, both patients and staff discussed the major transitions from CrCU to the ward and discharge home from the ward. Transitions in care following critical illness are a common theme in the CrCU literature and have been the subject of multiple studies and reviews (Bench et al., 2011, Minton & Carryer, 2004, Lee et al., 2005, Salmond et al., 2011). Research regarding transfer from CrCU to the ward suggests that patients need to be prepared for discharge by receiving adequate information and explanation (Bench et al., 2011) and that patients need time to become accustomed to reductions in the level of care and support (Minton & Carryer, 2004, Lee et al., 2005, Salmond et al., 2011). This current study confirms these findings, with most patients feeling some degree of apprehension about the step down in levels of care anticipated on the ward. However, patients appeared to be relieved to be leaving the CrCU and returning to the more 'familiar' ward environment. Only one patient felt they were moved too soon, as they still felt too weak, and had been unable to do anything for themselves on their return to the ward.

In the current study, the outreach team discussed their role in providing continuity and follow-up. If time permitted, the team introduced themselves to the patients the day before transfer so that patients would see a 'familiar face' on the ward, a practice that has been discussed as beneficial to patients in the wider literature (Pattison et al., 2007, Bench et al., 2011). However, the only patient who recalled the outreach nurse visiting her on the ward had needed multiple visits from the outreach nurse to monitor her clinical condition. Patients suggested there was a lack of involvement and choice in the decision-making process surrounding transfer to the ward, suggesting that opportunities to involve and empower patients and families are possibly being overlooked when the outreach nurses pre-visit patients. The staff interviews indicated that the outreach team did prioritise acute and physical care, with most outreach nurses focusing on checking patients' clinical parameters and progress rather than discussing wider needs with patients.

In a study exploring hospital discharge, Laplum et al. (2010) showed that patients felt that discharge home was a key transition, and whilst some perceived it to be a sign of progress, many patients feared their health would deteriorate as they were no longer being guided and monitored by healthcare professionals. This current study identified similar themes, with patients on the one hand desperate to prove to staff they were ready for discharge but then shocked about how vulnerable they felt on returning home

due to loss of reassuring contact with healthcare professionals. Some patients felt they needed to monitor their conditions for fear of relapsing health. This finding is endorsed by Laplum et al. (2010) who reported that patients were suddenly expected to take back ownership of their health yet lacked adequate individualised information about exactly what activities they could do and what to expect next. Lee et al. (2005) suggested that hospital discharge is often a rushed process and the way staff delivered information did not leave time for informative discussions with patients or their caregivers (Lee et al., 2005).

Findings from this current study add to the literature surrounding transitions in care by showing the discrepancies between the views of CrCU staff and patients about which transition is the most important. The EBCD methodology enabled patients to take a helicopter view of the whole recovery pathway. This allowed patients the opportunity to consider these transitions in the context of the whole recovery journey rather than as single events, and this revealed new insights. The CrCU staff considered that transfer from CrCU to the ward was the most significant transition and, as such, this received the greatest input of resources. Both the discharge coordinator role and critical care outreach visits were established to provide planning and assessments around transfer to the ward, yet CrCU staff were seldom involved in the hospital discharge process. In contrast to staff, most patients felt positive about their transfer from CrCU to the ward but negative about their hospital discharge. The emotions and key words associated with hospital discharge revealed that patients felt 'pushed out' or 'dismissed' from hospital in a chaotic and poorly coordinated fashion and, once home, they felt alone, isolated and uncertain. At the joint patient and staff event, some staff appeared surprised that hospital discharge was so challenging for patients and wanted to engage with patients and families about how this process could be improved.

It is likely that targets to prevent CrCU readmissions and improve patient safety on the wards has improved the transfer experiences for CrCU patients at the study location⁴. In addition, the ICNARC dataset over the last five years shows that, nationally, patients are being discharged earlier from hospital despite the duration of CrCU stay remaining constant, and perhaps some patients felt their rushed hospital discharge was a reflection of the pressure for hospital beds. It is also likely that the absence of CrCU

⁴ The discharge coordinator role was not established when the patients in this study were on CrCU.

teams in the hospital discharge process, and outside of the CrCU itself, means that important CrCU-related needs such as physical frailty may be unidentified on the wards and remain unassessed before the patient leaves hospital. The absence of CrCU staff involvement in the hospital discharge process also reduces the opportunity to handover important CrCU related patient information to community-based care teams or GPs. In addition, patients and families do not have the opportunity to hold discussions with experienced CrCU staff about what to anticipate on returning home and where to access help and support following discharge. These are important issues to address as the incidence of PICS in CrCU survivors is high (Maley & Stevens, 2019), yet knowledge of PICS is reported to be low amongst non CrCU healthcare professionals (Daniels et al., 2018).

One key touchpoint identified in this study was that, following hospital discharge, CrCU survivors unexpectedly found themselves to be ‘patients at home’ for a significant time. Some patients needed ongoing care from community-based teams and family members as they were unable to perform even simple self-care activities and reported having very little information or choice about these facilities and teams. For some patients, their ongoing care was managed entirely by family members with little support or information for either patients or families to advise them what to expect or where to find help and advice should they have any problems or questions. Many patients commented that they would not have been able to manage at home without family care. In addition, patients felt that they had to wait, or even fight for the resources they needed to undertake activities, as the hospital discharge process was poorly planned and coordinated. It is clear that the CrCU did not have any positive impact on the initial period of recovery from critical illness. Whilst some patients did attend follow-up clinic and peer support groups, these were accessed at least three months into the recovery process and had no impact on the period of biggest adjustment and struggle for the patients and their families. These findings are echoed by Prinjha et al. (2009) who found that the first few months of recovery were the most difficult and patients wanted follow-up soon after hospital discharge. Importantly, for this current study, some patients had no contact with follow-up services at all and so received no positive impact at any time.

7.4.2 Joining the dots: Coordinating care

A King’s Fund Report into the provision of co-ordinated care for people with complex chronic conditions, suggested that when people are managed across fragmented healthcare systems, they risk sub-optimal care experiences and outcomes (Goodwin,

Sonola, Thiel, & Kodner, 2013). The issues described by patients with chronic and long-term conditions parallels those identified in the current study in terms of continuity and appropriateness of care. When looking at the wider literature about different care models, it becomes increasingly clear that PICS has many of the elements of a long-term condition with complex care needs. Some CrCU clinicians recommend that current models of chronic disease management could be used as a framework for care following critical illness, adding that institutions may be more confident in funding models which have a proven record of improving patient outcomes (Haines et al. 2019). Adhikari et al. (2010) highlight that the ageing population is increasing the proportion of critical illnesses caused by comorbid disorders rather than single disorders. The increasing number of patients with pre-morbid chronic illness experience the most prolonged recovery periods after critical illness (Azoulay et al., 2017). Managing CrCU recovery within a chronic illness framework is an interesting proposition which is likely to gain more traction due to global trends in the aging population and has the potential to deliver services that are more responsive to patients' needs. Organisations such as the World Health Organisation (<https://www.who.int/servicedeliversafety/areas/people-centred-care/ipchs-what/en/>) and NHS England (<https://www.england.nhs.uk/integrated-care-pioneers/resources/patient-care/>) highlight the need for continuity of care and co-ordination as an essential part of person/people/patient-centred care.

Findings from this current study suggest that follow-up services are resource driven and that there is a lack of coordination of care as no one person has overall responsibility for all the elements of the recovery journey. Staff described how different aspects of the recovery service were delivered by different healthcare professionals but there was little sense that this was aligned to an overall strategy and appeared instead to be comprised of fragmented and disparate silos of care. Staff were unclear about the limits and boundaries of care provision, and they appeared to make self-determined assumptions about their own roles and responsibilities and those of others. Care delivery following critical illness could be considered as a series of individual entities rather than a coordinated approach to recovery with clear goal, targets and outcomes. Staff were unclear about the remit of follow-up care provision. Co-ordination at this level is about interdisciplinary communication and working together to a common goal, namely meeting patient's needs. Whilst there was some discussion of communication between staff groups, this was often at an informal or ad hoc level.

Services were neither evaluated for effectiveness nor aligned to patient needs and were instead arranged at fixed time-points and according to eligibility criteria. Indeed,

most staff were unaware of the practical difficulties patients endured on a daily basis until they attended the joint patient and staff event. These findings suggest feedback about patients following critical illness was for the most part only available when the patient accessed a part of the service, for example by attending the CrCU follow-up clinic. There was no tracking of patients' progress, outcome measures were not routinely collected, and patient and family satisfaction surveys were seldom carried out.

Without the involvement of patients to identify which services they find useful and what additional resources they need, services can only be based on staff assumptions of patients' needs, and this can be problematic. In a recent study by Nedergaard, Haberlandt, Reichmann, Toft and Jensen (2018) differences were found in the priorities identified by patients, doctors and nurses about which outcomes are more important to patients following critical illness. This stresses the importance of ensuring that services are aligned to patients' needs, and that these needs are identified and prioritised. However, in the current study, staff discussed how limited resources restricted the ability to improve services, or even measure their effectiveness. Assumptions of effectiveness were evident throughout this study and meant that sometimes patients' needs were unmet. For example, staff assumed that patients would access follow-up clinics if they needed help without any reassurance that the system was effective in delivering invitations or evidence that patients understood the purpose of the clinic. Some patients in this study did not receive invitations and others did not attend because they did not appreciate how the follow-up clinic could benefit them. Recent research by Haines et al. (2019) found that patients were reluctant to attend follow-up services when they were uncertain whether it would be useful for them, especially if it meant time away from home, and family members had to miss work. With challenges in securing resources for follow-up services widely reported, the authors suggest that resolving such issues are important in order to demonstrate value by ensuring clinics are fully attended, and by patients who need them.

In this current study, patients often had to seek out help by themselves in order to access support for issues that became apparent following discharge from hospital. In the face of ongoing frailty, and emotional upheaval, patients felt that the additional burden associated with trying to secure the support they needed, could be avoided. At the joint patient and staff event, many patients said they did not know about the CrCU follow-up clinic or the Support Group and had felt there was no longer term support available to them. Some patients had found resources via GPs, by searching on the internet or revisiting the hospital Patient Advisory and Liaison Service. Patients

recommended that a dedicated care coordinator would help to identify support and resources and would provide a named contact to help them with issues or advice following discharge.

The NHS Plan (<https://www.england.nhs.uk/long-term-plan/>) highlights that barriers between organisations, care teams and funding streams need to be removed in order to provide joined-up care that prioritises the needs of the increasing number of people living with long-term conditions. The NHS England House of Care Framework, (<https://www.england.nhs.uk/ourwork/clinical-policy/ltc/house-of-care/>) highlights some reasons why there is a lack of integrated care around people with long-term conditions. For example, services are aligned around single conditions with no one having an overview of the whole of the patients' care needs. In addition, physical health is prioritised, patients' records are inaccessible between settings, services react to complications rather than pre-empting them, and patients' own expertise and capacity to self-care are disregarded. It is clear that the issues and needs that patients identified in this current study echo those of patients with long-term conditions, as highlighted in the House of Care framework. This highlights the need for an integrated model for follow-up services.

In summary, this study exposed many inconsistencies, variations and gaps in care delivery experienced by patients throughout the recovery process. Follow-up services operated as individual entities, had no overarching goal or strategy and prioritised the interests of the service over those of the patients. The lack of continuity and coordination of care created challenging obstacles and issues for patients during recovery. Misalignment of services resulted from delivery based on staff knowledge, perceptions and experience, unfounded conclusions about effectiveness and resource centred design. A key principle of person-centred care involves offering coordinated care and services, yet this service lacked overall coordination by a dedicated member of staff.

7.5 “Standing On Your Own Two Feet”...Enabling Self-Directed Recovery

This section completes the discussion about the person-centred care to improve patients recoveries by considering how to support patients in navigating their own recovery journeys. Care that is humanised, personalised and coordinated, as outlined in the previous sections, creates a strong foundation from which patients can retain

more independence during critical illness and enhance their ability to self-direct their care during recovery. In essence, what remains is the need for a framework of appropriate resources which patients can access whenever they need. This is important as patients can take months or years to fully recover from PICS, and there is limited evidence to date about how to effectively prevent or treat it (Connolly et al., 2014). This discussion considers how to provide proactive services and flexible resources to meet the differing and evolving recovery journeys of individual patients.

7.5.1 Start as you mean to go on

Critical illness is associated with an array of issues that relate to the critical illness itself and the associated CrCU related experiences. The Society of Critical Care Medicine is endorsing the ABECDF bundle in CrCU, developed as an approach to making organisational changes that will shift the CrCU culture towards optimising patients' recoveries and outcomes (Marra, Frimpong, & Ely, 2016). This bundle encompasses; assessment, prevention and management of pain; spontaneous awakening and spontaneous breathing trials; choice of analgesia and sedation; assess, prevent and manage delirium; early mobility and exercise; and, family engagement (Marra et al., 2016). Whilst a systematic review of the efficacy and outcomes of using the bundle is currently underway (Moraes et al., 2019) this initiative demonstrates the shift in CrCU to preventing avoidable harm to patients as the initial stage in promoting improved recovery and outcomes.

Patients become aware of many of the issues associated with critical illness and CrCU early on during recovery, whilst they are in the hospital setting. Grosseline, Hollenbeke, Clerckz and Langer (2019) suggest that early physical rehabilitation, which starts in the CrCU and continues throughout the patients' recovery is recommended to prevent or attenuate the effects of critical illness. In the UK, the NICE rehabilitation guidelines (NICE, 2009, 2017) remain the influential guidance informing care and service provision. NICE guidance recommends that, during the CrCU stay, rehabilitation plans are co-created with patients at risk of ongoing morbidity, which can then follow the patient throughout their recovery pathway. The co-creation of plans with patients is intended to ensure that rehabilitation goals are person-centred.

Whilst patients in this current study did not discuss being involved in co creating rehabilitation plans, either on CrCU or the hospital wards, some did mention their negotiations with ward based physiotherapists regarding their daily physical therapy. It is difficult to determine if rehabilitation plans were person-centred, as patients

appeared to be largely guided in their activities by physiotherapists on CrCU and the wards. Corner et al. (2019) suggest that, on CrCU, patients have delirium, impaired cognition and are sometimes unaware of their physical condition, which changes rapidly. In these circumstances the authors suggest that patients have a 'desired paternalism' as they do not feel able, or know how to take control, whereas later, with increasing autonomy, patients want to be fully involved in planning and decision-making.

In this current study it is unclear whether 'desired paternalism' or a lack of opportunity effected patients' involvement in making rehabilitation plans. Patients either did not recall or did not discuss rehabilitation plans in the hospital setting, with the exception of one patient who received care in a rehabilitation ward. On the whole, patients did appear to feel mostly supported with regaining their physical strength and mobility. However, following hospital discharge patients were shocked by the amount of effort needed to perform even simple activities. It was only at this point that they understood the full impact of their physical weakness and realised they were still 'patients at home.' This suggests patients were not being prepared for the process of recovery at home by practicing individualised self-care activities based on person-centred goals. True patient involvement in planning daily physical therapy activities, based upon realistic goals and ambitions, provides a means of restoring patients' autonomy through shared decision-making, which is especially important in the aftermath of critical illness. It is possible that time pressures on in-patient physiotherapists and occupation therapists and the constant demand for hospital beds forces physical therapy goals towards meeting the mobility requirements for hospital discharge.

The staff interviews suggested that lack of resources, or the prioritisation of acute care, limited the allocation of a rehabilitation specialist to the team to provide bespoke therapy sessions centred upon enabling patients to complete tasks to support their independence. However, in addition to resource constraints, cultural influences may also dampen patients' attempts to resume self-care and regain independence. The patient interviews revealed examples of how patients had to fit in with the way care was provided for them, rather than being encouraged to care for themselves. One patient described how he had to ask the staff to teach him to perform some tasks which then allowed him to take over his own care, such as managing the percutaneous feeding regimes. This positive shift from staff care to self-care was highly motivating for this patient, allowing him to monitor progress, set targets and resume responsibility for his own health. However, this participation was arranged at the patients' request, rather

than being routinely offered. Tobiano, Bucknell, Marshall, Guiane, & Chaboyer (2016), in a paper exploring patient participation in care in the acute hospital setting, found that some nurses practiced in a controlling and task orientated manner, preferring to use established routines rather than encouraging patient participation. Such findings suggest that overcoming organisational and educational barriers is needed to promote staff behaviours that promote self-care activities in patients. Improving patient and family engagement in care in the acute setting is increasingly being linked to better self-management, shorter lengths of hospital stay and reduced use of healthcare services (Goodridge et al., 2018). However, the increasing specialisation and the condition specific focus in healthcare settings possibly obscures from staff the longer-term impact on patients and families that non-participatory models of healthcare are creating.

7.5.2 Reframing recovery

The findings from this current study suggest that staff perceived ‘rehabilitation following critical illness’ from a reductive viewpoint, with services arranged around rebuilding strength and managing psychological conditions. The organisation of follow-up service provision, in the form of follow-up clinics and patient support groups, appears to be focussed upon providing psychological support and addressing patients’ memory gaps. Whilst focus on individual elements of PICS is necessary to understand how to improve outcomes for future patients, this study showed that it failed to improve the experiences of patients during their recovery. Indeed, the reality of survivorship in this current study involved prolonged efforts by patients and their families to address physical, emotional and social challenges, and forced them to do this with resources that were not ideally positioned to meet their individual needs. In a recent paper, Haines et al. (2019) reported that endorsement for CrCU follow-up clinics and peer support groups was challenged by lack of funding, the use of ‘donated’ time from clinicians and non-attendance of patients. These findings emphasise the need for services to focus upon what will improve patients’ experiences and quality of life during their recovery journeys.

Whilst CrCU follow-up clinics are increasing internationally, opinions about their efficacy and cost effectiveness continue to be debated in CrCU arenas (Willaert, Vijayaraghavan, & Cuthertson, 2019). Qualitative evidence suggests that follow-up clinics have allowed a more comprehensive understanding of the complex problems and chronic care needs that patients experience during recovery (Corner et al., 2019). However, evidence from recent randomised controlled trials (PRACTICAL and

RECOVER) have illustrated that follow-up clinics are not cost effective as they have failed to demonstrate any effectiveness on clinical outcomes (Willaert et al., 2020). In this current study, very few patients accessed the follow-up service, though those who did appreciated the appointment for redressing memory, emotional and psychological issues and questions relating to their physical conditions. Some patients had attended cardiorespiratory rehabilitation programmes which offered physical exercise sessions and educational classes on a range of subjects, that patients attended over several weeks with the same group of patients. These programmes were highly regarded by the patients, as they improved their fitness, met their needs for tailored information and provided peer support from other patients and families. Whilst similar programmes have been tested for patients following critical illness, these have not been shown to provide any benefit to patient outcomes. However, similar to follow-up clinics, evidence suggests that these programmes improve patients' experiences during their recoveries (Battle, James, Temblett, & Hutchings, 2019; Connolly et al., 2014; Taito et al., 2019).

Findings from this current study suggest that many patients and their families appeared to navigate the recovery process themselves. As patients gradually regained autonomy they resumed more responsibility for their recoveries. By far the most important aspect of recovery for patients was goal-setting and achieving recovery targets. Indeed, achieving goals was the most positively rated touchpoint of the whole patient journey, associated with regaining both independence and autonomy. Following hospital discharge, patients developed autonomy by setting increasingly ambitious goals and demonstrated creativity in the ways they achieved these. It is unclear whether involvement in planning and goal setting during the hospital stay would give patients the groundwork for the self-directed goal setting later on during recovery, and this warrants further exploration in future studies. However, findings from the current study indicate that achieving goals is highly valued by patients, and that working with patients to determine what matters to them and providing guidance on how to develop reasonable goals to meet their own longer-term ambitions is likely to benefit CrCU patients during recovery.

Alternative options to follow-up clinics and rehabilitation packages have also been proposed by some clinicians who have compared PICS to other long-term conditions (Iwashyna, 2010). Iwashyna (2010) suggested that survivors of critical illness and survivors of cancer face similar struggles during recovery, and CrCUs can learn from cancer survivorship programmes (Iwashyna, 2010). Indeed, many CrCU patients are cancer patients, with the percentage of cancer patients admitted to CrCU reported as

between 6 and 23 % in European CrCUs (Bos et al.; Shimabukuro-Vornhagen, Böll, Kochanek, Azoulay, & von Bergwelt-Bailedon, 2016). Iwashyna (2010) summarises the similarities between cancer and critical illness survivorship: patients have a difficult disease process accompanied by physical changes; in-patient care is highly specialised; recovery is associated with profound uncertainty; patients feel disconnected from support networks; care following hospital discharge is complex and disorganised; and, patients rely on families for provision and coordination of care. The progression from survival to survivorship in cancer treatment goals creates increased demands for healthcare resources, resulting in efforts to help more people access self-directed care (Jefford et al., 2013). With critical illness, survivorship demonstrates a similar progression; it is possible that applying lessons learned from the successes of cancer survivorship programme could improve the recovery process of CrCU patients.

Goodwin, Sonola, Thiel et al. (2013) recommend the use of appropriate care packages to stabilise patients' health over prolonged timeframes in less costly environments than care organisations. This approach has been successfully implemented in cancer care programmes in the UK and adapted for use internationally, in the USA, Canada and Australia (Jefford et al., 2013). The National Cancer Survivorship Initiative in England promoted a cultural shift away from the focus on acute illness to recovery, health, wellbeing and return to work (Jefford, et al., 2013). As part of the recovery service, the initiative recommended supported self-management and tailored support during recovery, together with measurement of important patient reported outcomes measures (PROMS).

The development of patient reported and patient important outcomes measures is gaining increasing importance in critical care practice. Originally, PROMS in critical illness were developed to address the heterogeneity in outcome measures used in studies exploring cancer survivorship (Dinglas, Faraone, & Needham, 2018). However, Wysham, Abernethy and Cox (2014) propose that patient reported outcomes reflect experiential concerns and can be developed to help predict outcomes for patients following critical illness in order to better align patient needs to healthcare services. This is important, as original outcome measures of survivorship have focussed on physical, cognitive and psychological domains yet these may not be reflective of outcomes that matter to patients. A recent review of qualitative studies did not identify cognitive issues as an important patient outcome, even though it is a defining component of PICS (Hashem et al. 2016). Interestingly, this was not identified as a significant touchpoint in this current study. Hashem et al., (2016) reported themes

across the following domains: global satisfaction with life, mental health, physical health, social health and ability to participate in social roles and activities. This current study reported physical, psychological, emotional, social and identity touchpoints as important aspects affecting patients' quality of life both during and after recovery, which corresponds closely with the findings of Hashem et al., (2016). The knowledge of what outcomes matter to patients is important information for determining the type and organisation of services during recovery.

The challenges of meeting patients' support, information and advice needs stresses the importance of providing a framework of services that patients can choose from, and also to make sure that all the components of the service come together to meet the variety of patient needs that patients report. Macmillan Cancer Support, one of the largest UK cancer charities, provides an example of a coordinated approach to recovery in their cancer recovery package (https://www.macmillan.org.uk/images/recovery-package-sharing-good-practice_tcm9-299778.pdf). Components comprised a holistic needs assessment and care planning, a treatment summary completed following each episode of care and sent to the patient and GP, a review at 6 months by the GP or practice nurse, and an education and support event to prepare the person for supported self-care. Whilst the individual components of a critical care recovery package would need to be informed by patients' needs and preferences, the coordination of these elements into one recovery package could provide a comprehensive range of support all under one umbrella.

In summary, findings from this study suggest that the care and services provided often failed to reach many patients and their families or address the comprehensive and long-term needs of those who did access these services. Co-ordinated and seamless care with the patient at the centre may go some way to resolving the lack of evidence of effectiveness for follow-up clinics and rehabilitation packages. Treating post-intensive care syndrome as a long-term condition with complex needs may allow experience from other specialities such as cancer care to inform the development of supportive frameworks. The survival of the NHS is dependent on supportive frameworks enabling self-care and promoting independence to allow best use of resources in a world of increasing demand on healthcare organisations.

7.6 Limitations

7.6.1 Methodology

The EBCD methodology was adapted in this study from the original approach advocated by Bate and Robert (2007). These alterations required careful consideration of the pros and cons of adapting the stages of the EBCD process and were made due to time constraints of conducting this research as a single researcher undertaking this study as a part-time PhD. One adaptation was the omission of any non-participant observation. Observation of both staff delivering services to patients during recovery would potentially generate more objective data about how staff interacted with patients and the nature of the care they provided. In addition, observational work which mapped the journeys of a number of patients through the recovery process could have indicated some existing gaps in service provision. Further, early fieldwork which involved observing the pathway of patients might have provided a better understanding of the members of staff who are involved in delivering care for patients during recovery, potentially indicating a wider sample for staff interviewing. In particular, this could have led to more insight from ward-based allied health professionals, a group of staff recalled and appreciated by many patients participating in this study. A challenge to conducting observational work for this project was that provision of CrCU-related services during recovery involved several different aspects, such as observing discharge processes, CrCU outreach visits and patient revisits to the ward. As these aspects of care are not usually delivered at pre-arranged times, it would be difficult to organise to observe them in action. One exception to this would be the critical care follow up clinic, which takes place at a specified time each week. Whilst the researcher has gained some informal feedback about follow up appointments, direct observation of a clinic appointment would provide useful triangulation of evidence to compliment the patient and staff interviews. However, a minority of patients in this study sample, and of the patients discharged from critical care, actually attend follow up clinics, so this observation is not the most representative of the recovery process. The researcher has some informal observation of peer support groups through attendance at a previous meeting prior to commencing this study. This provided the opportunity to chat with patients about their experiences after critical illness and provided the researcher with some confidence when approaching the formal patient interviews during this study.

In addition to omitting non-participant observation, a separate staff feedback event was not held. The advantage of omitting the staff event was to allow time for the researcher to move ahead with the next stages of the study, the disadvantages were that it was not possible to validate the staff findings with the staff group and determine their collective opinions about priorities for service improvement. However, a number of staff

who were interviewed were no longer in the same roles and this required the selection of further staff to participate in the next stages of the study. In addition, plans to undertake stages five and six are being explored following the completion of this study and the researcher is currently involved in informing staff in the local setting about the findings of this study and advising on plans for the future development of services.

At the time of commencing this study the researcher had not been in a practitioner in the CrCU practice setting for five years. However, even having a CrCU background could influence patients' willingness to divulge negative experiences about care and services. Patients were given some researcher background prior to starting the interviews which served as both an ice-breaker and informed them that the researcher no longer practiced as a CrCU nurse. The findings of this study demonstrate that patients were able to discuss their experiences with candour. With a background in CrCU nursing the researcher also had to be mindful of the inclination to pursue information about the CrCU rather than recovery out of interest and experience of this area. However, the narrative approach to interviewing allowed patients to discuss issues which were important to them. As all patients discussed their stay in CrCU this appeared to be an important part of their sense-making for their recovery experiences and this, in turn, led to the identification of one of the key areas for service important that would otherwise have remained hidden.

7.6.2 Sample

This was a single centre study conducted in the CrCU of a busy teaching hospital with challenging environmental issues. The CrCU has a higher than national average bed occupancy level which means the CrCU is under continual demand for beds, there is a high throughput of patients, which places additional demands on CrCU staff. Whilst the local community has a large ethnic population, the sample for this study were all white. One Asian patient expressed an interest in participating, however his condition prevented this during the data collection time-frame of the study. Otherwise, the patient demographics (e.g. age/sex/comorbidities) and levels of care provided is similar to other CrCUs across the UK.

The training for the CrCU doctors and nurses is nationally standardised and the type of treatments and care delivered is representative of the UK, although there may be some cultural and organisational differences between CrCUs. The patient sample for this study is generally representative of the national case mix. Two of the patients, one having complex upper gastrointestinal surgery and one a major trauma patient could be

considered as tertiary specialities. However, these are not unique tertiary specialities, with many other CrCUs around the country providing similar services.

The sampling was designed to be varied to capture the viewpoints and experiences of a range of different patients. However, as the patient participants responded to invitations to participate in the study it can be assumed that the patients felt they had contributions to make to the study. The patients in this study all experienced issues during recovery, and so their recovery journeys may not be representative of those patients with fewer problems following critical illness. By implication, patients with fewer issues are less likely to need support from recovery services. A further limitation is that no family members were interviewed, although there was some contribution from relatives during the co-design event. Whilst family members do have an important supporting role in the recovery process, the scope and resources for this study precluded their experiences being captured in individual interviews. However, family members will be invited to participate in the future co-design events in order to ensure that service redesign considers their needs as well as those of patients.

With regards to staff selection, the staff had experience in critical care and particular roles within the recovery services. As no ward based staff were interviewed, care has been taken not to draw any conclusions or assumptions about the knowledge, beliefs and experiences of ward based staff unless it has been referenced in the wider literature. Nurses, doctors and psychologists were represented in the staff sample but no allied health professionals such as physiotherapists, occupational therapists or speech and language therapists were included in the staff interviews, which is a weakness of the study. At the time of the interviews there was no formal rehabilitation role for any allied health professional apart from the CrCU psychologist. However, at the time of the co-design event a rehabilitation specialist physiotherapist was seconded into the follow-up role which added a valuable contribution to the discussions.

7.6.3 Data collection

The decision to film the interviews and create a patient film added complexity to the research process. Additional ethical considerations needed to be considered prior to data collection and the equipment necessary to film and edit the patient interviews needed to be purchased. The researcher also needed to learn how to use the equipment and edit the film. Whilst this increased the study length, it was a worthwhile process as the film is unique in that it has portrayed the whole recovery journey and

effectively demonstrated to staff what patients experienced. As such this is a valuable resource for education and training and a unique contribution to the evidence base.

The data collection and the patient feedback and joint patient and staff events were held towards the end of the study and involved staff currently involved in recovery services. As such, the study is comparing former patients' experiences with the current provision of services. Importantly, patients and staff continued to be engaged in the process. The same sample of patients took part in the joint patient and staff event, and all the patients who were interviewed had wanted to attend, though not all were available on the day itself. In addition, due to a technical problem the scores from the interactive quiz were unavailable to use at the joint patient and staff event and a postal questionnaire was needed to recapture these scores. This was done as quickly as possible whilst the event was still fresh in patients' minds but the scores may have differed from the originals. Without the scores on the day, the rollercoaster nature of the emotional map was missing, though the experiences expressed at each touchpoint were available.

The EBCD methodology uses formal co-design meetings with staff and patients/carers to redesign aspects of the service that have previously been highlighted for service improvement by patients/carers and staff. Whilst it was beyond the scope of this PhD study to implement the co-design phases of the EBCD methodology, the process of co-design did actually begin at the joint patient and staff event. The collaborative nature of the discussions gave patients the opportunity to share common experiences with their peers and other families, which naturally generated patient suggestions of ways in which services could be improved. The event also represented the first opportunity for staff to talk to patients/carers about their experiences of the services they provided. Hearing these experiences, and the ways in which current provision of services were failing to meet several patient needs, proved to be a significant impetus for staff to create changes to services. Staff in particular began to consider and suggest ways to fill the gaps in service provision identified through the EBCD process, such as provision of a welfare visit to the patient on the general wards by critical care staff. The event enabled patients and families the opportunity to shape this new idea, which has subsequently been further developed following the completion of this study. As such, the informal process of co-design which began at the event demonstrated the value of this approach and generated enthusiasm amongst both patients and staff to participate in formal co-design meetings.

7.6.4 Impact of duration of doctoral programme on Experience-Based Co-Design

This EBCD study took place over six years as it was undertaken in parallel with full time employment and as part of a PhD. This was a time-consuming approach for a single researcher as part of a PhD process. Whilst this current study has met the objectives outlined by the research, further stages are needed utilising the EBCD methodology for implementation of the co-design event priorities. The prolonged timeframe could have impacted the engagement of both patients and staff, though this did not happen. Significantly, all the original patient participants are keen to be involved in any further stages of co-design. The patient feedback event and the joint patient and staff event provided the opportunity for patients to share their experiences with peers and this aspect of the EBCD process appeared to be an enjoyable one. Importantly, no new investment in staff or other resources has occurred over the study timeframe, although compliance to the assessments outlined in the NICE guideline is slightly improved. Nationally there have been no significant guidelines published that have affected the findings of this current study. GPICS V1 and V2 have been published but have refined the models set out in the NICE guidelines and previous critical standards rather than adding any material differences.

7.7 Summary

Modern healthcare systems are moving away from resource-based services to patient-centred care. Patient-centred care has to be designed in collaboration with patients and the EBCD model has enabled the collection and interpretation of important data to challenge the foundations of the follow-up and rehabilitation services. The traditional emphasis on treating conditions is, perhaps, a reductive approach. In the arena of CrCU survivorship, research which has focussed on the common conditions patients experience following critical illness has yet to determine a conclusive evidence-base to direct practice. The use of EBCD to map the emotional touchpoints of the recovery journey showed the misalignments of the fixed service components to the variable trajectory of the recovery journey. Offering standardised and inflexible services fails to recognise patient diversity and offers no individualisation of services to meet their unique needs. The use of patients' experiences to inform service delivery places a different emphasis on the goals and outcomes for follow-up services. Redesigning care delivery based on priorities that matter to patients creates the potential to provide services that truly meet the needs of the patients they support. Improving continuity across the healthcare system, and coordinating services, especially for people with

diverse support needs, offers a way for staff to relieve some of the struggles and improve patients' experiences during recovery. Better understanding patients' and families' experiences offers a way to improve the recovery journey and the potential to expedite recovery.

8 Conclusion

8.1 Introduction

This final chapter presents the conclusion to the thesis, drawing together the contributions to new knowledge originating from this work and the implications of this knowledge for both local practice and wider healthcare itself. This EBCD study adds to the literature regarding patients' experiences of recovery after critical illness and demonstrates how this knowledge can be applied to improve healthcare experiences.

8.2 Contributions to new knowledge

Using an EBCD methodology to improve services for patients following critical illness has offered an original approach to research within critical care rehabilitation. As a result, this thesis offers some unique contributions to knowledge, not only in the arena of critical illness, but in the approach to service improvement itself. In this section the contributions made by this thesis are presented, as follows; recovery is a journey not set in a fixed time or location; continued effort is required to change the traditional CrCU 'survival' mindset; preventing dehumanisation on CrCU by recognising emotional harm and delivering person-centred practice; and using EBCD as a continuous improvement approach.

8.2.1 Recovery is a journey not set in a fixed time or location

This study provides original insight into recovery as a journey and the emotional touchpoints that characterise that journey for patients. The key critical illness and recovery experiences that mattered most to patients in this study formed the touchpoints of the recovery journey and demonstrated how recovery encompassed more than physical and psychological health. Recovery was also about regaining autonomy, self-esteem, self-efficacy and self-confidence. The mapping of this journey has also revealed points at which patients interacted with services and highlighted gaps where services were not synchronised with patients' needs. The recovery journey enabled staff to fully appreciate the far-reaching and all-encompassing impact of critical illness on daily living for patients and families during their prolonged recovery periods. This in turn provided a common context for patients and staff to reference when considering the development of services.

In this study, depicting patients' narratives as a single journey highlighted to staff the ways in which the recovery journey failed to synchronise with the fixed and inflexible

follow up services that are provided for patients, and demonstrated why these often failed to meet patients' needs. Whilst all patient journeys are individual to themselves, many patients experience common events but at different times. In essence, there are predictable elements and patients need access to support when each of these needs arise, not when directed by healthcare services. A key improvement should be the development of flexible, reactive and patient centred healthcare services.

8.2.2 Continued effort is required to change the traditional critical care 'survival' mindset

Critical care medicine is a young speciality compared to other more established medical disciplines. With the speciality arising out of a need to treat life threatening illness, the tradition adopted a survivorship mindset, with a focus on 'fixing' and "saving" acutely unwell patients. Success was measured in terms of whether or not a patient survived until CrCU discharge with little awareness of the patient beyond the critical care boundaries. Whilst recent decades have uncovered the considerable burden of survivorship for patients, families and healthcare services, this study demonstrated how the traditional mindset continues to influence daily practice in the CrCU setting.

The CrCU gaze towards what is urgent and life-saving is more immediate and obvious than the consideration of what happens next. In this aspect, more established disciplines lead the way forward in terms of how refocussing outcomes can change practice. Cancer Care has shifted treatment away from survival alone as an aim, to consideration of the quality of that survivorship. Management of patients with chronic and long-term conditions have challenged traditional ways of delivering services from service orientated delivery to patient centred supportive frameworks. In contrast, conventional service delivery models following critical illness have persisted and changed very little from those described two decades ago in Comprehensive Critical Care. The adoption of supportive self-care models and a move away from the infrequently attended follow up clinics and seldomly accessed support groups may transform the patients experiences and ultimately outcomes of recovery.

8.2.3 Preventing dehumanisation on critical care by recognising emotional harm and delivering person-centred practice

Critical illness is a dehumanising experience for patients. In this setting the patient's physical condition becomes the major focus of healthcare staffs' attention. In the context of life-threatening illness this appears to make sense to both staff and patients. The immediate need to save a life supercedes all other considerations. CrCU staff

automatically take charge and the patient surrenders control. Yet this is only one aspect of the patients' overall stay in CrCU. What follows immediate and life-threatening events for patients is a journey of progress and setbacks, and this can make it unclear to both staff and patients at what point patients can resume autonomy and self-control. The default state of staff power and patient helplessness is harmful and could easily prevail unconstrained unless staff both appreciate the impact this has on patients and actively assume responsibility for providing humanised care.

Investigation into the effects of dehumanising care in CrCU is a recent area of interest in some international critical care arenas, although there has been very limited evidence, or interest, to date from UK settings. This study adds to the wider debate on this subject by proposing that dehumanising care strips patients of their self-efficacy and is in itself a set-back to recovery as patients' need autonomy, self-esteem and self-confidence to navigate the recovery journey and embrace the challenges of self-directed care. Improving patients' experiences following critical illness must begin within the CrCU itself, to redress the elements that can cause additional burden and complications for patients' during recovery.

The impact of critical illness on a person's identity is inevitable; dehumanising care, characterised by a devastating loss of dignity and respect, is preventable. A shift in perspective towards treating a person rather than treating a condition presents the foundation from which to cultivate humanised care and mitigate emotional harm,. Person centred care should become a benchmark of practice for critical care services moving forward, rather than an added bonus.

8.2.4 Using Experience-Based Co-Design as a continuous improvement approach

This study represents the first use of the EBCD methodology to explore recovery from critical illness and demonstrates the value of this approach to capture targeted evidence to inform service improvement. The use of EBCD methods allowed a richer depth of insight than the traditional feedback methods such as surveys, questionnaires or anecdotal stories that normally inform service improvement. This approach has expanded the wider knowledge about the recovery process for patients following critical illness, whilst challenging healthcare staff assumptions locally about the efficacy of services. The co-design event allowed direct challenge of staff assumptions concerning critical care survivorship, PICS and the services that are presumed to support patients. Staff reported how financial and time restrictions place limitations on follow-up services,

yet increasing the funding of staff time to deliver services using the current configuration would not necessarily improve patients' experiences or outcomes. This study has questioned the fundamental premises and assumptions upon which services are based, demonstrating misalignment with the recovery experiences of patients and a need to clarify the objectives, purpose and efficacy of follow-up services.

The conclusions drawn from use of EBCD in this study demonstrate that this approach offers more than a stand alone service improvement methodology. The EBCD methodology, which draws significantly on the assumptions of dialogical organisational development, could be used to continually challenge assumed ways of working in healthcare practice. Dialogical organisational design methods deliberately disrupt the way a group usually thinks by replacing the common narratives which are generated by those in power (staff) with narratives representing the whole group. In this study, representing patient experiences in the form of a recovery journey created a disruptive image that challenged staff perceptions about how their services were meeting patients' needs. Disrupting the narratives of healthcare staff released them from their established way of thinking about recovery and follow up and created the energy to engage in the change process and the conditions under which new ideas could surface. Dialogical organisational development allows the collective generation of new images that then influence how the group think and act. In this study, generative images such as a 'patient at home' triggered staff to reconsider how hospital discharge should be improved to better support patients' needs on returning home.

The progression from individual data capture to collaborative service redesign is key to the EBCD process. Data capture alone does not guarantee that services will be based on what patients need rather than meeting staffs' objectives. The collection of individual patient stories is used widely within healthcare settings, yet services continue to develop based on reducing important risks. For example, a key remit of the critical care outreach service is on averting unnecessary admissions and readmissions. Knowing patients' experiences does not mean staff will develop services based on what patients want. The key is collaboration between fully informed stakeholders who have *all* the relevant data. Whilst insight might emerge from individual methods of data collection, it is only when all the interviews are shared that a collective understanding of issues is revealed and pertinent ideas are generated to improve services.

Patients felt valued as a result of their involvement in the EBCD process, endorsing the dialogical organisation development ethos of promoting egalitarianism and

empowerment. Both patients and staff in this study felt that an ongoing programme of EBCD methods, particularly the patient and staff joint event would be an efficient way to efficiently capture an abundance of feedback to inform further improvements to care and services.

8.3 Implications of this thesis

8.3.1 Implications for local practice

This study has demonstrated that emotional harms from CrCU experiences can have a negative and long-lasting impact on patients during recovery. This is an important area for further research as the implications of emotional harm may result in a failure to engage with treatment, self-directed care and possibly the avoidance of healthcare settings during recovery. Within the local setting, a study evaluating respect and dignity in CrCU is currently underway to begin the process of redressing this issue.

This study identified that addressing patients' emotional and psychological needs was a major priority for service improvement. Key touchpoints identified by patients in this current study were related to the emotional impact of the illness itself and the psychological issues following critical illness. However, the staff perspective reveals that the focus of care in the hospital setting centres upon the patient's clinical condition. From a CrCU perspective the infrastructure prioritises the care of patients with acute and deteriorating clinical conditions over those who are recovering. The impact of these cultural and organisational influences reduces the attention and resources directed towards patients' psychological, emotional and wider recovery needs. This is an important bias to overcome as this study identified that most patients reported emotional responses and/or psychological symptoms following critical illness and for some patients these were still ongoing years after being discharged from critical care. An important next step for practice locally is to continue with the EBCD process and engage with patients and staff on how to implement the priorities for service improvement. This process has already begun at the study location with a project to explore the feasibility and effect of a welfare visit to identify patient needs during their ward-based stay.

EBCD can be used as an integral approach to continual improvement within the CrCU setting. This would also present the opportunity to update resources, such as the patient film, to ensure they reflect experiences that are grounded in current practices. One practical method to maintain patient involvement in service delivery would be to

establish a CrCU patient and family advisory group, comprising former patients/families and staff members who meet on a regular basis to advise on the delivery of CrCU care and services.

The emotional reaction of the former patients on viewing the film demonstrated that it accurately captured the experiences of critical care survivorship. In addition, the film produced a powerful and thought-provoking response from staff involved in recovery services. The film has recently been used (with patient consent) to educate junior doctors in the clinical setting to inform them of the recovery process for patients and illustrate the unintentional behaviours that lead to dehumanisation in care delivery. The film will soon be used to demonstrate patients' experiences of critical illness to preregistration nursing students and to train master's practitioners about the EBCD methodology. In addition, the findings of this research, together with the patient experience film are going to inform a session about how therapists can impact patient experiences as an element of the master's programme for allied health professionals. As such, this film is introducing a novel addition to healthcare professional education and training. The capture of this narrative in film is a unique way of portraying critical care survivorship as a whole journey with the patient as a person at the centre. A local challenge is how the patient narrative film could be used alongside other resources to inform and educate patients who are at the early stages of recovery. This could help to signpost to patients and their families the challenges that lie ahead and direct them towards resources to support them through these challenges.

8.3.2 Implications for wider healthcare

The EBCD methodology brought the patient's voice into service design and provided original evidence and insight to the design of follow-up services. The use of the local patients on the film made the recovery journey 'real' for the clinicians, rather than a speculative or abstract idea. Traditional quantitative research, such as randomised controlled trials, have shown limited evidence of improving outcomes for patients from either follow-up clinics or critical care rehabilitation programmes. Guidelines for the Provisions of Intensive Care Services standards and NICE guidelines that drive the commissioning for follow-up clinics and critical care rehabilitation services are based mainly on anecdotal expert opinion rather than evidence from conclusive trials. The standards are mainly concerned with assessment and identification of issues in a uniform approach and comprise limited evidence about what to do when problems are identified. If follow-up services are designed to support patients, it makes more sense to align them to the recovery journey than inconclusive evidence, consensus opinion or

staff assumptions. This EBCD study defines the recovery journey and indicates how qualitative evidence has the capacity to inform the evidence base for service commissioning. This is important because the number of follow-up clinics is growing worldwide despite lack of evidence of effectiveness, and the follow-up clinic model remains in essence the same as the original recovery model described in Critical to Success in 1999 (*Audit Commission*, 1999).

In the era of ageing populations, chronic illness and multimorbidity, person-centred care offers a proactive, holistic and sustainable model of healthcare that can meet peoples' needs whilst reducing healthcare costs (Coulter, Roberts, & Dixon, 2013, Alfano, Jefford, Maher, Birken, & Mayer, 2019). The findings from this study recommend that critical care turn its gaze outwards to explore models of care in chronic and long-term conditions, or cancer recovery programmes which have demonstrated success in improving outcomes that are important to patients. Indeed, patient reported and patient important outcome measures are gaining traction in a number of specialities. This current study contributes to the limited evidence regarding outcomes that matter to critical care survivors. Shoring up the evidence-base of patient important outcomes could contribute to more patient appropriate and realistic outcome measures for future research studies into follow-up and rehabilitation programmes. People-centred, as opposed to disease-centred healthcare is gaining momentum, and is now a global strategy of the World Health Organisation (WHO, 2014) and person-centred care is being driven by governments and healthcare policy organisations across the world (Kitson, Marshall, Bassett, & Zeitz, 2013). Person-centred care has often been considered the 'poor-relation' to other quality markers such as safety and efficiency in healthcare settings (Maher, 2015). However, findings from this study are now being applied in the local setting as part of embedding more person-centred care into clinical practice. In particular, lessons around the emotional impact of illness, including disempowerment and helplessness are informing interventions currently being developed at the study location to empower patients in other specialities. This demonstrates the growing recognition that patients' experiences have an essential role to play in informing the improvement of healthcare.

The view that the physical and psychological consequences of critical illness can be mitigated by preventative care within the CrCU setting is gaining traction, with interventions such as the ABCDEF bundles, or individual elements of these, becoming more integrated into CrCU practice. However, the findings from this current study suggest that dehumanisation on CrCU is a hidden, rather than obvious, harm and

should be included in these strategies. Humanising CrCU needs to start with building more understanding amongst staff of what aspects of care are dehumanising and its emotional impact. Delivering more humane care within the CrCU and beyond requires that patients' experiences are recognised and considered as important issues for targeted management within the CrCU and not just viewed as inevitable consequences of critical illness and being in the critical care environment. Establishing criteria to define emotional harm and undertaking systematic measurement of respect and dignity in CrCU could raise awareness of the issues and guide more humane care provision.

In conclusion, this study exploring recovery following critical illness using an experience-based co-design methodology recommends the development of CrCU services that are humanised, personalised and coordinated to give patients a strong foundation to retain independence and enhance their ability to self-direct their recovery.

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APPENDIX 1

Summary table of critical appraisal

Reference	Scope & purpose questions		Design, data collection & sampling strategy questions			Analysis questions	Interpretation questions		Relevance/ transferability	Overall quality
	Clear rationale & aims	Study contextualised	Method apparent & suitable for intent	Data collection & apparent & suitable	Sample / sampling & method suitable		Analytic approach suitable	Context described & audit trail clear	Use of data to support	
Ramsay et al. (2013)	Clear.	Yes - around how current outreach services developed.	Yes. Qualitative method embedded in RCT	Yes - appropriate for purpose.	Sample slightly skewed towards sickest patients.	Clearly described & appropriate.	Process of interpretation clearly described.	Comprehensive & relevant use of original data.	Reinforces what is known about transitions & ward-based care. Sickest patients recruited - may not be fully applicable to all CrCU patients.	High.
Ågård et al. (2012)	Clear.	Briefly - review does not fully describe context.	Yes appropriate for purpose.	Yes, & described clearly. Data saturation achieved.	Multi-site. Narrow inclusion/ exclusion criteria justified.	Adheres strictly to GT, clearly described.	Context comprehensively described with clear audit trail.	Use of data makes decision trail very clear.	Age 35-70 sample excludes some CrCU patients. Some contradiction of current evidence - sample focussed on moving forward , not re-living traumatic experiences	High.
Bench et al. (2011)	Clear.	Clearly. Limited literature review in this paper but covered in other linked papers.	Yes – first stage of MRC framework for complex interventions.	Yes – focus group design to generate qualitative data through group interaction (though focus groups didn't mix separated patients/relatives from staff).	Yes. Large sample of patients, relatives and staff from two UK hospitals.	Yes, critical realism perspective with content analysis approach well described.	To some extent – more details of how focus groups were conducted would be helpful.	Yes, really good use of participant quotes and the excerpts of full group interactions are illuminating.	Very clear patient and relative focus. Limited a little by lack of ethical diversity but new insight into considerations needed for effective information provision, and the goals of CrCU discharge information.	High.
Lapum et al. (2011)	Clear.	Yes, thoroughly described with technological emphasis relevant to study.	Yes, describing the construction of meaning through storytelling within narrative framework.	Good - narrative interviews at two time points & use of journals to document experiences as they occurred.	Yes. Good sample size & even in terms of male/female.	Yes. Narrative framework / narrative mapping.	Yes & journals provided detailed context.	Lengthy quotes from participants used.	Yes, though Canadian study & heart surgery patients, the slant is on technological environment, which is standard within CrCUs. New details re preparation for discharge & reconfiguration of discharge & follow up.	High.

Reference	Scope & purpose questions		Design, data collection & sampling strategy questions			Analysis questions	Interpretation questions		Relevance/transferability		Overall quality
	Clear rationale & aims	Study contextualised	Method apparent & suitable for intent	Data collection apparent & suitable	Sample sampling / method suitable		Analytic approach suitable	Context described & audit trail clear	Use of data to support	Evident?	
Chaiung (2011)	Clear.	Yes – but deliberately limited in line with the GT approach.	Yes – very comprehensively described.	Good – in-depth interviews at two time points together with some direct observation.	Theoretical sampling appropriate but sample appears to lack variety.	Yes – constant comparative methods described.	Good audit trail - participant verification of emergent categories but context not fully described.	Good use of participant quotes & easy to follow decision trail.	Single site & small, elderly sample, mostly with respiratory illness, so interpretation limited to this population. Good consolidation of what is already known. Adds insight into the continuum of dependence & independence as a dynamic process.	High – sample lacks variety but themes are informative.	/
Cox et al. (2009)	Clear.	Partly - very concise background only.	Qualitative study involving both patients & main carers between 3 & 12 months.	Yes - semi-structured interviews with patients & carers. Random assignment to <u>1 to 3, 4 to 6, 7 to 9</u> & <u>10 to 12</u> months after CrCU.	23 ARDS patients & 24 caregivers. Thematic saturation reached.	Colaizzi's qualitative methodology – described process of coding & thematic framework development.	Context & sample very thoroughly described & clear audit trail. Inter-rater reliability achieved.	Yes – participant quotes clearly support interpretation.	Yes – whilst sample is ARDS this study adds insight into the factors that modulate well-being or reduce quality of life during recovery. Highlights differences between patient & caregiver perceptions. Robust analysis gives confidence in themes. Male skewed patient sample & female skewed caregivers sample.	High – very well conducted & described study with attention to quality.	/
Lee et al. (2009)	Clear.	Very well.	Yes – rationale for qualitative approach and use of ‘timing it right’ framework.’	In-depth interviews guided by relevant interview guide.	Yes – good description of sampling process involved & good sample size - ARDS condition.	Yes – use of framework for analysis.	Clear audit trail stated & multiple researchers – good description of context.	Participants' quotes appear consistent with interpretation.	Relevant to ARDS patients (which relates to sicker & longer-stay CrCU patients). Good evidence about educational needs throughout recovery. Useful focus on changing healthcare & support needs.	High.	/
Prinjha et al. (2009)	Clear.	Clearly.	Yes – clearly described.	Yes – comprehensive approach.	Yes - National (UK) based study using narrative approach with large sample study.	Yes – well described.	Yes – allows understanding of interpretation process.	Yes. Quotes to illustrate findings.	One of few studies that includes people who haven't received follow-up. Captures a wide range of patient experiences following critical illness. Highlights patient-centric value of follow-up services.	High – well conducted study.	/
Storli et al. (2009)	Clear.	Clear background of current studies.	Yes – comprehensive description of hermeneutic-phenomenological approach.	Yes – in-depth interviews with conversational approach (not full sample at second time point).	Yes – specific aim for in-depth exploration rather than diversity of sample	Well described & good consideration of ‘pre-understandings’ of researcher.	Good – use of field notes, encounters, diaries & interviews. Very well presented.	Yes – quotes & diary inputs.	Original findings – add deeper insight about how interventions (e.g. diaries, follow up, CrCU revisits) are perceived by patients. Suggests supporting patients to find their own meanings, not staff just transferring information to patients.	High.	/

Reference	Scope & purpose questions		Design, data collection & sampling strategy questions			Analysis questions	Interpretation questions		Relevance/transferability		Overall quality
	Clear rationale & aims	Study contextualised	Method apparent & suitable for intent	Data collection apparent & suitable	Sample sampling / method suitable		Analytic approach suitable	Context described & audit trail clear	Use of data to support	Evident?	
Williams (2009)	Clear	Very well.	Yes - phenomenological approach suited to exploring the impact of narrative reconstruction of traumatic CrCU events.	Interviews at two time-points conducted on	Yes - 11 patients good sample size for this approach	Limited description - only analysis from five patients' was used in this paper	Limited description	Yes – clear use of quotes to illustrate findings.	Good explanation about what is required in rebuilding narratives appears widely relevant. Provides good insight into why reconstructing narratives is both challenging but important for patients.	High – small sample for analysis but the depth of analysis has revealed key insights.	/ Low medium/ high
Engstrom (2008)	Clear.	Yes – good background provided.	Limited details – narrative approach.	Yes.	Limited detail given – admission categories suggest general CrCU. Good sample size.	Yes – describe thematic content analysis.	Yes - study well described but lacks information about researcher perspective.	Yes – quotes supported interpretations.	Useful - exclusively focussed on psychological experiences but reinforces other studies – adds new info about impact of diaries on families. More male patients & female carers may skew findings.	High.	
Field et al. (2008)	Clear.	Very persuasive & constructive argument about relocation stress given as context	Yes - narrative enquiry with analysis based on modified grounded theory approach	Used DIPEX study interviews (Oxford Uni) – and comprehensive description given on referenced DIPEX website.	National UK study - maximum variation sample includes broad range of experiences. Possible recall bias for patients' whose CrCU admission was years ago.	Yes – used many grounded theory approaches & very clearly described.	Yes - context of care well described - thorough description of the analysis process & comprehensive reporting of the findings.	Very illustrative quotes used extensively.	Findings relevant to all CrCU patients - informs patient recovery immediately post-ICU and what can delay that recovery on general ward. New insight – look beyond assuming relocation stress is environmental & organisational, as staff training & availability can lead to stress, anxiety, depression & vulnerability on transfer, & may delay their recovery.	High quality study – well conducted with relevant findings.	
Gardner et al. (2005)	Clear.	Well-designed study with attention to research quality.	Yes exploratory – so qualitative approach.	Yes - semi-structured interviews & schedule shown.	Describes purposive sampling though only 8 patients from one cardiac CrCU.	Yes process of thematic analysis clearly described.	Well contextualised in terms of patient & setting.	Participant quotes throughout findings gives confidence in themes.	Sample is cardiothoracic though themes appear relevant to broad range of CrCU patients. New insights - patients reach a turning point & this is something that has little attention in the literature. Focus more on hospital stay, not whole of recovery.	High – very well conducted & described	

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	Clear rationale & aims	Study contextualised & aims	Method apparent & suitable for intent	Data collection apparent & suitable	Sample / sampling method suitable	Analytic approach suitable	Context described & audit trail clear	Use of data to support	Evident?	Low medium/ high
Egerod et al. (2013)	Clear.	Well described context.	Specific method not discussed.	Approach suitable to capture intended data.	Unclear -only nurses – no other MDT perspective.	Reliable approach & convincing findings.	Clear description of context but no audit trail described.	Descriptive rather than interpretative.	Conceptual model for follow up care is useful for service improvement. Suggests harmonisation of follow up & move to patient empowerment.	Medium.
Deacon (2012)	Clear.	Briefly – useful stats about patients' ongoing difficulties & available support.	Survey method used online open-ended questionnaire - may have limited range of experiences	Debatable – approach restricts opportunity for in-depth exploration.	Self-selecting sample, mostly from two websites which limits inclusivity.	Loosely based on GT – is this most effective for this data type?	Limited context only presented.	Participant quotes used.	Self-selecting sample, 90% female. Half sample from USA & had single disease category (ARDS). Findings support those of other studies rather than adding new material.	Medium.
Storli et al. (2008)	Clear.	Concise & relevant link between existing research & current study.	Phenomenological lifeworld approach appropriate to reveal meaning of lived experiences.	Yes - in-depth interviews as 'guided conversations.'	10 patients – good size for study type - good age range, both men & women, range of specialities.	Van Manen approach used - partially described.	Data presented as description then interpretation is difficult to follow. Limited audit trail.	Yes – verbatim quotes used.	Some – involves 10 patients at 10 years post CrCU & generally adds a little depth to what is already known. Difficult to assess argument for recovery as a journey in quest of meaning from description of interpretation.	Medium.
Pattison (2007)	Clear	Brief & quite generic – was this a deliberate grounded theory approach? Aims to inductively generate theory from new data.	Yes – mix of grounded theory with in-depth interviews & additional semi-structured questionnaires about service implementation.	Yes – in-depth interviews to capture experiences of follow-up, CrCU experiences & service improvement needs. Patient advisory group of helped design & review questionnaires.	Yes – single centre but large sample appropriate for study – limited to surgical cancer patients. Theoretical sampling mentioned.	Unclear – very limited details included.	No audit trail, no researcher details. Sample & setting described.	Yes – appear in line with interpretation.	Limited transferability as specific to two groups of cancer patients. The length of time they had spent in CrCU was 48 hours & over - patients likely to be well-prepared for their CrCU stay as elective population.	Medium due to limited description of research processes.

Reference	Scope & purpose questions		Design, data collection & sampling strategy questions			Analysis questions	Interpretation questions		Relevance/transferability		Overall quality	
	Clear rationale & aims	Study contextualised	Method apparent & suitable for intent	Data collection apparent & suitable	Sample / sampling method suitable		Analytic approach suitable	Context described & audit trail clear	Use of data to support	Evident?		
Lefebvre et al. (2005)	Clear.	Yes – comprehensive background & rationale for current study.	Yes – rationale given for qualitative approach with reflexive & dialogic aspects.	Yes - multicentre study involving range of sites & incorporating interviews with patients, carers & healthcare professionals.	Yes - sampling done to gather diversity of experiences. Very large sample size	Maybe – used only the initial five interviews to develop framework for remaining interviews – could have limited themes.	Limited description of context but good description of patient/carer sample. None of professional sample. Little other detail given.	Limited – all quotes gathered into a table rather than interspersed through text. Difficult to determine how analysis led to interpretation or conclusions.	To some extent – more description of analytic approach would help with assessing appropriateness but the many of the conclusions appear relevant to both TBI and CrCU patients. New insights about facilitates healthy partnerships between all involved in TBI recovery. Description of the problems experienced at the re-integration phase of recovery & the social isolation & marginalization is a significant finding too.	Medium – more detail of research methods would be helpful.	/	
Minton et al. (2005)	Clear.	Yes – clear literature review & background.	Limited description – qualitative design using interviews.	Yes – semi-structured interviews with open ended questions based on literature review.	Fair – exclusion criteria limited sample size to six patients in the time frame.	Very unclear – limited description.	No. Neither context nor audit trail were described.	Yes participant quotes.	–	Limited – only interviewed up to six months after illness. No new insight gained from this small sample but findings do consolidate the evidence to date, particularly early evidence of dehumanisation.	Medium.	
Adamson et al. (2004)	Clear.	Good background & context for current study	Qualitative aspect of a larger study (not described)	Yes - describes semi-structured interviews using guide (included) with back up questions based on responses.	Recruitment method ineffective & convenience rather than purposive sampling (patients best able to articulate their experience).	Limited description – appears to be thematic analysis.	No, but sample described in table. No audit trail.	Yes, comprehensive use of participant quotes.	–	Limited – interviewed at six months & only six patients agreed to take part..several refused. Recruitment process likely to have introduced bias to exclude patients who had more ongoing problems or wanted to avoid discussing disturbing experiences.	Medium.	
Maddox et al. (2001)	Clear.	Good background & context about physical & psychological problems post CrCU.	Unclear described as interpretative.	Yes -semi structured interviews - sample questions shown which are broad & open ended.	Maybe - describe purposive sampling but only included five patients & five significant others.	Yes - reference Strauss & Corbin & constant comparative method.	Limited context but audit trail included.	Very few quotes included.	Limited – small sample, minimal description of sample & setting. Has generated some contradictory evidence but this could be related to the small sample & fact that patient & significant other were interviewed together.	Medium.		

Reference	Scope & purpose questions		Design, data collection & sampling strategy questions			Analysis questions	Interpretation questions		Relevance/transferability		Overall quality
	<i>Clear rationale & aims</i>	<i>Study contextualised & aims</i>	<i>Method apparent & suitable for intent</i>	<i>Data collection apparent & suitable</i>	<i>Sample sampling / method suitable</i>		<i>Context described & audit trail clear</i>	<i>Use of data to support</i>	<i>Evident?</i>	<i>Low medium/ high</i>	
Sawdon et al. (1995)	Unclear. Is broadly about patient perceptions of the impact of CrCU on their health & their use of medical services.	No. Is No.	No - not to collect patient experiences. This study seems to be designed to collect outcomes data.	States semi-structured interviews with patients. Did not include the semi-structured interview questions, & used several validated measurement scales to collect data.	Large sample – 57 patients but very limited description of this sample.	Unsure – states the use of thematic content analysis with no other detail at all.	No. The process isn't described at all. The sample & setting is not described in any detail. No audit trail.	Very few participant quotes used.	Early paper exploring outcomes in patients following CrCU discharge. Study uses the information gathered to improve services, which include stepping down ICU patients to HDU & arranging for the set-up of an outpatient clinic.	Low – unable to rate quality higher as paper excludes major details about the methods & limited data about experiences.	/

APPENDIX 2

Table of included studies

Year	Author	Title	Country	Design	Sample	Themes
2013	Egerod I Risom SS Thomsen T Storli SL Eskerud RS Holme AN Samuelson KAM	ICU recovery in Scandinavia: a comparative study of intensive care follow-up in Denmark, Norway and Sweden	DenmarkNorway Sweden	Qualitative multi-centre comparative Telephone interviews Also use of data from previously conducted study in Sweden	Follow-up nurses Denmark-8 Norway -18 Sweden- 5	Follow-up has different approaches and unclear goals and outcomes so difficult to compare follow-up programmes Focus mainly on what has happened and what deficits remain Conceptual model of ICU follow-up made 1. <i>During ICU stay</i> - patient diary written by nurses and sometimes family 2. <i>3-5 days post ICU transfer</i> - ICU nurse follows up patient on ward 3. <i>Post hospital discharge</i> – 1 month - information material sent to patient 1-2 months - invitation to follow-up visit 2-3 months - follow-up visit, nurse-led or interdisciplinary, anxiety, depression, HADS, PTSS 3, 6, 12 months - additional follow-up, telephone contact, repeat SF-36 Follow-up needs to be integrated with general strategy of wellbeing and recovery to reduce attrition

Year	Author	Title	Country	Design	Sample	Themes
						and selection bias and enable programme evaluation Follow-up should have paradigm of empowerment and not focus on deficits
2013	Ramsay P Huby G Thompson A Walsh T	Intensive care survivors' experiences of ward-based care: Meleis' theory of nursing transitions and role development among critical care outreach services	UK	Longitudinal qualitative, embedded in mixed methods study 1 year following hospital discharge Reference to Meleis et al.'s (2000) model of transitions	20 patients Interviews with critical illness survivors enrolled in the RECOVER RCT	<i>Multiple simultaneous, complex transitions</i> Health - illness – health, high tech - general care, security –unpredictability / vulnerability, helplessness - independence In ICU patients sedated and amnesia, delirium, delusional memories common Patients give fragmented accounts of severity of illness, ICU stay, ward transfer, early ward experiences Patients suddenly recognise profound debilitation and functional limitations and are dependent on staff for self-care <i>Healthy transitions inhibited by staff</i> Ward staff indifference and insensitivity to patients' basic care needs or helping them make sense of their experiences or psychological distress Care was fragmented and non-specialty specific, and there was poor continuity and shortfalls in communication Patients felt isolated and vulnerable at the reduced immediacy of care and demoralised at care which failed to meet needs but reluctance to voice their

Year	Author	Title	Country	Design	Sample	Themes
						<p>concerns</p> <p>Patients mastered new skills to get information and more support from staff</p> <p>and demonstrated self-determination such as 'getting on with it' and 'putting on brave face'</p> <p>To negotiate going home patients needed to determine staff's criteria for discharge</p> <p>CCOS staff can engage with and educate patients and staff and support individuals' inner resources such as self-determination</p>
2012	Ågård AS Egerod I Tønnesen E Lomborg K	Struggling for independence: a grounded theory study on convalescence of ICU survivors 12 months post ICU discharge	Denmark	Grounded theory Semi-structured interviews	18 patients partners 5 Danish ICUs	<p><i>Struggling for independence</i> Patients struggling for independence over the year involves 'feeling ones way' 'getting a grip' 'maintaining and refining.'</p> <p>Involved 3 modalities: recovering physical strength, regaining functional capacity and resuming domestic roles. These followed a trajectory characterised by training, perseverance and continued hope for recovery.</p> <p>Increasing any aspect of functional level increased the patients' momentum to keep struggling for independence</p>
2012	Deacon KS	Re-building life after ICU: a qualitative study of the patients' perspective	UK, USA, Canada	Survey using a web-based, open-ended questionnaire administered by the UK	35 participants (only 5 male) half ARDS	<p><i>Information and education</i> Information – what happened/what to expect Memories hazy, confused, non-existent. Didn't realise how sick they had been.</p>

Year	Author	Title	Country	Design	Sample	Themes
				ICU Steps network, and the inter-national Acute Respiratory Distress Syndrome website	diagnosis America, Canada	UK, Was what they were experiencing normal? Info/education for family members and healthcare staff outside of ICU - managing expectations of the patient (may look ok, but need long time to recover) Assessment and therapy – physical and psychological available as ongoing programme Personal support - emotional burden critical illness - individual counselling/support groups (other critical illness provide understanding and reassurance that their experiences were normal). Named person to coordinate and contact about rehab process
2011	Bench SD Day T Griffiths P	Involving users in the development of effective critical care discharge information: a focus group study 11 patients; 8 relatives; 23 health care professionals	UK	8 Focus groups interviews	11 patients; 8 relatives; 23 health care professionals Staff - central London hospital Patients/ relatives - London and Coventry	<i>Considerations for effective provision of information</i> need to consider enormity of the experience, Abandonment/vulnerability at loss of close relationships with ICU staff Information blockers – concentration/absorption difficulties, communication problems, ward staff lacked knowledge and time Delayed/rushed discharges <i>Goals of critical care discharge information</i> Understanding what to expect Desire to know what had happened - record of what had happened or medical summary of progress, images, photos, mirrors help recognise readiness for

Year	Author	Title	Country	Design	Sample	Themes
						<p>discharge, identify patient specific needs/set realistic goals, frame transition as increase in independence</p> <p>Feel safe/reduce anxiety with adequate information about discharge</p> <p>Need right information/right timing and right amount</p>
2011	Lapum J Angus JE Peter E Watt-Watson J	Patients' discharge experiences: returning home after open-heart surgery	Canada	<p>Narrative enquiry</p> <p>Narrative based interviews and journals</p> <p>2-4 days post ICU discharge</p> <p>3-4 weeks post hospital discharge</p>	<p>16 patients: 8 men, 8 women</p> <p>1 hospital, 1 clinic. Toronto, Canada.</p>	<p><i>Thrown to the wolves</i></p> <p>Patients engaged in self-surveillance and self-advocacy as suddenly responsible for self-care as no one to keep track of them and insufficient follow-up meant they felt unprotected and abandoned to harm</p> <p>GPs had inadequate experience but no expert follow-up provided</p> <p>Care pathways meant hospitals in a rush to get rid of patients before they ready to self-care and discharges were rushed</p> <p><i>Double-edged sword</i></p> <p>Patients felt unsafe at home as no longer monitored and no healthcare providers nearby leading to vulnerability and catastrophic fears</p> <p>Familiarity and comfort of own surroundings countered this and make them optimistic</p> <p><i>I don't know what is normal now</i></p> <p>Unfamiliar body sensations after surgery so become hyper-vigilant and needed reassurance these</p>

Year	Author	Title	Country	Design	Sample	Themes
						<p>sensations normal</p> <p>Patients reported self-surveillance to figure out what was 'normal' and mitigate feelings of vulnerability and anxiety</p> <p>Discharge material didn't help as omitted many issues of real importance to patients</p> <p><i>Walk that fine line</i></p> <p>Information provided about pathways of recovery were difficult to discern, not time sensitive or specific to context so patients improvised pathways</p> <p>Ambiguity about stages of recovery so based progress on disappearance of bodily sensations and regaining functional abilities</p> <p>Plateaus in recovery were frustrating and if they didn't meet the expected recovery rate or were uncertain about returning to active lifestyle they suffered psychological issues, shifts in identity and ambiguities about future</p> <p>Essential to have family and friends at home to provide assistance</p>
2011	Vico CL Chiang	Surviving a critical illness through mutually being there with each other: a	Hong Kong	Grounded theory Interviews during hospital stay and 3 months post	6 patients and 5 family	<p><i>Being there with</i> Patient - sense of support when family present Family - feeling of having contributed to patient's recovery</p> <p><i>Coping</i> Being together coping mechanism. For</p>

Year	Author	Title	Country	Design	Sample	Themes
		grounded theory study		hospital discharge		<p>patients - help them cope with their high levels of stress. For families - help them cope with uncertainty/unpredictability of situation ('one day at a time,' 'learning to adjust')</p> <p>Lack of some resources in hospital/professional follow-up support in community made it more difficult for the family to support patient/harder to recover</p> <p><i>Self-relying</i> Patients experiment with regaining their physical and psychological independence. In ICU – maximum dependence/attachment to families. This reduced with recovery and both patients and family gained independence from each other</p>
2009	Cox, CE, Doherty, SL, Brandon, DH, Whaley, C, Attix, DK, Clay, AS, Dore, DV, Hough, CL, White, DB, Tulsky, JA	Surviving Critical Illness: The Acute Respiratory Distress Syndrome as Experienced by Patients and Their Caregivers	USA	Qualitative Semi-structured Interviews Participants randomly assigned to interviews at either 1-3 months, 4-6 months, 7-9 months, or 10-12 months after critical care discharge	23 ARDS patients and 24 caregivers from medical and surgical ICUs from 1 academic centre and 1 community hospital	<p><i>Pervasive memories of critical care</i> Contradictory co-existence of general amnesia and presence of terrifying dreams, flashbacks and vivid memories persisting</p> <p><i>The day to day impact of new disability</i> all participants discussed profound and jarring disability that interfered with basic activities of daily living. Debilitating insomnia, fatigue, tremors, pain. For some new trauma-associated disability (loss of limb/paralysis) superseded all concerns. Nearly all reported weakness was central to their post-ICU</p>

Year	Author	Title	Country	Design	Sample	Themes
						<p>experience even months after discharge</p> <p>Substantial, persistent cognitive defects</p> <p>Emotional lability, depression, anxiety, enduring fear and foreboding of illness recurrence</p> <p><i>Critical illness defining the sense of self</i></p> <p>Transformative effects of surviving a debilitating critical illness – new requirements for ongoing medical care, body image alteration, financial strain, workplace and family upheaval.</p> <p>Some participants troubled by belief that others didn't appreciate their mental/physical transformation by illness</p> <p><i>Relationship strain and change</i> Importance of strategies to adapt to life changes – optimism, hope, support from friends and family, spirituality, antidepressant/anxiolytic medication, self-sufficiency, goal setting (for example returning to work), sense of humour</p> <p>Some adjusting poorly, denying majority of symptoms, persevere on regrets/missed opportunities, frustrating uncertainty of recovery</p>
2009	Lee CM Herridge MS Matte	Education and support needs during recovery in acute respiratory distress	Canada	Qualitative In-depth interviews using	25 survivors from Toronto ARDS cohort	<p>Support needs of ARDS survivors change across time and key phases of recovery</p> <p><i>Critical illness</i> (ICU) patients have information needs</p>

Year	Author	Title	Country	Design	Sample	Themes
	A Cameron JI	syndrome survivors		structured interview guide Used phases of 'Timing it Right Framework'		(best given to family) and need emotional comfort <i>Stabilisation</i> (ward) patients realise seriousness of illness and rely on caregivers for information Fears as less surveillance than ICU Need physical rehabilitation and psychological counselling <i>Preparation for home discharge</i> patients need information on recovery expectations and to ensure availability of community resources <i>Early home adjustment</i> There is a lack of preparation for long-term sequelae Patients feel emotional abandonment and need community support and help for adapting to independent living Also want to learn from others with similar experiences <i>Long-term adjustment</i> Focus is on secondary prevention and health maintenance Support for patients re-integration into society and returning to work Still need for additional clinical care and psychological support
2009	Prinjha S Field K	What patients think about ICU follow-up services: a	UK	Narrative design	34 former ICU patients	<i>Continuity of care</i> organised prior to hospital discharge is extremely important for ongoing

Year	Author	Title	Country	Design	Sample	Themes
	Rowan K	qualitative study		In depth interviews	Whole of UK	<p>monitoring and information</p> <p>Patients suggested initial phone call after hospital discharge</p> <p><i>Receiving information in follow-up</i> on physical and psychological concerns</p> <p>Diaries helpful for information and dates but should be given before the follow-up appointment</p> <p>Many had no memory of ICU and experienced dreams and hallucinations so asking questions at follow-up reduced anxiety and helped them move on</p> <p>ICU visit helped put pieces together and complete the picture</p> <p><i>Expert reassurance</i> discussion with consultants, tests, referrals and being told about other patients who had similar experiences</p> <p>Being told what was normal progress helped patients cope with problems and tough days</p> <p>GPs and private counsellors had little to no knowledge about their ICU stay so couldn't answer questions</p> <p><i>Giving feedback</i> to staff about poor standard care and to give thanks</p> <p><i>No follow-up</i> some had follow-up from other departments such as surgery but others were upset as</p>

Year	Author	Title	Country	Design	Sample	Themes
						not offered follow-up and so no chance for monitoring and referrals, nor to find out details of ICU stay. Some didn't want follow-up as didn't want to go back to the ICU.
2009	Storli SL Lind R	The meaning of follow-up in intensive care: patient's perspective	Norway	Qualitative In-depth interviews	6 men and 4 women originally but 4 died Norway	<i>Dairies</i> Diary is gift through which patients encounter care and is seen as person rather than as a medical case Purpose of helping patients recover and establishing links between perceived experiences and factual events Diary describes patient's struggle for survival and can excite strong emotions Diary helps patients understand why it takes long time to recover strength <i>The conversation</i> Diaries and open questions posed by nurses act as opening for reflection and interpretation Conversation allows validation and 'normalisation of strange experiences' by meeting a qualified listener who listens for long enough for patient to put thoughts into words Patient often thinks they are alone in having experienced 'being somewhere else that is dangerous' whilst in ICU and needs to be taken seriously and confirmed as relevant

Year	Author	Title	Country	Design	Sample	Themes
						<p>Listeners need to avoid trying to correct or explain but allow full story to come out so patients can discover possible connections and meanings and events can fall into place</p> <p><i>The return visit</i></p> <p>To sense the room first hand - sounds, smells, feelings - provides confirmation for the patient - process of disproval that what they thought they heard/experienced was actually piece of equipment</p> <p>Sensory impressions from room (to feel the room) brings experiences to the surface as the room has 'ambiance' of its own which can transport patients back to the situation so 'things fall into place' and become clearer</p> <p>Evokes strong emotions so need trustworthy staff accompanying to make it feel safe</p>
2009	Williams, SL	Recovering from the psychological impact of intensive care: how constructing a story helps	UK	Phenomenology	5 patients	<p><i>Serious illness is significant to our identity.</i> Patients find it difficult to build their illness narrative following CrCU and this is distressing. This limits our ability to share our story and for others to support us.</p> <p>Threat to life needs to be stored, processed and understood to prevent a repeat of the event.</p> <p><i>To construct a story needs:</i> the facts about what</p>

Year	Author	Title	Country	Design	Sample	Themes
						<p>happened; filling the memory gap of the illness and what was experienced; integrating patients' own memories with other info through repeated retelling and editing of the story; integration of experiential and chronological time to reduce sense of disorientation; need to understand why something happened in order to be better able to respond to any recurrence</p> <p><i>Retelling their story helps</i> patients regain control of their lives (this is essential if there have been lifestyle changes); also allows shared understanding with others so people feel less isolated; patients can regain personal and subjective wellbeing by providing a way for them to understand their critical illness and transform it into a meaningful or beneficial experience; the more temporally, causally, emotionally, thematically and autobiographically coherent the story the more potential to transform the distressing experience to a beneficial one.</p>
2008	Engstrom Andersson Soderberg S	A S Re-visiting the ICU Experiences of follow-up visits to an ICU after discharge: a qualitative study	Sweden	Narrative interviews 3 to 9 months after follow-up visit	9 patients 9 family Sweden	<p><i>Receiving strength from returning together</i> helped with recalling information given, relatives found visit a good way to support patient</p> <p><i>Making sense of the critical illness experience</i> Getting to know what had happened and why -</p>

Year	Author	Title	Country	Design	Sample	Themes
						<p>speaking to family; meeting people who had cared for them; returning to ICU; diary/photographs. Diaries - valuable but upsetting Seeing ICU room/equipment – helpful, didn't often remember staff, recognised sounds from monitors - gave sense of proportion.</p> <p>Helped talking to staff who understood about nightmares and hallucinations - didn't think they were mad</p> <p>Relatives - visit gave them answers/appreciated others filling in the gaps for patients too</p> <p><i>Feeling grateful to have survived</i></p> <p>Revived memories of difficult time but good to see where the patient had been and how they had now come back to life. Meeting staff - express thanks</p> <p><i>Possibility of improving care</i></p>
2008	Field K Prinjha S Rowan K	One patient amongst many: a qualitative analysis of intensive care unit patients experiences of transferring to the general ward	UK	Narrative enquiry Interviews	34 participants Patients/ carers across whole of UK	<p><i>Care and support</i></p> <p>Ward nurses too busy, inattentive, poor handover, expect too much of patients, differing attitudes and some stern, ignorant of post ICU complications (saw physical weakness as laziness)</p> <p>Medical staff ignorant of patient condition – inadequate handovers</p> <p>Patients identified stressors as being left to struggle with poor sleep, inadequate diet, no strength for basic</p>

Year	Author	Title	Country	Design	Sample	Themes
						<p>care</p> <p>Felt shock, trauma, vulnerability, anxiety and worry about being alone at night</p> <p>Patients had to adjustment from 1:1 care to 'one patient amongst many'</p> <p>When staff treated them sternly some lost self-respect and others felt pushed to make a significant step forward</p> <p><i>Ward organisation and management</i></p> <p>Patients unprepared for busy ward environment and reliant on relatives for basic care needs and gaining information as staff too busy to ask for help</p> <p>Upset when promised equipment did not arrive</p> <p>Transfer problems are not just about relocation stress as patient accounts highlight environmental, organisational, staff training and availability issues which</p> <p>leads to stress, anxiety, depression, vulnerability and delayed recovery</p>
2008	Storli SL Lindseth A Asplund	A journey in quest of meaning: a hermeneutic-phenomenological study on living with memories from intensive care	Norway	Phenomenological Guided conversations	10 patients Norwegian university hospital	<p>Delusional memories are triggered by bodily experiences</p> <p>Discussion helps make connections with real events</p> <p>Unpleasant feelings part of life</p> <p>Experience makes consider mortality</p>

Year	Author	Title	Country	Design	Sample	Themes
	K					
2007	Pattison NA Dolan S Townsend P Townsend R	After Critical Care: a study to explore patients' experiences of a follow-up service	UK	Qualitative using semi-structured questionnaires and in-depth interviews	27 patients UK cancer hospital	<i>Rehabilitation</i> ICU issues (communication/and cancer specific issues) Follow-up valued – discussing feelings and hearing about common experiences reduced worry and improved recovery <i>Fatigue</i> Challenges return to work (confirms place in society) Learn to pace oneself <i>Memories</i> Little or no memories of ICU Dreams, flashbacks, hallucinations, nightmares (related to time, ICU environment, sedation) <i>Uncertainty</i> Cancer (further treatment, prognosis, future) Transfer to ward (good as recovering, anxiety about being left alone) Looking for positives (fortunate to have cancer identified and survived it) Being pre-prepared about ICU helpful Longer ICU stay means longer recovery (not moving on quick enough)

Year	Author	Title	Country	Design	Sample	Themes
						<p><i>Reassurance</i></p> <p>Follow-up with doctors and nurses allowed discussion of physical changes and recovery, helped understand critical illness and cancer (allayed fears)</p>
2005	Gardner G Elliott D Gill J Griffin M Crawford M	Patient experiences following cardio-thoracic surgery: an interview study	Australia	Semi-structured interviews 6 months following cardiac surgery	8 patients 4 male 4 female Australian	<p>Being sick related to patients realising seriousness of illness and feeling that life is put on hold</p> <p>Turning point when realised getting better (such as able to mobilise again)</p> <p>Getting better means starting to live again</p> <p>Companionship important during hospitalisation, collegiality from other patients</p> <p>Negative emotions and depression linked to serious physical illness</p> <p>Sometimes had changed life view - for some in a good way for others a negative one</p> <p>Patients and family need realistic and consistent messages about physical and mental recovery at all stages</p>
2005	Lefebvre H Pelchat D Swaine B Gélinas I Levert MJ	The experiences of individuals with traumatic brain injury, families, physicians and health professionals regarding care provided throughout	Canada	Qualitative. Reflexive and dialogic approach. Semi-structured interviews	8 patients with moderate to severe TBI 14 families 22 health professionals 9 physicians	<p><i>Information</i> communication and sharing information (what happened, disability, prognosis), guarded information by doctors (don't want to cause upset/false hope – but means uncertainty for families</p> <p><i>Uncertainty</i> mostly felt at point of social reintegration, lack of prognosis – feel doctors holding</p>

Year	Author	Title	Country	Design	Sample	Themes
		the continuum				<p>back information – delays progress – families continually seeking out</p> <p><i>Relationships</i> Good – staff listen, establish trust – collaborative and supportive relationship. Bad – lack of time, treated like object of care – negative self-esteem – patient and family unsupported. Care structured round care team and then delivered to patient – prevents autonomy and partnership. Staff don't consider family have skills to be regarded as part of care team. Communication essential between all members of care team – hierarchical relationships barrier to collaboration, need to recognise each other's expertise</p> <p><i>continuity of care and services</i></p> <p>worst at point of social reintegration</p> <p>lack of material and professional resources delays physical and cognitive recovery</p> <p>No follow-up so patients feel isolated</p> <p>Lack of staff compromises quality of care</p> <p>Incomplete or missing information on transfer (most staff lack information of what happened to patient before and following their own phase of care)</p> <p>Adaptation needed for persons with TBI and their family</p>

Year	Author	Title	Country	Design	Sample	Themes
2005	Minton C Carryer J	Memories of former intensive care patients six months following discharge	New Zealand	Qualitative using in depth interviews	6 former ICU patients at 4-6 months post ICU discharge	<p><i>Loss of control and dependence on technology</i> when they awoke they realised how sick they were and that it was out of their hands to do anything about it</p> <p><i>Distorted thoughts</i> all participants had varying degrees of recall of ICU and found it difficult to differentiate between memories of ICU, the ward and their dreams. Memories of vivid and frightening delusions and nightmares for all patients which were still happening after discharge home</p> <p>Descriptions of ICU as a place they did not know which was distressing for some</p> <p>When did remember ICU it was stressful to see emergency procedures carried out on other patients, the noises of other patients was distressing and this, together with the noises the staff made, prevented sleep</p> <p><i>Memories of procedures</i> all had some degree of memory of procedures which were more vivid if they caused pain or distress, such as chest physiotherapy, insertion and removal of tubes and drains</p> <p><i>Proximity to death</i> threat of death present before, during and after ICU stay. Some thought about how close to death they had been once they learned how sick they had been</p>

Year	Author	Title	Country	Design	Sample	Themes
						<p><i>Moving on</i> ICU discharge distressing as change from 1:1 nursing and observation to side room on general wards. Some had ongoing confusion, others vulnerable and alone as coming to terms with what had happened</p> <p>Recovery at home presented own hurdles physically (at 6 months many had not returned to previous levels of fitness) and psychologically (nightmares about going back into hospital, flashbacks and hallucinations). Time spent trying to piece together what had happened on ICU</p>
2004	Adamson A Murgo M Boyle M Kerr S Crawford M Elliot D	Memories of intensive care and experiences of survivors of a critical illness: an interview study	Australia	Qualitative using in depth interviews	6 former ICU patients at 6 months post ICU discharge Australia	<p><i>Recollections</i> varied from no recall to vivid recall of certain events</p> <p>Recollection of dreams or hallucinations for some</p> <p>On whole not much recall of staff, equipment or first or last days in the ICU</p> <p>May be related to medication, length of ICU stay or time since ICU discharge</p> <p><i>Reactions</i> Ranged from acceptance, avoidance, apprehension, powerlessness, anxiety and depression</p> <p><i>Comfort/discomfort</i> some had no pain on ICU and some did have lack of sleep, pain and anxiety but felt secure due to the attentiveness of the nursing staff</p> <p>Others had vivid memories of pain</p>

Year	Author	Title	Country	Design	Sample	Themes
2001	Maddox M Dunn SV Pretty LE	Psychosocial recovery following ICU: experiences and influences upon discharge to the community	Australia	Interpretative Semi-structured interviews 6-15 weeks following discharge	5 patients 4 family Australia	Recovery period (moving on) Sleep deprivation/exhaustion Slow to resuming energy levels/ normal roles – frustrating, not anticipated, eagerness to resume pre-illness status/move on from the sick role Factors influencing recovery <i>prior experiences</i> (learned coping strategies), <i>memories of ICU</i> (varying recall, nightmares, inability to communicate anxieties/pain so couldn't resolve their issues, impression of ICU was being very sick - unable to relate events/ spasmodic interruptions to an otherwise sedated state. <i>social support</i> including family, friends and professional assistance <i>Positive attitude/independent spirit/self-determination</i> not to have outside help/ inner strength - required to survive and recover. No one acknowledged psychological sequelae or need for psychological recovery Support from family invaluable - this put stress on the families Plethora of community based services - not well used Counselling perceived negatively - asking for help equated with failure and social disgrace.

APPENDIX 3

Patient Information Sheet



Patient Information Sheet

The care experiences of patients following their discharge from the Critical Care Unit.

INVITATION

You are being invited to take part in a research study. Before you decide whether or not you would like to take part, it is important that you fully understand why the research is taking place and what your involvement would mean. Please take time to read the following information carefully and discuss it with other people should you wish to do so. It will explain the aim of the research study and what you will be expected to do should you wish to take part.

Thank you for taking the time to read this information

What is the aim of the study?

The physical and emotional impact of critical illness may be felt long after a patient is discharged from the Critical Care Unit. The quality of follow-up services provided to patients who have suffered from a critical illness may influence the recovery process. The purpose of this study is to understand the experiences of patients recovering from critical illness with the aim of improving the quality of follow-up care.

Why have I been approached?

You have been approached because you have spent time as a patient on a Critical Care Unit.

Do I have to take part?

No. You have been given this information sheet to keep and read at your convenience. Once you have considered this information it is entirely up to you to decide whether to take part. Should you decide not to participate, you do not need to do anything more. Your care will not be affected whether or not you choose to participate in the study.

What will happen if I decide to take part?

Should you decide to take part the researcher will go through the information sheet with you and will discuss the various aspects of the study. You may decide to be involved in part or all aspects of the study. The various aspects of the study are as follows:

Version 2 25/10/15

Interviews The researcher will arrange an interview with you at a time and place that is convenient for you. The interviews will last approximately one hour and will be video-recorded if you are happy. If you prefer not to be video-recorded you may, instead, opt to be audio-recorded, or have the researcher take notes during your interview. You may stop the interview at any time and ask the researcher to amend the video or audio-recording or written notes. The video or audio-recording will be transcribed and anonymised so you will no longer be identifiable on the transcript. You will be asked if you want to receive a written copy to check and as the researcher to amend as you wish. If your interview is video-recorded, parts of it may be used in a short 'trigger' film which captures the care experiences of patients involved in this study. The trigger film is shown to healthcare staff at a future co-design meeting in order to inform the service improvement process. Some of these members of staff may have cared for you. The researcher will show you which parts of your video-recording will be used and you will be able to decide whether you are happy for them to be included or not. If you are happy you will be asked to sign a consent form to confirm your agreement for the use of sections of your video-recording.

Patient experience event An event day is held for patients taking part in this study to meet and together identify areas in which follow-up care and services can be improved. At this event you will have the opportunity to discuss the highs and lows of your care experiences and to review whether these experiences have been conveyed in the trigger film. If you decide not to attend the patient experience event you will be sent a copy of the video to review and will be asked if you would like your part in the film to be edited or deleted.

Co-design meeting A half-day co-design meeting will be held in which you will meet again with other patients and also with healthcare staff who are interested in improving care for patients following critical illness. The healthcare staff will be shown the 'trigger' film, and together you can decide as a group recommend what aspects of care should be improved and given the opportunity to take part in this improvement process.

Stages of Consent A staged approach to consent has been planned to allow you to participate in the study to the degree with which you are comfortable. You will be asked to sign a consent form at the following stages:

1. Consent to an interview.
2. Consent to the use of sections of your video recording to make a short trigger film to show to healthcare staff, some of whom may have been involved in your care.

3. Consent to the use of your video recording in the context of the whole trigger film, again with the understanding that it may be viewed by healthcare staff who may have been involved in your care. You may decide at this stage that you do not wish to be present at the meeting with healthcare staff where the film will be shown.

It is possible that if a large number of patients are interested you may not be able to take part in the study.

We anticipate that the interviews from this study may be of benefit in the future for educational purposes such as training healthcare staff and for informing other patients and the public about recovery from critical illness. You will be given the option of being contacted by the researcher in the future to discuss the use of quotes from the transcript of your interview, or for the use of sections of the video-recording. Examples of how patient films have been used to provide education and information can be found at the healthtalk.org website. Again, you will be asked whether you are happy for the use of your transcript or video-recording and if you are happy, will be asked to sign a consent form to confirm your agreement.

What are the possible benefits of taking part?

Your participation in this study will allow you to share your experiences of the care you have received and give you the opportunity to help improve the quality of care for patients recovering from critical illness.

Are there any disadvantages to taking part?

Although we will endeavour to keep inconveniences to yourself at a minimum, this study does ask that you take time out of your schedule to participate in some, or all the activities listed in this information sheet. However, should you decide that you no longer wish to continue with the study, you are free to withdraw from it at any time, without having to give an explanation.

We understand that recovering from critical illness can be difficult and it is possible that you may become upset during the interview or meetings. Should this happen, you can pause the interview or leave the meetings for as long as you need, or you can withdraw from the study altogether. If required, the researcher will provide details of how to access additional sources of support such as the critical care follow-up clinic or may advise you to contact your general practitioner.

Will my details be kept confidential?

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Your personal details will be kept strictly confidential and will only be seen by the researcher. Transcripts of the interviews/interviewer notes will have your name removed and contain an identifying (ID) number so that your identity will be anonymous in any written research reports and publications. Your ID number will be cross-referenced with your name and contact details to allow the researcher to contact you as required or to enable your data to be withdrawn from the study, should you wish. With your permission, these details will be kept confidentially for up to five years to allow the researcher to contact you about any future study related or additional educational or informational projects.

All information and materials collected in the study will initially be recorded or transferred into an electronic file using a hospital Trust encrypted and password-protected computer. All information and materials will be then be stored electronically on secure servers at the Trust and written materials stored in a secure office in the research department at the hospital during the study.

If your interview is video-recorded you will be asked to sign a copyright agreement that assigns ownership of the film to [REDACTED] NHS Trust, where the researcher is employed. Sections of your video-recording may appear on the short 'trigger' film to be used in this study, and could also be used in future staff training and patient and public informational projects. Whenever the researcher plans to use sections of your video-recording for this study or future educational or informational purposes you will be given clear details of how the video-recording is to be used, the intended purpose of using it and which sections will be used. You will be informed of where the video-recording will be accessible and by whom (e.g. the research team, other patients, healthcare staff, university staff and students or the wider public arena). You will always be given the option to decline the use of your film in any of these ways or you may ask that the researcher only use selected parts of your film.

What will happen to the results of the research?

The findings of this study will be presented within forums at the hospital Trust and university and may lead to recommendations for improvements to local healthcare services. The research will be written up for publication in academic journals and for presentation at healthcare conferences. You will be sent a copy of the findings of this study and invited to a 'celebration event' on completion of the study where the findings and any recommendations for healthcare improvement will be presented to patients and staff.

Who is organising this research?

This study is being undertaken as part of a PhD qualification at the University of Central Lancashire by Jackie Baldwin, a research nurse at [REDACTED] Hospitals NHS Trust. The study is being supervised by Dr Rob Monks and Professor Kinta Beaver from the University of Central Lancashire.

Who has reviewed this research?

This study has been scientifically reviewed as part of the researcher's PhD programme at the University of Central Lancashire. The study has been discussed and approved by an independent group of people, the ...Research Ethics Committee. This group protects the rights, dignity and wellbeing of research participants and ensures that research is conducted ethically. This study has also been reviewed by the Research and Innovation Committee at [REDACTED] NHS Trust.

What can I do if there is a problem?

Any complaint with the way you have been dealt with during the study or any possible harm you might suffer will be addressed by the researcher who will do her best to answer your questions. If you wish to discuss the way you have been dealt with independently from the research team you may contact the Patients' Advice and Liaison Service on 01772 522972 or 01257 247280. If you wish to complain formally, you can do so through the NHS complaints procedure. For details of this and a copy of the leaflet '*Information on how to compliment and complain or make a suggestion*', please contact:

Customer Care

Tel: 01772 522521

Email: customercare@lthtr.nhs.uk

If you are interested in taking part or discussing this study further, telephone, email or write to:

Researcher

Jackie Baldwin

Address

[REDACTED]

Tel

Email

Jacqueline.baldwin@lthtr.nhs.uk

APPENDIX 4

Patient Interview Guide

Using patient experiences to improve recovery from critical illness

Opening Section:

Introductions and talk informally about the nature and purpose of the research.

Easy introductory questions to collect contextual information, establish rapport and ease the patient into the interview: age, relationship status, employment

Main areas to be explored:

What are your experiences of care
during your recovery?

What expectations did/do you have
about your recovery?

What are your experiences of ongoing
physical or emotional problems?
How does this make you feel?

Narrative section:

Interview to be based flexibly around a
descriptive and temporal account of the
patient's story of illness and recovery.

Aim to open up the subject and allow
patient to raise issues most relevant
to themselves.

- ‘***What happened when you first became critically ill?***’
- ‘***What happened after you left the critical care unit?***’

As the story is recounted, explore good and bad moments that shape patient's personal experiences of the service. Use amplificatory, exploratory and explanatory prompts.

Semi-structured section:

Use questions to explore issues raised by the patient during their narrative.

Use direct questions if main areas to be explored have not already been raised.

- ***How do you feel your recovery is going?***
- ***Can you tell me anything that sticks in your mind during your recovery?***
- ***Do you feel you have made progress?***
- ***What have you found to be particularly good?***
- ***What have you found to be particularly bad?***
- ***Who has helped you the most?***
- ***What has helped you the most?***
- ***What have been the important stages of your recovery from critical illness?***
- ***What have been your memorable experiences of care during recovery?***
- ***Could anything have been done differently?***
- ***Do you have any suggestions for how things could be improved?***

Again, use amplificatory, exploratory and explanatory prompts.

Closing section:

May be possible to use summary questions to sequence events and order the dataset.

- ***'So the first thing that happened was...then.... and then...and the final outcome was....'***

Prompts

Use prompts to explore descriptive responses

in greater depth, draw out additional information and probe reasons, feelings, opinions and beliefs.

Amplificatory

You have said.....can you tell me a little more about.....

Can you give me an example

What gave you that impression

What is it exactly that you liked/disliked

What did....say/do that made you feel....

Exploratory

How did you respond when.....

What did you feel like when.....

Why did you think it was important to....

What effect did that have on you...

Did that help you in any way..

How did your approach change when you found that out

Explanatory

What was it that made you...?

What makes you say that...?

What was it about...that made you decide to...?

How did that feel?

What would you have like to have been done differently?

What suggestions do you have for how things could be improved?

What went well and what didn't go so well?

APPENDIX 5

Development of major and minor themes

Planning for Change

Planning for different stages (transitions) – working as a team, different roles, involving patients so they feel in control

Planning for admission to CCU – but not possible with emergencies

Planning for discharge to ward – drastic change of environment, knowing what to expect, stepping down, bridging the gap, daunting for pt, more so for family, pts have become dependent, ward staff not aware what pts should be capable of

Planning for discharge home from outset, not just transfer to ward – need information for GP's

Planning for the future – long-term recovery, patients unaware of challenges ahead

Patient participation in planning and changing services

Needs effective communication between different HCP's (e.g. diabetic nurse, stoma nurse)

'It's just about continuity and safety again, isn't it? It's just making them feel that they're not just a parcel that's just being moved around and things are being done to them, but that they're actually a part of it...' (S01, Outreach Sister).

"...you've got a bit more peace of mind that everybody does know what they're doing...and hopefully reducing the risk of them bouncing back to critical care, because you've put all that work in place before they've actually left." (S03, Critical Care Sister, Discharge Coordinator).

"So it's making sure that when they leave the unit they've got a plan in place from orthopaedics, a plan in place from plastics, or a renal plan, if that's what they need." (S03, Critical Care Sister, Discharge Coordinator).

"We were still getting these complex patients who had been on the unit for 40, 50 days and then they get discharged at 1 o'clock in the morning..." (S01, Outreach Sister).

"...so they [ward nurses] do come and introduce themselves to the patient. And today they actually collected the patient and took her up to the ward." (S03, CrCU Sister, Discharge Coordinator).

"We didn't establish her on a normal insulin regime as she was discharged to the ward...and she just deteriorated very rapidly, very rapidly, and ended up coming back, [to CrCU] rather than us making a decision to do it before she went." (S04, Nurse Consultant).

“...often we just think about admitting people, getting them through intensive care and that’s good enough for us, whereas actually...you’re not just consigning them to a week of intensive care. You’re basically saying, for the next 12 to 18 months, if you survive you’re going to deal with the consequences of these illnesses and the burden of the illnesses.” (S07, Consultant in Intensive Care Medicine).

“I would have to say on the whole people look forward to being discharged from critical care because it’s that forward step isn’t it?... But it’s just so very different isn’t it being in a ward area to being in critical care where you can see a member of staff virtually all the time.” (S02, Outreach Sister).

“I think some of it is cultural, that we’re in critical care, and we depend upon a monitor...and taking lines out and things, they like to keep them in because we still might need to take bloods...and it’s time saving in some respect, but at the same time it’s the worst thing for the patient to suddenly remove all that monitoring and then go, “Yeah, you’re fine now, you can go to the ward.” (S03, CrCU Sister, Discharge Coordinator).

“So today, we’ve had a girl who has major trauma and she’s been with us for 41 days, so it’s took a week of preparing her for the ward, talking to her about there is going to be this transition, and she will be going to the ward, and encouraging staff to start stepping her down...” (S03, CrCU Sister, Discharge Coordinator).

“I think there’s a potential lack of awareness that we should be working towards discharge[from CrCU] as soon as possible and preparing the patient and preparing family...But I think probably we underestimate the importance of the discharge [from CrCU] process and what an impact it can have on recovery.” (S02, Outreach Sister).

“We’ve always sent them to the ward thinking the ward sorts out the [home] discharge, so we don’t look at that, do we, from critical care?” (S03, CrCU Sister, Discharge Coordinator).

“I don’t think there’s very much out there for them at all at the moment.” (S01, Outreach Sister).

“...we still haven’t really taken on board that kind of continuum...It’s making sure that these patients recover to the best of their potential, that they don’t get [re] admitted, that there’s things like really good handovers so that GPs get the information. That treatment episode doesn’t just finish with them when they come in through those walls or leave them.” (S07, Consultant in Intensive Care Medicine).

“...there are a lot of nurses who are already seeing many of our

patients and we probably don't have conversations with them...A lot of those people will go on to see these patients for a long time after we've [critical care team] seen them." (S04, Nurse Consultant).

APPENDIX 6

Research Ethics Committee Approval Letter (*name now changed from Baldwin to Twamley*)



National Research Ethics Service
North West - Lancaster Research Ethics Committee

Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0207 104 8020

04 November 2015

Mrs Jacqueline Baldwin
Research Nurse


Dear Mrs Baldwin

Study title: Using Experience-based Co-design (EBCD) to capture and understand patient experiences following critical illness and to co-design healthcare services with staff and patients to improve care provision for recovering patients
REC reference: 15/NW/0791
IRAS project ID: 181961

Thank you for responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Mrs Carol Ebenezer, nrescommittee.northwest-lancaster@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Copies of advertisement materials for research participants [EBD Resource Poster]	1	01 September 2015
Copies of advertisement materials for research participants [EBD]	1	12 August 2015

Resource Leaflet		
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Liability letter]		28 July 2015
Interview schedules or topic guides for participants [Patient Interview Guide]	1	02 September 2015
IRAS Checklist XML [Checklist_03112015]		03 November 2015
Letters of invitation to participant [invitation letter for follow-up patients]	1	12 August 2015
Letters of invitation to participant [invitation letter for former patients]	1	12 August 2015
Participant consent form [Patient consent 1]	1	12 August 2015
Participant consent form [Patient consent 2]	1	12 August 2015
Participant consent form [Staff consent]	1	12 August 2015
Participant consent form [Stage 2]	2	25 October 2015
Participant consent form [Stage 3]	1	25 October 2015
Participant information sheet (PIS) [Patient]	1	13 August 2015
Participant information sheet (PIS) [Healthcare Staff Information Sheet]	1	20 August 2015
Participant information sheet (PIS)	2	25 October 2015
Participant information sheet (PIS) [Healthcare Staff Information Sheet]	2	25 October 2015
REC Application Form [REC_Form_18092015]		18 September 2015
Research protocol or project proposal	1	01 September 2015
Summary CV for Chief Investigator (CI) [Jacqueline Baldwin CV]		29 July 2014
Summary CV for supervisor (student research) [Rob Monks CV]		02 June 2015

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form

available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

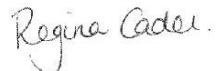
We are pleased to welcome researchers and R&D staff at our training days – see details at
<http://www.hra.nhs.uk/hra-training/>

15/NW/0791

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely



Signed on behalf of:
Dr Lisa Booth
Chair

Email: nrescommittee.northwest-lancaster@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to:



APPENDIX 7

Summary of staff findings

Summary of Staff Findings			
Planning for Change	Continuity	Needs and Expectations	Information Provision
<p>Aim of planning To prepare patient changes in intensity of support between settings CrCU Staff focus on ↓readmissions ↓risk of deterioration Lesser focus on patient vulnerability and anxiety No involvement in discharge home. Longer-term plans only at follow-up clinic.</p>	<p>Care/ services Fragmentation between settings No coordination of care. Specialities work in silos <u>Bridge between CrCU and the wards</u> CrCU staff focussed on acute care Ward staff unfamiliar with CrCU complications <u>Care and information</u> GPs ill-informed about CRCU admission or rehab plans. Limited CrCU interaction with other specialist services. <u>Passing on responsibility</u> No one responsible for whole of recovery or for unmet patient needs. Outreach focus on Acute care <u>Limited resources</u> Follow-up services small part of everyone's role. Acute/physical priority over holistic/recovery. Constraints limit service provision/time to secure resources/evaluate the service.</p>	<p><u>Knowing what to expect</u> Staff do not discuss with patients what to expect after critical illness, <u>Reactive services</u> Services should be reactive and individualised as patients' needs vary and evolve. <u>CrCU follow-up clinic</u> Best place to manage psychological issues. Too few invited as resources restrict availability. <u>Misunderstanding about CrCU follow-up clinic</u> Patients may not understand or avoid clinic <u>Psychological needs and support</u> Psychological issues centred on CrCU delirium. acceptance/adaptation. <u>Psychologically oriented questions</u> Patients reluctant to discuss issues and ward staff unaware of issues. Most staff deferred to CrCU psychologist. <u>Normalising experiences</u> Helps patients disclose issues and seek help. <u>Empowerment, control and confidence</u> Patients needed to regain these elements though staff unsure how.</p>	<p><u>Information needs and preferences</u> Key area for service improvement Knowing best time and format for information important <u>Talking and listening to patients</u> Information not just about written literature but about talking to patients and understanding what they want to know. <u>Using innovation to provide information</u> Social media, internet, etc., provides new opportunities for providing information.</p>

APPENDIX 8

Summary of patient findings

Summary of Patient Findings			
Surviving	Towards Independence	Reconstructing Reality	Reshaping life and identity
<u>Dehumanisation</u> Dark depressing environment. Loss of individuality, agency and grasp on reality. Social isolation, unpleasant interventions. <u>Delirium</u> Terrifying hallucinations and nightmares. What is real and what isn't?	<u>Reacting to dependence</u> Unexpected weakness. Leads to vulnerability, and disheartenment. <u>Rushing to independence</u> Early efforts to build strength and perform self-care needs. Incremental goal setting.	<u>Psychological symptoms</u> Anxiety, nightmares, intrusive thoughts for months to years. Reluctance to share. CrCU psychologist helps patients to cope. Early recognition needed <u>Altered memories</u> Incomplete or unreal memories Families key to reconstruction. Staff and revisits help too.	<u>Emotional responses</u> Uncertainty of survival, unpredictability of recovery, loss of agency. Unexpected feeling low, tearful, anxious and guilty Frustration over responses. Family and peers helpful <u>Impact on identity</u> Adaptation to socio-cultural environments. Positivity and target setting boosted self-confidence. Variable long-term impact <u>Adjusted life</u> Permanent changes to identity, attitudes and lifestyles.

APPENDIX 9

Summary of joint patient and staff event findings

Summary of joint patient and staff event findings			
Improving the CrCU Experience	Addressing Emotional and Psychological Needs	Positioning Patients at the Centre of Services	Developing a Supportive Framework to Promote Recovery
CrCU environment, care and treatment create additional burden for recovery. Patients want more communication and interaction with staff and others. Care should be individualised and personalised. Explanations, without unnecessary information overload.	<p>Need to understand differences between needs.</p> <p>Emotional responses are associated with life threatening nature of illness, uncertainty about recovery, vulnerability of dependency, prolonged timeframe of recovery.</p> <p>Psychological symptoms are associated with delirium and CrCU memories.</p> <p>Reluctance to share due to mental stigma and avoidance. Men more reluctant to admit to both issues.</p> <p>Difficulties with identification of needs were non CrCU staff lacked knowledge of CrCU related issues; prioritisation of physical care in hospital; GPs lack insight; families recognise patient issues but are not asked.</p> <p>Psychological in-reach and follow-up clinic have limited appointment and ineffective referral systems.</p> <p>All staff need to recognise emotional / psychological responses and signpost/ arrange support in hospital. CrCU staff should provide in-hospital emotional welfare visit. Services need to be sensitive and flexible to meet patients' needs.</p>	<p>Prioritisation of services around acute care so fewer resources are available recovering patients.</p> <p>No specific CrCU aftercare programme - recovery services fit around acute services, dependant on donated time.</p> <p>Wards have narrow focus and CrCU related issues are overlooked.</p> <p>Community services are misaligned to recovery needs.</p> <p>Quality of care varies.</p> <p>Support unavailable for long term issues.</p> <p>Follow-up clinic not widely available.</p> <p>Follow-up services need to be reactive to individual patient circumstances.</p> <p>Clearly explain what support is available and offer this flexibly.</p> <p>Follow-up should provide information, education, physical therapy, emotional and peer support, and integration with other community services.</p>	<p>Transitions in settings associated with obstacles to ongoing care and cause patients stress, anxiety and frustration.</p> <p>Patients and family have little say.</p> <p>Hospital discharge is very chaotic and fails to secure timely resources.</p> <p>Patients visit multiple departments and GPs to deal with their ongoing health issues.</p> <p>Relevant patient records are not shared between services and patients have to provide the information.</p> <p>Patients left searching the internet as no one can answer their questions.</p> <p>Plan transitions with patient and family to address their needs and concerns.</p> <p>Develop accessible information and provide map of services so for patients and families to access help when needed.</p> <p>Provide personalised information with a named contact as link back into services or advice.</p>