Using the Clinical Records Interactive Search (CRIS) to Investigate the Effectiveness of Mental Health Rehabilitation Services

Christian Dalton-Locke

Division of Psychiatry, University College London

A thesis submitted for the degree of Doctor of Philosophy (PhD)

2022

Principal supervisor:	Prof. Helen Killaspy
Secondary supervisor:	Dr Louise Marston
Tertiary supervisor:	Dr Johan Thygesen

Declaration

I, Christian Dalton-Locke, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature: **Date:** 1st August 2022

Acknowledgements

I would like to thank my supervisors Helen, Louise and Johan, for simply being so fantastic. You have each provided me with inspiration and valuable support throughout my studies. I would especially like to thank Helen, for your confidence in me that has helped change the way I think about myself and what I can achieve. I hope someday to be able to provide the support to others that you have provided to me and so many others.

Thank you, Leo Koeser, for your kindness, acting as a sounding board for my project ideas and making the whole PhD experience feel like a less lonely one. Thank you also to Peter McPherson and Sarah Ledden for your double screening and quality assessments. I am sure it was not the most exciting of tasks, but I knew I could count on you both.

Thank you, Justin Yang, you were always so quick and helpful with my CRIS and SQL queries.

Thank you also to Bryn Lloyd-Evans, Luke Sheridan Rains, and Rob Stewart. Your advice at the point of my upgrade helped steer me towards finishing my PhD.

Thank you to my mum and dad, my brother and sister, and Charlotte, for always being there for me and for always believing in me. Ten years ago, I definitely would not have thought I would be achieving something like this, and would not have, if it wasn't for you.

A big thank you to Natasha. Without your endless patience, belief, and constant reassurance, I would not have got to this point. I know that your own thesis will be fantastic (and I had better make it into your acknowledgements!). And of course, a thank you to my work from home supervisor, Chloe. Even if at times you demanded my full attention be taken away from working on my thesis and placed upon you, without those breaks, I would still be trying to figure out how to do propensity score matching.

Abstract

Background

The Clinical Records Interactive Search (CRIS) de-identifies electronic health records. The aim of this PhD was to investigate the effectiveness of mental health rehabilitation services using the Camden and Islington NHS Foundation Trust (CIFT) CRIS database.

Methods

The feasibility of using CIFT CRIS to identify a sample of individuals who had used mental health supported accommodation services was explored. A systematic review of the effectiveness of mental health rehabilitation services was undertaken. A further study using CIFT CRIS to compare inpatient service use before and after an admission to an inpatient mental health rehabilitation unit was conducted, and the feasibility of using propensity score matching to identify a comparison group was investigated.

Results

A total of 2,477 individuals were identified as a current or previous resident at a local supported accommodation service, but around a third were estimated to be false positives as the use of this type of service was not recorded systematically. The review identified 33 studies, of which, four reported reductions in inpatient service use after an admission to an inpatient rehabilitation unit. However, there were substantial limitations to these studies. The CRIS study investigating inpatient rehabilitation, identified a sample of 172 patients with a mean exposure period of 4.4 years (SD 2.2) before, and 5.2 years (SD 2.4) after, their rehabilitation admission. With adjustment for potential confounders, inpatient service use reduced by half after the rehabilitation admission compared to before (IRR 0.520, 95% CI 0.367 to 0.737). Propensity score matching methods proved unfeasible in identifying a valid comparison group.

Conclusions

CRIS can be used to investigate the effectiveness of inpatient mental health rehabilitation. Inpatient rehabilitation is associated with a reduction in subsequent inpatient service use, but the existing research lacks valid comparison groups and therefore the degree to which causality can be inferred is limited.

Impact statement

The findings from this PhD represent an important contribution to the research on the effectiveness of mental health rehabilitation services and add to a growing evidence base that supports investment in these specialist services. They therefore have potential to benefit thousands of people with particularly severe and complex mental health problems. This PhD also expands the evidence for the utility of the Clinical Records Interactive Search (CRIS) system in mental health rehabilitation research. Two of the four studies reported in this thesis have already been published in peer reviewed open-access journals (PLoS ONE and Frontiers in Psychiatry), whilst another submission is planned.

Around one-in-five people who become unwell with psychosis will go on to have treatment resistant symptoms and complex health problems. They will develop what has been termed as 'complex psychosis'. The 2020 NICE Rehabilitation for Adults with Complex Psychosis Guideline recommends that each healthcare region should have a defined local mental health rehabilitation pathway comprised of specialist rehabilitation services providing a range of support, including inpatient rehabilitation units, community rehabilitation teams, and supported accommodation. The guideline recommends these services work in tandem to support a person with complex psychosis towards their optimal level of independence.

This PhD provides new evidence on the effectiveness of inpatient mental health rehabilitation, showing that inpatient service use after the rehabilitation admission is reduced by half when compared to the period before the rehabilitation admission. Almost all healthcare regions in England do have inpatient rehabilitation units, however the level of provision does vary considerably between localities. This finding adds weight to the recommendation in the NICE guideline for greater consistency in their provision.

The systematic review conducted identified and synthesised the findings of 33 studies reporting the effect of rehabilitation services on inpatient service use and successful move-on (i.e. moving to a lower level of support without hospital re-admission). One of the most consistent findings, reported in countries across Europe, was that supported accommodation reduced inpatient service use but that less than half of those living in such settings moved on from these services in the expected timeframe of two years. This finding suggests that

supported accommodation services provide, for many people, an appropriate level of support to help them live in the community successfully and avoid readmission to hospital. It also suggests that arbitrary timeframes for moving people on are inappropriate and unrealistic and a more individualised approach should be taken.

This PhD also demonstrates the utility of CRIS in mental health rehabilitation research, as well as its limitations and areas for future research. While mental health rehabilitation research is challenging and costly via traditional means (i.e. recruiting patients to a trial, interviewing them, and monitoring the effectiveness of an intervention over a period of several years), research using CRIS may provide a viable alternative for addressing many research questions on rehabilitation. For example, to date there are no studies which evaluate the entirety of the rehabilitation pathway: CRIS could be used to address this.

Table of contents

List of figures

List of tables

List of abbreviations

Accom.	Accommodation
ACT	Assertive community treatment
ATE	Average treatment effect
ATET	Average treatment effect on the treated
BH	Boarding home
BPR	Boston Psychiatric Rehabilitation
CIFT	Camden and Islington NHS Mental Health Foundation Trust
CI	Confidence interval
CBT	Cognitive behavioural therapy
CCG	Clinical Commissioning Group
CCM	Clinical case management
CCU	Community care unit
CPA	Care Programme Approach
CPRD	Clinical Practice Research Datalink
CQC	Care Quality Commission
CRIS	Clinical Records Interactive Search
CTO	Community treatment order
DTP	Day treatment programme
EHR	Electronic health records
ePJS	Electronic Patient Journey System
FSP	Full Service Partnership
FU	Follow-up
GPRD	General Practice Research Database
Halluc.	Hallucinations
HES	Hospital Episodes Statistics
HF	Housing First
HoNOS	Health of the Nation Outcome Scale
IAPT	Improving Access to Psychological Therapies
ICD	International Classification of Diseases
IMR	Illness Management and Recovery
IQR	Interquartile range
IRR	Incident rate ratio

Kemp.	Kempering
MHA	Mental Health Act
NDOO	National data opt-out
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for
NLP	Natural language processing
NR	Not reported
NRES	National Research Ethics Service
Obs.	Observation study
PICOS	Population, intervention, comparison, outcome, and study design
PIN	Personal identity number
Pos.	Positive
PPI	Patient and public involvement
Pros.	Prospective study
PROSPERO	The International Prospective Register of Systematic Reviews
QoL	Quality of life
QuEST	Quality and Effectiveness of Supported Tenancies for people with mental health problems
RCT	Randomised controlled trial
Rehab.	Rehabilitation
Res.	Residential
Retro.	Retrospective study
SD	Standard deviation
SE	Standard error
Serv.	Service
SH	Supported housing
SLaM	South London and Maudsley NHS Foundation Trust
SQL	Structured Query Language
SuRe	Sustainable Residence
Surin.	Surinemeplain
TAPS	Team for the Assessment of Psychiatric Services
TAU	Treatment as usual
UK	United Kingdom

UCL	University College London
US	United States
WHO	World Health Organisation
Yr	Year

1 Chapter 1: Introduction

The studies reported in this thesis were funded by a 1+3 UK Research Institute Economics and Social Research Council (ESRC) studentship, comprised of a one-year full-time Master's Course (UCL's Mental Health Sciences Research MSc) followed by a three-year full-time PhD. The studentship commenced October 2017 and ended December 2021 and included a three-month extension due to disruptions caused by the COVID-19 pandemic.

This thesis focusses on using the Clinical Records Interactive Search (CRIS) system to evaluate the effectiveness of mental health rehabilitation services. CRIS is a tool developed by the National Institute of Health Research (NIHR) Biomedical Research Centre to de-identify and structure electronic health records to enable their use in research (1-3). Mental health rehabilitation services support adults with complex and severe mental health problems to gain and regain skills and achieve their optimal level of independence. The current approach to mental health rehabilitation is borne out of the deinstitutionalisation of mental healthcare, which in England primarily occurred during the latter half of the 20th century. Today in England, mental health rehabilitation consists of a range of different types of inpatient and community services, or components, which together form a mental health rehabilitation care pathway. Although individuals on the pathway may also receive support from other sources, the core components of the rehabilitation pathway are inpatient rehabilitation units, supported accommodation services, and community rehabilitation teams.

Initially, the plan was to conduct an 18-month prospective observational study comparing outcomes for residents of mental health supported accommodation services in areas where services are provided by a single provider with areas where there are multiple providers. This initial plan was primarily informed by my observations as a research assistant on the NIHR funded QuEST study (Quality and Effectiveness of Supported Tenancies for people with mental health problems; Reference RP-PG-0610-10097), a five-year project investigating the quality and effectiveness of mental health supported accommodation services in England (4-8). This plan was refined following my MSc project.

My MSc project explored the feasibility of using CRIS to evaluate the effectiveness of mental health supported accommodation services. At the time of my MSc studies (2017/2018), CRIS

had recently been implemented at Camden and Islington NHS Foundation Trust (CIFT), producing the CIFT CRIS database (9). Although I concluded from my MSc project that it was possible to use CRIS to identify a large sample of individuals who had used supported accommodation services, use of these services were not systematically reported (10).

I therefore considered how CRIS might be used more effectively to investigate other components of the rehabilitation pathway. Inpatient service use is systematically recorded on CRIS, and so I planned a study using the CIFT CRIS database to compare inpatient service use before and after an inpatient rehabilitation admission. Prior to carrying out this study, I carried out a systematic review of the international literature on mental health rehabilitation services that reported on inpatient service use and/or move-on to less supported settings. I found that there was evidence to suggest inpatient service use was reduced in the period after an inpatient rehabilitation admission compared to the period before, but that there were substantial limitations to these studies. These findings informed how the results of my planned CIFT CRIS study would fit within the current evidence and informed the next study in my thesis, where I used propensity score matching as a method to develop a valid comparison group for patients who have had an inpatient rehabilitation admission.

In this thesis I report on the studies completed for my studentship. To provide the relevant background to these studies, in the next two chapters I detail how the contemporary mental health rehabilitation pathway came to be (Chapter 2) and the development and function of CRIS (Chapter 3).

1.1 Thesis aims and objectives

The aim of my thesis was to investigate the effectiveness of mental health rehabilitation services using the CIFT CRIS database. My objectives were to:

I. Explore the feasibility of using the CIFT CRIS database to identify individuals who have lived in a mental health supported housing service (Chapter 4)
II. Conduct a systematic review of studies reporting on the effectiveness of mental health rehabilitation services, including international peer reviewed articles which report inpatient service use and/or move-on to less supported settings (Chapter 5)

III. Compare inpatient service use before and after an inpatient rehabilitation admission using the CIFT CRIS database (Chapter 6)

IV. Using the CIFT CRIS database, apply propensity score matching methods to develop a valid comparison group for individuals who have had an inpatient rehabilitation admission (Chapter 7)

2 Chapter 2: Mental health rehabilitation

2.1 Introduction

This chapter details how the contemporary approach to mental health rehabilitation has evolved over the last several centuries, from a period where mental health care was provided exclusively in large asylums, to now where it is predominantly delivered in the community. Three of the four studies reported in this thesis are set in Camden and Islington, two neighbouring inner London boroughs with an established mental health rehabilitation pathway. This chapter therefore ends with sections reporting the statistics on the sociodemographic and mental health morbidity of these two London boroughs and how they compare to the rest of London and England, and a description of the local mental health rehabilitation pathway in this area.

2.2 The asylum era

Many historical accounts of mental health treatment include, or even focus on, the history of Bethlem (11). It exists today as a modern psychiatric hospital situated in Beckenham, England, about 12 miles south of London, but has been in continuous operation for over 600 years and is the longest running psychiatric hospital in Europe. It is not clear exactly when it started to specialise in mental health, but it was not what the hospital was originally intended for when it was first founded in 1247. However, by the late 14th century it was clear that most patients were admitted to the hospital predominantly for 'lunacy' or 'insanity' (11). Early treatments included exorcisms, bloodletting and purgation (humoral theory) (12), hydrotherapy (cold baths) (13), and social isolation, and there is evidence that there was use of manacles, chains and stocks (14, 15), although the extent that these forms of restraint were used is unclear.

Public institutions like Bethlem were rare in England during the 17th and 18th centuries (16). During that time, most of those exhibiting signs of insanity would stay with their families or their care was contracted out by their parish of origin (17). A parish was a geographical area in countries of Christian denomination which provided local governance. The contracted care generally consisted of the parish paying a 'keeper', an individual often coerced through their own dependence on the parish, to house the person and care for them (17). An alternative to this kind of boarding out was the workhouse, also referred to as a poorhouse or a pauper

farm (17-19). These workhouses were occupied by both 'lunatics' and 'paupers' (although most of the lunatics were paupers (20)), and would either work the farm or be tasked with local civil work such as repairing roads. The conditions were dire and designed in a way to act as a deterrent, a motivation for the public to seek their own wealth and a better life. It is important to note at this point that the English law, in particular the Poor Law, did not discriminate between the pauper and the lunatic during the 17th and 18th century (16).

People who were considered too dangerous or disruptive for the pauper farms were confined in gaols (prison), or in one of the few public institutions such as the Bethlem or a private 'madhouse'. Madhouses were private enterprises that were originally designed to serve the wealthy but through the 18th century a growing proportion accepted 'pauper lunatics'. Seemingly, any entrepreneur could open a madhouse implying that their purpose was "custodial rather than therapeutic" ((21); p.41), and this continued to be the way they operated even after they required licencing following the Act for Regulating Private Madhouses becoming law in 1774 (21). However, this Act still had a meaningful impact in that it was the first legislation to recognise lunacy as having a medical basis, and it stipulated that anyone detained in a licenced madhouse must have a medical certificate.

Despite private licensed madhouses accepting pauper lunatics, most resided in gaols or pauper farms. New government legislation in the early 19th century, the County Asylums Act 1808, paved the way for the development of government funded mental health institutions in an attempt to address this. Previously, the few mental health institutions which were public, including Bethlem, were voluntarily funded, and were becoming increasingly exclusive with increasingly longer waiting times. The aim of the act was to remove pauper lunatics from pauper farms and prisons to places where they could receive treatment. However, the 1808 Act did not make it obligatory for a local authority to provide a public asylum and in the following 20 years only nine county asylums were opened (22). Hodgkinson detailed the provision for pauper lunatics through the 19th century (14). In 1837, almost 30 years after the 1808 Act was passed, less than half of the known and confined 6,402 pauper lunatics were patients at county asylums (2,610, 41%), a similar proportion were still living and working in pauper farms (2,389, 37%), and the remainder were confined to private madhouses (1,403, 22%) (14). In addition, at around the same time an estimated 4,000 pauper lunatics were

living with and being supported by family and friends (14). The reluctance by local authorities to open county asylums can be attributed to the cost. It was considerably cheaper to house pauper lunatics in the pauper farms than it was to treat them in county asylums, almost 10 times cheaper in some cases (14). However, as noted by Hodgkinson, there was a growing recognition from central government that an increasing proportion of paupers were insane, and that often it was the head of the family who was affected, resulting in families becoming destitute and more people becoming reliant on the state (14). This growing recognition appeared to set the scene for new legislation at the mid-point of the 19th century.

The 1845 Lunatic Asylums Act made it mandatory for local authorities to provide a county asylum within three years. It also ensured greater scrutiny of record-keeping at county asylums, and any lunatic still working on a pauper farm had to be moved to an asylum where there was a space or receive a medical visitation every three months where there was no space. Not moving a lunatic from a pauper farm to an asylum because of expense was no longer acceptable (14). Although the 1845 Act and subsequent legislation was relentlessly enforced by the chairman of the newly formed Metropolitan Lunacy Commission, Lord Shaftesbury, and did increase the provision of county asylums and powers to remove lunatic paupers from pauper farms, many of those suffering from mental illness remained due to the cost and many pauper farms built on-site 'insane wards', which 'Guardians' (appointed heads of pauper farms), often argued were akin to county asylums. This was despite conditions in these facilities being no better, and often far worse, than they were before. Typically, the ward was located in the attic or the basement of the pauper farm, had little ventilation, there was minimal supervision, and 'treatment' consisted entirely of mechanical restraint (14). The demand for county asylums in the late 1850s started to exceed their supply, partly due to them becoming places of refuge for chronic patients rather than a temporary residence for the curable. As a result, many asylum patients regarded as harmless and non-violent, the vast majority, were moved back to the pauper farms to make-way for new, more acute admissions (14).

However, the dire conditions of pauper farms did not improve and the general public's dissatisfaction with the situation began to grow. A Lancet inquiry into pauper farms, carried out between 1865 and 1867, deemed they were unfit for accommodating lunatics (23). The

Metropolitan Poor Act of 1867 soon followed, providing legislation that all lunatics and 'imbeciles' be transferred to an appropriate facility. This led to greater expansion of the asylum population; in 1869, there were 25,460 pauper lunatics residing in county asylums compared to 11,103 in pauper farms (14).

Fuelled by growing public unease about the conditions in the expanding asylums, a new, more humane, approach to mental healthcare began to evolve. 'Moral Treatment' was based on the provision of a secure, welcoming, and comfortable environment where desirable behaviour was rewarded and encouraged. The Retreat in York was an exemplar of this approach in the UK, though the movement had its origins in France and Italy, led by medical practitioners such as Vincenzo Chiarugi and Phillipe Pinel (24). In fact, other asylums in Manchester and Bristol started to adopt Moral Treatment values shortly before the Retreat opened, suggesting a wider sociological movement (25). However, it was The Retreat which received the most attention and was the most influential in terms of how the county asylums later developed in England.

The York Retreat preceded the first county asylum by around half a century, and was founded in 1796 by William Tuke, a Quaker. Its founding was motivated by the death of a fellow Quaker, Hannah Mills, whilst she was a patient at York Asylum and who was denied visits by her Friends (other Quakers) simply on the grounds that she was in private treatment (26). Horrified by this, William Tuke endeavoured to go against the current practice and ensure that The Retreat was primarily based on kindness. Initially, The Retreat only accepted Quakers but it did later open to other members of the public. The staff to patient ratio was very high, the total number of patients was limited to around 30 at any one time, a familial atmosphere was engendered, and patients were treated on an individual basis (24). Rather than try to cure patients there was an emphasis on first doing no harm and providing an environment which fostered recovery. Boredom was observed to be detrimental to recovery, so meaningful activity was devised through a small farm with animals on site and encouragement of various arts and crafts activities (the York Retreat is also regarded as the birthplace of modern occupational therapy) (24). It was also observed that 'madness' and undesirable behaviour was often a response to previous maltreatment, and continuing to treat people this way was unlikely to improve their condition (24).

The Retreat was highly influential in redefining what was regarded as acceptable and appropriate in the treatment of madness (25) and helped to shift the 'trade in lunacy' (27) exploited by the private madhouses and pauper farms. County asylums started out as small and were based on the same humane principles at The Retreat. The Norfolk Lunatic Asylum in Norwich opened in 1814, the second county asylum to open in England with around 70 patients in its early years (28). This is in stark contrast to the asylums constructed in the second half of the 19th century, required to meet the increasing demand as described previously. By the end of the 19th century, asylums in London housing 2,000 patients were being constructed and as these became ever more overcrowded, conditions worsened and the humanistic principles they were founded on could not be maintained.

2.3 The fall of the asylums and the deinstitutionalisation of mental healthcare

The Mental Treatment Act of 1930 brought about substantial sociological change (29). Asylums were now to be referred to as mental health hospitals, and lunatics were to be referred to as 'persons of unsound mind'. All legal distinction between private and pauper patients were removed and called for the disconnection of mental healthcare with the Poor Law. For the first time, the conditions whereby someone could be admitted voluntarily to a state-funded public asylum or mental hospital were specified. The Act also legislated the provision of 'outpatient clinics'. This is noteworthy in that it signalled the start of a trend towards shifting the locus of mental healthcare from building based institutions to the community.

Deinstitutionalisation is the term widely used to describe the process by which healthcare transitioned from the hospital to the community, enacted by closing hospitals and increasing provision of care in the community. The term 'institution' is closely linked to the work of Goffman. In the 1950s and 1960s, he observed what life was like in mental hospitals (30). He described them as 'total institutions' in the same way as prisons; places that are self-contained, rule bound and closed off from the outside world. Such institutions are governed by staff and inhabited by inmates with very clear boundaries between them. Inmates are demoralised because they no longer need to work to provide for themselves as the institution provides for all their needs. Inmates are also separated from their families and can no longer perform their familial role(s). The institution strips people of individuality, often insisting on

inmates wearing a uniform and having minimal personal possessions. In these ways, inmates become 'institutionalised'. A full discussion of the drivers of deinstitutionalisation is beyond the scope of this thesis, but a significant accelerant was the growing public unease about the social exclusion associated with mental hospitals, many of which had been built during the Victorian era on the outskirts of towns and operated as self-sufficient entities, with their own farms, laundries, and manufacturing workshops.

Deinstitutionalisation is measured by the reduction in mental health inpatient beds and increase in the provision of community care. The Mental Treatment Act of 1930 clearly had an impact on the latter. In 1925 there were 25 community services in England, 10 years later there were 162 (11). Further expansion of care in the community was slow in the following years and came to a halt during World War Two. However, the end of the war and the establishment of the NHS through the National Health Service Act of 1946, which came into effect on 7th June 1948, provided the foundations by which progress could continue. The NHS took control of all the mental health hospitals, all healthcare services were free at the point of contact, and the state was made responsible for the prevention of illness, care, and aftercare. There were two other key acts which came into effect on the same day as the National Health Service Act: the 1946 National Insurance Act and the 1948 National Assistance Act (31). The three acts combined made the state responsible for providing its citizens with healthcare, housing, and a minimum income for the unemployed. Consequently, the poor and mentally ill no longer had to depend on mental hospitals for housing. Although social housing was first introduced in the 19th century, it was not properly established until these acts came into effect.

Around this time, it is noteworthy that some of the most controversial psychiatric treatments in history were being developed, such as electroconvulsive therapy, insulin shock therapy, and frontal lobotomies (32). Although they were reserved for the most ill patients, it was estimated that around 60,000 frontal lobotomies were performed across Europe and the US between 1936 and 1956 (33). These treatments were something of a throwback to the approach taken during the 18th century prior to the Moral Treatment movement, perhaps as a result of growing inpatient numbers, the increasing unsustainability of the current status quo (the old Victorian buildings and estates of the asylums were falling into disrepair and the

costs of upkeep were becoming more and more unmanageable), and the increasing pressure to find a 'cure' for mental illness.

A breakthrough came with the discovery of a new, less invasive form of treatment. In 1949, French army-surgeon, Henri-Marie Laborit, observed how patients treated with promethazine (a derivative of phenothiazine), which was being used to prevent surgery shock, subdued agitated patients and made them indifferent to their environment. It was considered at the time as a temporary 'pharmacological lobotomy' (34). Although, its use in psychiatry was slow to develop, the pharmaceutical industry soon took notice and the discovery marked the beginning of the psychopharmacological era in mental healthcare (35). The increasing use of pharmaceuticals in psychiatry and a shift away from more invasive forms of treatment which required inpatient observation, added to the growing consensus that patients could be treated successfully in the community. This was despite evidence that the new medications did not substantially affect the number of inpatient admissions or discharges (36). However, the new focus on medications emerged at around the same time that Goffman published his influential work on institutions (30), and contributed to the growing consensus that patients could and should be treated in the community.

The 1959 Mental Health Act soon followed and specified the circumstances when a person could be detained for observation as a mental health inpatient against their will:

> *"…he is suffering from mental disorder of a nature or degree which warrants the detention of the patient in a hospital under observation (with or without other medical treatment) for at least a limited period; and that he ought to be so detained in the interests of his own health or safety or with a view to the protection of other persons."* (para. 4.25 (37))

It made clear that the purpose of detaining someone on mental health grounds was to provide observation and/or treatment, and manage risk to themselves and others (37). It provided greater restrictions on who could be sent to hospital against their will. Shortly after the 1959 Mental Health Act was passed, the Minister of Health, Enoch Powell, gave his famous 'water tower' speech (38), calling for the closure of mental health hospitals. Unlike the new pharmaceuticals, this legislation did have an impact on inpatient numbers. In 1950, there

were 147,300 mental health inpatients in England and Wales, by 1970 there were 106,400 (39). In 1971, the government policy 'Hospital Services for the Mentally Ill' (40) formally set out plans to gradually phase out large mental hospitals and replace them with psychiatric units within District General Hospitals. By 2010 there were just 22,700 mental health inpatient beds in England and Wales (39). As the number of inpatients decreased, the number of outpatients increased. In 1950 there were 102,800 outpatients, by 2010 this number had more than quadrupled to 413,900 (39).

2.4 The development of care in the community during the 20th century

The development of community services started with the provision of psychiatric outpatient clinics in district general hospitals, as part of the Mental Treatment Act of 1930. However, for the next 40 to 50 years most people receiving mental healthcare were still doing so via the large remote mental hospitals. The 1975 white paper 'Better services for the mentally ill' (41) aimed to address this. It emphasised mental illness as a social issue and added to the previous calls for deinstitutionalisation. It set out government policy objectives for the care received in the large remote hospitals to be replaced by local integrated services in the community including supported accommodation, day care services, and social support. It called for these services to be multi-professional, and so multidisciplinary community based mental health teams started to develop. As well as psychiatrists and nurses, these gradually expanded to include occupational therapists, psychologists, and social workers.

The introduction of the Care Programme Approach (CPA) in 1990 (42) provided a statutory framework for how community mental healthcare should be provided, specifying the level of severity of need required for an individual to be allocated a care co-ordinator and a CPA care plan. The care-coordinator was a named healthcare professional responsible for ensuring the individual was able to navigate and access appropriate treatment and support for their mental health needs. Primarily, the CPA was introduced to prevent people with mental health problems becoming lost to services and going unnoticed in the community. Other changes have since taken place, with the introduction of increasingly specialist community teams and further efforts to improve access to mental healthcare for those who are not so unwell that they require a CPA care plan (e.g. Improving Access to Psychological Therapies (IAPT)). The

CPA framework remains the mainstay of how mental healthcare is organised in England today, though a new Community Framework is due for implementation imminently.

The implementation of the CPA is reflective of the concerns many held regarding deinstitutionalisation. Initially, the concern was that those discharged from hospital would be abandoned to the streets and prisons. These concerns were then largely subsumed by greater focus on the risks posed to the public by people with mental illness, fuelled by incidents such as the 1992 murder of Jonathan Zito by a person diagnosed with schizophrenia, Christopher Clunis (43). The debate over community versus hospital care was rife within psychiatry in the latter years of the 20th century (44, 45) and received widespread attention in the media. It led to the Health Secretary, Frank Dobson of the Labour Party, claiming in 1998 that "care in the community has failed" (46), but empirical investigation indicated otherwise.

2.5 Evaluation of deinstitutionalisation

The Team for the Assessment of Psychiatric Services (TAPS) followed 670 patients discharged to the community from two long-stay psychiatric institutions between 1985 and 1993 (47, 48). Closure of both hospitals was planned as part of a deinstitutionalisation programme which included the provision of new, staffed community placements. This sample did not include 72 long-stay patients deemed inappropriate for community discharge but who were later discharged and formed part of another sample reported in a separate study (49). For the sample of 670 patients, the median length of stay in the two institutions was 21 and 28 years, and the vast majority had a diagnosis of schizophrenia. The evaluation used a range of standardised tools measuring clinical and social outcomes, completed via patient interviews, staff interviews, and review of health records. At the final five-year-follow-up, despite having lived in hospital for the best part of three decades, their clinical symptoms remained stable in the community and there were significant improvements in social functioning and the size of their social networks. Perhaps most telling was how participants felt about their new environment. When asked if they wanted to stay in their community homes, 84% said yes whereas only 30% had said yes when they were asked the same question before being discharged from hospital.

The 72 patients who were considered not suitable for discharge to a community setting were eventually discharged to one of four facilities that provided a more gradual psychiatric rehabilitation in houses based within a smaller hospital campus (49). At the final five-year follow-up, the severity of positive psychotic symptoms remained stable but negative symptoms did increase. There was, however, a substantial reduction in the number of severe behavioural problems over time. There was no change at one-year follow-up in behavioural problems, but by the five-year follow-up, on average, each patient had one less severe behavioural problem compared to when they were discharged from hospital. This reduction was most significant for aggressive behaviours. Similarly, improvements in managing activities of daily living (e.g. domestic chores, personal care) were not seen at one-year follow-up but were evident at five-year follow-up. Moreover, at the final five-year follow-up, 40% of the sample had been able to move-on from their original placement to a more independent community setting.

The TAPS studies convincingly demonstrated, with a large sample and a high follow-up rate, that people who had been residing in what was a highly restrictive, institutional setting for decades could, with appropriate support, live successfully in the community (47, 48). Contrary to what many feared at the time, long-term patients discharged from institutions into the community did not deteriorate, but in fact, they benefited from their new environment and their social functioning improved. The authors also demonstrated that successful outcomes could also be achieved for those with the most complex mental health problems when a more gradual approach to rehabilitation was adopted (49).

2.6 Criticisms of deinstitutionalisation

Although the TAPS studies appeared to show that deinstitutionalisation could be successful if carefully planned and when the appropriate community support was put in place, there continued to be concern about whether the process has really led to people living in less institutional settings. Based on findings from a pan-European study, Priebe and colleagues (50) argued that people were often being moved from one type of institution to another type of institution, and described this phenomenon as ‘reinstitutionalisation’. These claims were based on data from England, Germany, Italy, the Netherlands, Spain, and Italy. The data showed that the number of new beds in forensic psychiatric units and supported

accommodation services created during the 1990s had exceeded the reduction of beds in general psychiatric hospitals across Europe.

It is, however, debatable whether supported accommodation services can or should be considered institutions in the same way that Goffman had described institutions (30). In the main, these services were less restrictive than mental hospitals, based in the community, and supported residents to gain the skills required to live in less supported settings. The residential services reported on in the TAPS studies (47-49) do not fit the definition of total institutions described by Goffman, but the TAPS services may not be representative of all mental health supported accommodation services. For example, a national survey of supported accommodation services in Italy, carried out in 2000, found "most facilities had somewhat restrictive rules about patients' daily life and behaviour that appeared similar to institutional settings" (p.547 (51)). There may be some cases, countries, or regions in countries where supported accommodation do resemble institutions to some extent, but again, as demonstrated in the TAPS studies, when residential services have a rehabilitative focus, residents have greater freedom and a better quality of life than patients in long-stay hospitals (47-49). This is in tune with the World Health Organisation's (WHO) 2020 QualityRights initiative which recognises that mental healthcare in many countries is of an inadequate standard, and aims to support countries to adopt a recovery approach to mental healthcare and reduce or abolish restrictive practices (52). To help achieve this, the WHO recommend the phasing out of remote mental hospitals (52).

Priebe and colleagues also questioned whether the observed increases in the prison populations across Europe were due to the closure of large mental hospitals (50). It is not the first time this has been suggested. Lionel Penrose in 1939 predicted that a reduction in the number of psychiatric inpatients would result in an increase in the prison population (53), and has since been referred to as the 'Penrose hypothesis'. Evidence for and against the Penrose hypothesis are still reported today, over 80 years later. An inverse relationship between the number of psychiatric beds and the size of the prison population over a period of decades have been found in South America (54), Norway (55), Ireland (56), and England (57).

Although this may seem like strong evidence for the Penrose hypothesis, the relationship between psychiatric beds and the prison population is complex and there are often alternative explanations for the association. The Norwegian study did find a reduction between the national number of psychiatric beds and increases in prison capacity over a 75-year period, but they also found that the size of the police force increased over the same period, and suggested this was confounding the relationship between psychiatric bed numbers and prison capacity (55). The authors concluded that "complex sociological changes in society" (p.56 (55)) had caused the increase in prison populations, rather than deinstitutionalisation. The English study looked at national level data between 1960 and 2018 and found that reduced psychiatric beds were strongly associated with an increased prison population up to 10 years later (57). This again appears to be strong evidence for the Penrose hypothesis. However, another study has shown that although the proportion of prisoners with mental health problems is high, this proportion appears to have remained stable during the study period (58), suggesting that there is not a direct effect of a reduction in psychiatric beds on the prison population.

The lack of a direct effect is supported by a systematic review of longitudinal studies reporting the number of incarcerations amongst people discharged from long-stay mental hospitals (59). They found 18 studies based in England, Scotland, Ireland, Northern Ireland, United States, Australia, Canada, Japan, and Albania, 11 of which reported no incarcerations during their follow-up period. The remaining seven studies reported very few incarcerations where the highest rate was 4.1% and the lowest was 0.3%. This systematic review does not show whether people who would be admitted to a psychiatric hospital instead go to prison because there are not enough psychiatric beds, but it is strong evidence that the vast majority discharged from mental hospitals are not ending up in prison. Associations between reduced psychiatric beds and increased prison population are often found when looking at data at the national level but the relationship is complex, can often be explained by other factors, and is usually not supported when looking at individual level data. The phenomenon of mistakenly applying findings derived from data aggregated at the group level (e.g. the national level) to individuals occurs often and has been term the 'ecological fallacy' (60).

2.7 A balanced mental healthcare system

Professor Rab Houstan, a historian of mental healthcare, posits that many influential perspectives on asylums and the development of psychiatry contrast sharply between "humanity and barbarity, knowledge and ignorance, and good and bad practice" (p.354 (61)). Houstan argues that a more nuanced approach when considering the history of mental healthcare and asylums ought to be taken when planning the present and future of mental healthcare, and cautions against the outright dismissal of inpatient care (61). It is a sentiment which appears to be supported by the current empirical research.

Thornicroft and Tansella (62) reviewed the evidence for inpatient and community mental healthcare and concluded that both are essential components of a comprehensive mental healthcare system. They provided a model for a mental healthcare system that varies according to a country's available resource (low, medium, or high) (63). At a minimum, both community and inpatient forms of treatment should be provided, but as the level of resource increases the level of complexity in the system and specialisation should also increase. In countries with a low-level of resource, community care should be delivered in primary care settings with specialist mental health support, and inpatient care should be available for cases which cannot be managed by primary care. Whereas countries with higher levels of resource should be delivering, or at least endeavour to deliver, differentiated services specialising in supporting specific mental health conditions or patient groups such as eating disorders and people with dual diagnosis. They should also be delivering services which specialise in mental health rehabilitation for people with treatment resistant, complex and longer-term mental health problems.

2.8 The contemporary mental health rehabilitation pathway in England

In 2005, a national survey of mental health rehabilitation practitioners in England asked participants to describe their understanding of what mental health rehabilitation is (64). The responses were collated into the following widely quoted definition:

''A whole system approach to recovery from mental ill health which maximizes an individual's quality of life and social inclusion by encouraging their skills, promoting independence and autonomy in order to give them hope for the future

and which leads to successful community living through appropriate support.''

p.163 (64)

It explains rehabilitation as best being understood as an integrated pathway comprised of different services providing graduated levels of support, rather than being something which takes place in a single inpatient unit or setting. It is a collaborative effort, involving multiple service providers, to support the individual towards a life with greater independence, social inclusion, and sense of purpose.

2.8.1 Patient demographics and clinical characteristics

The vast majority of people who use mental health rehabilitation services today have complex psychosis, and will have a primary diagnosis of either schizophrenia, schizoaffective disorder, or bipolar affective disorder (65). The International Classification of Diseases is an international diagnostic tool currently on its 11th version (66). It classifies schizophrenia as the presence of hallucinations, delusions and/or thought disorder (collectively termed 'positive symptoms') in addition to social withdrawal, and a lack of motivation, interest and concentration ('negative symptoms'), which can be continuous or episodic. Schizoaffective disorder is similar to schizophrenia but also includes 'affective' symptoms such as depressive (e.g. low mood, lack of interest) or manic states (e.g. euphoria, irritability, high energy, grandiosity). Bipolar affective disorder is characterised by episodes of mania, often followed by episodes of depression. Common features of people using mental health rehabilitation services include treatment resistant symptoms, functional impairment (difficulty managing everyday activities such as self-care, cleaning, shopping, etc.), and difficulties with interpersonal skills.

Estimated incident rates of first episode psychosis vary from 34 to 86 per 100,000 person-years, with an increased rate in younger adults (under 30 years of age), men, ethnic minority groups, lower socioeconomic status, urbanicity, and area deprivation (67, 68). It is estimated that around 20% of people presenting with their first episode of psychosis will go on to develop the kinds of severe and complex mental health problems that require rehabilitation services (69). What maintains the severity of their mental health problem and develops it into a treatment resistant disorder is complex and variable between individuals. Of people

supported by mental health rehabilitation services, around two-thirds are male, with a mean age of around 40, and most have been in contact with mental health services for between six and 20 years (65, 70). They are likely to have had repeated psychiatric admissions (around half have had at least four) (70). Around one-in-four have a history of assaulting others, 65% have a current risk of self-neglect and 17% have a current risk of self-harm (65).

People with complex, longer-term psychosis are more likely than the general public to have a range of other health conditions. The most common physical health comorbidities are obesity, diabetes, cardiovascular disease, and pulmonary conditions. A report by Public Health England in 2018, using a large sample of general practice records extracted from The Health Improvement Network, compared the rates of various physical health conditions in people with a 'severe mental illness' (a term often used to refer to people with mental health problems that are debilitating both in social and day-to-day functioning, usually consisting of people with a diagnosis of schizophrenia, schizoaffective disorder, or bipolar affective disorder) with the general population (71). They found people with severe mental illness had 1.7 times greater risk of obesity, 1.9 times greater risk of diabetes, 2.1 times greater risk of chronic obstructive pulmonary disease, and 1.6 times greater risk of stroke. Side effects of medication, specifically, metabolic syndrome (72, 73), and negative symptoms which reduce motivation and activity, alongside lifestyle factors such as poor diet (74) and smoking (75), all go some way to explaining these increased rates.

Pre-existing neurodevelopmental disorders, such as learning disability (76), attention deficit/hyperactivity disorder (77) and autism (78), are also more commonly found in people with severe mental illness. In addition, substance misuse is common amongst this group. Estimates of prevalence vary and depend on the measures used but indicate that around a quarter of people with schizophrenia misuse alcohol, and a similar proportion misuse illicit substances (79). Due to their complex problems, this group have lengthy admissions, high support needs on discharge and account for about half of the total mental health spend (80).

2.8.2 Inpatient mental health rehabilitation services

Most inpatient mental health beds in England are designated as 'acute' inpatient beds. They are designed to treat individuals who are acutely unwell and cannot adequately be treated in

the community. The average length of stay in an acute ward is around 28 days and the primary form of treatment is pharmaceutical. Rehabilitation wards differ from acute wards mainly in regard to their longer-term approach to treatment and having a greater focus on improving skills that are necessary for living well in the community, such as cooking and managing finances. This section describes inpatient mental health rehabilitation services in England.

In 2009, a national survey of NHS inpatient rehabilitation units in England (65) found that all 60 NHS Trusts operating at the time provided at least one such unit. From the 52 Trusts which participated in the survey, a total of 133 inpatient units were identified with a mean number of 14 beds, providing a total of 1,809 beds of which 1,647 (91%) were occupied. Approximately two-thirds of the patients were male (n=475, 64%), the mean age was 40 (SD 13), around three-quarters had a diagnosis of schizophrenia (n=511, 73%), and they had been in contact with mental health services for a median of 13 years (interquartile range (IQR) 6 to 22).

The vast majority of surveyed units consisted of single bedrooms only (124, 93%), and most provided separate women-only and mixed-gender communal areas (113, 89%) (65). Almost three-quarters were located in the suburbs (96, 72%), a fifth were in inner cities (26, 20%), and the remainder were in rural locations (11, 8%). Over the previous 12 months, there was a median of 10 new admissions to the unit (IQR 6 to 19), with a median of six from acute inpatient services (IQR 3 to 11), one arriving from the community (IQR 0 to 3), and one from forensic mental health inpatient services (IQR 0 to 1). All of the inpatient rehabilitation units had access to a psychiatrist, but in almost a third of units the psychiatrist was based outside of the service (38, 30%; data were missing for six of the 133 units regarding staffing). They all had nurses and social workers based on the unit, 90% had access to an occupational therapist (114), 83% had access to a clinical psychologist (106), almost half had access to an arts therapist (61, 48%), a similar proportion had access to a volunteer (60, 47%), and almost a third had ex-patients working in the service (40, 31%). The overall mean staff to patient ratio was 1.58 (SD 0.47).

All the units used individualised care plans (65), and the vast majority provided individualised programmes of activities (126, 95%). Regarding treatments received by patients, most were

prescribed atypical antipsychotic medication (mean 70%, SD 22%), and a third were prescribed clozapine (mean 33%, SD 20%), a specialist antipsychotic medication for treatment refractory psychotic symptoms. A mean of one patient per service was receiving family psychoeducation (SD 2) and two were receiving cognitive behavioural therapy (CBT) (SD 3), but most who received CBT had fewer than 10 sessions (85%). There were a wide range of links with community resources reported: 95% of units had links with local sports facilities, 74% with local religious organisations, 61% with entertainment venues such as cinemas, 53% with local cafes, and 20% with other community organisations. Per unit, a mean of one patient was attending college (SD 1), and in 14% of services there was at least one patient using a mainstream employment scheme.

More recently, in April 2019, the Care Quality Commission (CQC) sent information requests to all registered providers of inpatient mental health rehabilitation services in England, including both the NHS and independent sector organisations (81). It was an update to a similar investigation by the CQC conducted in 2017 (82). The 2019 request was sent to 114 providers and identified a total of 320 inpatient mental health rehabilitation units, providing almost 4,500 beds. Over half of the units (53%) were provided by the independent sector rather than the NHS. Almost three-quarters of units (73%) described themselves as 'locked rehabilitation', a term and type of service not recognised by the Royal College of Psychiatry's Rehabilitation Faculty (83) (see below in this section for their classification of inpatient rehabilitation units). The independent sector provided 90% of these so called 'locked rehabilitation' units. The median length of stay was 308 days but ranged from less than a month to over 20 years and was substantially longer for patients in the independent sector (415 days) compared to the NHS (225 days). Independent sector units were mostly 'out of area' (i.e. not within the patient's home area) and the median distance from the patient's home for independent sector patients was 31km compared to 6km for NHS patients. The distance was greatest for locked independent sector units at 36km.

Treating patients outside their local area, often referred to as 'out of area placements', are contentious because they dislocate the patient from their family, friends, community, and community mental health team. Promoting family relationships and helping the person access local community resources are important aspects of the mental health rehabilitation

process and thus out of area placements can disrupt this. There can also be difficulties in the patient returning to their local area due to the greater distance the community team have to travel to visit them, and the distance the individual must travel to visit any local community accommodation service. Consequently, these issues often cause delays to discharge planning. Due to the additional time that people spend when placed out of area, these are also estimated to be twice as expensive compared to local NHS placements. The CQC have been very critical of the situation:

> *"We are particularly concerned about the high number of people in 'locked rehabilitation wards'. These wards are often situated a long way from the patient's home, meaning people are isolated from their friends and families… We concluded that, too often, these locked rehabilitation hospitals are in fact long stay wards that institutionalise patients, rather than a step on the road back to a more independent life in the person's home community. In a number of cases we found that these hospitals did not employ staff with the right skills to provide the high-quality, intensive rehabilitation care required to support recovery. This could result in people using these services feeling hopeless and powerless, and failing to fulfil their potential to regain control of how they live their lives." (p. 5 (84))*

The CQC also received data on 3,212 of the 3,662 people (89%) occupying a rehabilitation bed at the time of the survey, and details regarding the funding of the placement (81). Almost two-thirds (65%) were men, 78% were detained under the Mental Health Act (MHA), and 14% were subject to a Ministry of Justice restriction order (i.e. permission must be given by the Ministry of Justice before they are discharged). No information was collected regarding diagnosis. In England, Clinical Commissioning Groups (CCGs) are responsible for the commissioning of healthcare services for the local population. Almost all CCGs in England (174/191, 91%) were found to have commissioned inpatient rehabilitation beds but there was considerable variation in the number of beds locally available (median beds per 100,000 population: 5.8, range: 0.3 to 31.0). The estimated total cost per year of all inpatient mental health rehabilitation was £535 million, two-thirds of which was spent in the independent sector. It has been argued before that the disinvestment of NHS inpatient rehabilitation care

has led to an increase in the provision of inpatient rehabilitation by the independent sector and the use of out of area placements (85). The findings from the CQC investigation supports this argument.

Although knowledge of the total number of mental health inpatient rehabilitation beds is useful in understanding the level of national provision, it does not describe the complexity of the rehabilitation system. In an attempt to ensure a more systematic approach, the Royal College of Psychiatry's Rehabilitation Faculty (83) recently published a typology of inpatient mental health rehabilitation services. It describes five different types as follows:

1. High dependency rehabilitation unit: provides comprehensive assessment and attempts to maximise the potential benefits of medication and psychosocial interventions, and reduce the frequency of challenging behaviours. Patients usually have significant risk histories and are detained under the Mental Health Act (MHA) 1983. Most will be referred from acute inpatient units but some will arrive from forensic units. Most admissions last around one year with the aim of discharging patients to community settings (either to a community rehabilitation unit or supported accommodation).
2. Community rehabilitation unit: primarily functions as a step-down service for patients discharged from high dependency rehabilitation units who continue to have complex needs which cannot be sufficiently met by supported accommodation. If the service is registered as a ward with the CQC then they may accept patients who are detained under the MHA 1983, if not, they can still accept patients subject to a Community Treatment Order (CTO).
3. Longer term high dependency rehabilitation unit: for patients with high levels of disability from symptoms that are treatment resistant and/or complex co-morbid conditions which require a longer period of inpatient treatment to stabilise. Most referrals are received from high dependency rehabilitation units.
4. Highly specialist high dependency rehabilitation unit: inpatient services designed specifically for patients with a complex longer term mental health problem and a specific comorbidity, such as a traumatic brain injury or autism spectrum disorder. Most patients are detained under the MHA, admissions usually last longer than two

years, and the aim is to stabilise and prepare patients for discharge to specialist long term supported accommodation services. Unlike types one to three which are usually commissioned by local CCGs, these units are usually funded at the national level by NHS England.

5. Low secure rehabilitation unit: for patients with a history of offending and/or very challenging behaviours and complex mental health problems, and are often subject to a Ministry of Justice restriction order. Patients are usually referred from other services on the forensic pathway, such as medium secure units, and are usually discharged to either a high dependency rehabilitation unit, a community rehabilitation unit, or mental health supported accommodation depending on the current level of mental health need and challenging behaviour. Like highly specialist high dependency rehabilitation units, these units are usually funded by NHS England.

2.8.3 Mental health supported accommodation

Mental health supported accommodation is regarded as a key component of the mental health rehabilitation care pathway, providing a bridge between being a patient at an inpatient rehabilitation service and independent living in the community (86). Moreover, access to adequate accommodation was declared by the United Nations as a universal human right (87, 88). However, individuals with complex and longer term mental health problems are a disadvantaged group at particular risk of having this human right violated, demonstrated by their disproportionate representation amongst people who are homelessness or living in inadequate housing (89). Appropriate housing is widely regarded as an important factor in an individual's health. It is also of fundamental importance in mental health rehabilitation. In a study of people with severe mental health problems, the housing environment has been found to uniquely predict psychiatric distress, recovery orientation, residential satisfaction, and adaptive functioning (90).

There are many different types of mental health supported accommodation service providing different levels of support and the terminology used to describe them is inconsistent (91). However, there are broadly three main types, distinguishable by the level of support they provide. Residential care provides the highest level of support. Due to the long term, high support needs of those who are referred to these services, there is often less focus on

enabling residents to move to lower levels of support; they are staffed 24-hours-a-day, seven-days-a-week, and day-to-day necessities such as meals and medication are managed by the staff. Supported housing services have more varied levels of staffing, ranging from 24-hours-a-day seven-days-a-week, to 9am to 5pm Monday to Friday, and provide time limited tenancies with the aim that residents will progress in their recovery and be able to move-on to less supported accommodation. Floating outreach services provide the lowest level of support. Visiting staff support individuals in their own self-contained, permanent tenancy providing practical and emotional support. The frequency of visits varies but typically start at two or three times a week with the aim of reducing this over time.

In England, all three types are usually staffed by non-professional support workers with clinical support provided by local NHS mental health community teams (and sometimes by specialist community mental health rehabilitation teams, as described below in Section 2.8.4). They are commissioned by local authorities and are usually provided by housing associations or voluntary organisations. The funding of these services is complex, with the housing and care components funded via different streams. The basic housing costs are usually funded by housing benefit (a welfare benefit for those on low income that covers rent) and often subsidised by 'block contract' arrangements with local authorities. Whereas the support component is predominantly funded by the local authority budget for adult social care (92).

Most mental health supported accommodation services in England are commissioned to provide placements for around two years, however, most individuals do not move to lower levels of support within this timeframe. A national study of mental health supported accommodation in England found that only 41% of residents successfully moved on to lower supported settings within 30 months without any subsequent hospital admissions, and this rate varied substantially according to the type of service. Of the individuals supported by floating outreach, two-thirds graduated to lower levels of support (67%), compared to around two-fifths of supported housing residents (39%), and one-in-ten living in residential care services (10%). The study also found that services that had a greater emphasis on promoting their clients' human rights and provided greater recovery-based practice were associated with higher levels of successful move-on (5).

2.8.4 Community mental health rehabilitation teams

Community mental health rehabilitation teams provide clinical input to residents of local mental health supported accommodation services. They are multi-disciplinary teams, and are usually comprised of nurses, social workers, psychiatrists, psychologists, and occupational therapists. They aim to support people to gain and sustain skills for community living and to support them through key transitions including moves from inpatient rehabilitation services to the community, from higher to lower levels of supported accommodation, and to an independent tenancy where appropriate. An important role of the community rehabilitation team is to help people access the right type of supported accommodation and work together with supported accommodation staff to ensure there is a consistent, joined-up approach to support the person on their mental health recovery. No less important is their role in supporting their patients to maximise the benefits of medications, access appropriate physical health assessment and treatment, engage with support and activities which help improve their skills and confidence in activities of everyday living (e.g. cooking, cleaning, managing finances), support them to engage in community activities and achieve their vocational goals by signposting and supporting their access to local resources (e.g. Recovery College (93), and Individual Placement and Support programmes (94)), as well as supporting them to establish and/or maintain relationships with families and friends. Around 60% of NHS Trusts in England have a community rehabilitation team (95), a slight increase since 2005, when about half of NHS Trusts provided them (64).

2.8.5 Current guidelines and the mental health rehabilitation pathway

Leading figures in the field of mental health rehabilitation have argued that people with longer term complex mental health problems have been poorly served in the years since deinstitutionalisation (96). This has been most clearly demonstrated by the disinvestment of NHS inpatient rehabilitation services and the continuing high rates of out of area placements (81, 84, 85). Indeed, it was not until 2020 when the first set of national guidelines describing how support for this group should be organised were published in England – The National Institute for Health and Care Excellence (NICE) guideline: Rehabilitation for adults with complex psychosis (86).

The 2020 NICE guideline recommends that all local mental healthcare systems should have a defined rehabilitation pathway, which includes the three components previously described: inpatient rehabilitation services, supported accommodation services, and community rehabilitation teams (Sections 1.5.2 to 1.5.4). The Guideline recommends that the exact complement of services required should be informed by a comprehensive review of local population needs (86). This population-level needs assessment should take into account the number of people living in the local area (and those who are the responsibility of the local authority if not living locally) with complex psychosis who: are currently receiving inpatient rehabilitation locally or out of area; have repeated or extended acute psychiatric inpatient admissions and may benefit from a rehabilitation admission; are currently admitted to a forensic inpatient service and once discharged will require further rehabilitation; or are currently using an early intervention service (a service designed for people with a first episode of psychosis) and showing signs that they may develop treatment resistant complex psychosis. A national prospective cohort study of NHS inpatient rehabilitation services carried out by Killaspy and colleagues found that 80% of referrals into this pathway come from local acute admission wards and 20% come from forensic mental health services (70), illustrating the importance of reviewing patients in these services when assessing the local need for mental health rehabilitation.

The NICE guideline describes a number of overarching principles that should be considered intrinsic to the commissioning, design, and practice of rehabilitation services (86). First, services and staff should work according to the recovery based approach (97). Adopting a recovery orientation primarily means working collaboratively with the individual to identify goals for treatment together and developing a plan to address these goals. This requires all members of the multi-disciplinary team (psychiatrists, nurses, social workers, occupational therapists, and psychologists) to assess patients and support them with their needs, with a strong focus on improving every day and social functioning as well as clinical symptoms. Rehabilitation services (both inpatient and supported accommodation) that have a greater recovery focus have been shown to achieve better patient outcomes, particularly in supporting people to progress to the next step in the rehabilitation pathway (i.e. achieving successful discharge from inpatient to community rehabilitation settings or moving successfully from higher to lower supported community settings) (5, 70).

Second, the pathway should be flexible enough to cater to individuals with different needs. Different stages in the pathway may take different lengths of time for different individuals and services should be responsive to this and avoid setting inflexible targets (e.g. for lengths of stay), whilst, at the same time, maintaining a recovery focus. Progress may not be linear, and individuals may benefit from going back a step in the pathway at different points in their recovery according to their changing needs. Individuals should also be able to enter the pathway at different points.

Third, the pathway needs to be well integrated. Progressing through the pathway and moving from one service to another can be stressful and disruptive to the individual (8, 98). There are many different types of service on the pathway, and they are most often provided by different organisations. Typically, inpatient services and the community rehabilitation team are provided by the NHS, and supported accommodation services are provided by the voluntary sector. It is important that these different services and organisations work in partnership to ensure transitions are smooth and all relevant information is communicated efficiently. Finally, the pathway should be managed by senior managers and commissioners to ensure good flow so that individuals are supported to move-on appropriately and placements continue to become available for those who need them.

2.9 Camden and Islington: Sociodemographic and mental health morbidity

Three of the four studies reported in my thesis takes place in Camden and Islington. Camden and Islington are both inner London boroughs with a combined population of around 527,631. Table 1 reports the sociodemographic and mental health morbidity of both Camden and Islington and shows how each borough compares to London and England. A much greater proportion of residents in Camden (43.0%) and Islington (46.5%) are in their twenties compared to London overall (15.6%) and England (13.9%). Almost half of people living in Islington (44.3%) and over a quarter of people living in Camden (27.1%) are living in the 20% most deprived 'Lower Layer Super Output Areas' (defined as small geographical areas of around 1,500 people) in England, substantially higher than the overall proportion in London (22.9%). There is a greater prevalence of people diagnosed with schizophrenia, bipolar affective disorder or other psychosis in Camden (1.46%) and Islington (1.53%) compared to London overall (1.11%) and England (0.94%). There is also a greater rate per 1,000 population

aged between 15 and 64 who use illicit substances (opiates and/or crack cocaine) in Camden (12.0, 95% CI: 8.9 to 14.8) and Islington (13.1, 95% CI: 10.2 to 16.0) compared to London overall (9.3, 95% CI: 8.9 to 9.9) and England (8.9, 95% CI: 8.7 to 9.2).

Table 1: Sociodemographic and mental health morbidity of Camden, Islington, London overall, and England

		Camden	Islington	London	England
Population (mid-2020 estimates)		279,516	248,115	9,002,488	56,550,138
Population density: Number of people per square km (2019)		12,393	16,321	5,701	432
Male (2020)		152,239 (54.5%)	142,915 (57.6%)	4,514,378 (50.1%)	27,982,818 (49.5%)
Age (2020)	**<20**	61,431 (22.0%)	48,802 (19.7%)	2,227,341 (24.7%)	13,330,355 (23.6%)
	20 to 29	120,087 (43.0%)	115,463 (46.5%)	1,401,333 (15.6%)	7,874,471 (13.9%)
	30 to 39	51,699 (18.5%)	51,163 (20.6%)	1,602,018 (17.8%)	7,562,861 (13.4%)
	40 to 49	36,776 (13.2%)	29,320 (11.8%)	1,275,998 (14.2%)	7,114,942 (12.6%)
	50 to 59	30,234 (10.8%)	24,753 (10.0%)	1,078,660 (12.0%)	7,637,133 (13.5%)
	60 to 69	20,714 (7.4%)	15,401 (6.2%)	723,718 (8.0%)	5,981,113 (10.6%)
	>69	24,274 (8.7%)	15,260 (6.2%)	780,311 (8.7%)	7,679,719 (13.6%)
Ethnicity (2011)	**Asian or Asian British**	19,034 (9.2%)	35,446 (16.1%)	1,511,546 (18.5%)	4,143,403 (7.8%)
	Black, African, Caribbean or Black British	26,294 (12.8%)	18,060 (8.2%)	1,088,640 (13.3%)	1,846,614 (3.5%)
	Mixed or multiple ethnic groups	13,339 (6.5%)	12,322 (5.6%)	405,279 (5.0%)	1,192,879 (2.3%)
	White	140,515 (68.2%)	146,055 (66.3%)	4,887,435 (59.8%)	45,281,142 (85.4%)
	Other	6,943 (3.4%)	8,455 (3.8%)	281,041 (3.4%)	548,148 (1.0%)
Employment and support allowance claimants for mental and behavioural disorders: rate per 1,000 working age population (2018)		31.7	35.8	22.5	27.3
Index of Multiple Deprivation score (2019)		20.1	27.5	21.7	21.8
Proportion of people living in the 20% most deprived areas (Lower Layer Super Output Areas) in England (2014)		27.1%	44.3%	22.9%	20.2%

	Camden	Islington	London	England
Opiate and/or crack users: rate per 1,000 (aged 15–64; 2016/17) (95% CI)	12.0 (8.9 to 14.8)	13.1 (10.2 to 16.0)	9.3 (8.9 to 9.9)	8.9 (8.7 to 9.2)
Prevalence of people with a depression or anxiety disorder (aged 16+; 2017)	19.4%	22.7%	16.9%	19.3%
Prevalence of people with a diagnosis of schizophrenia, bipolar affective disorder and other psychoses (all ages; 2017/18)	1.46%	1.53%	1.11%	0.94%
New cases of psychosis: estimated incidence rate per 100,000 (aged 16–64; 2011)	39.2	51.9	40.6	24.2

CI = confidence interval.
All the statistics reported in this table are sourced from the Office for National Statistics (99, 100) and Public Health England (101), using data provided by the 2011 Census and the monthly reports published as part of the Mental Health Services Dataset.

2.10 Camden and Islington: The local mental health rehabilitation pathway

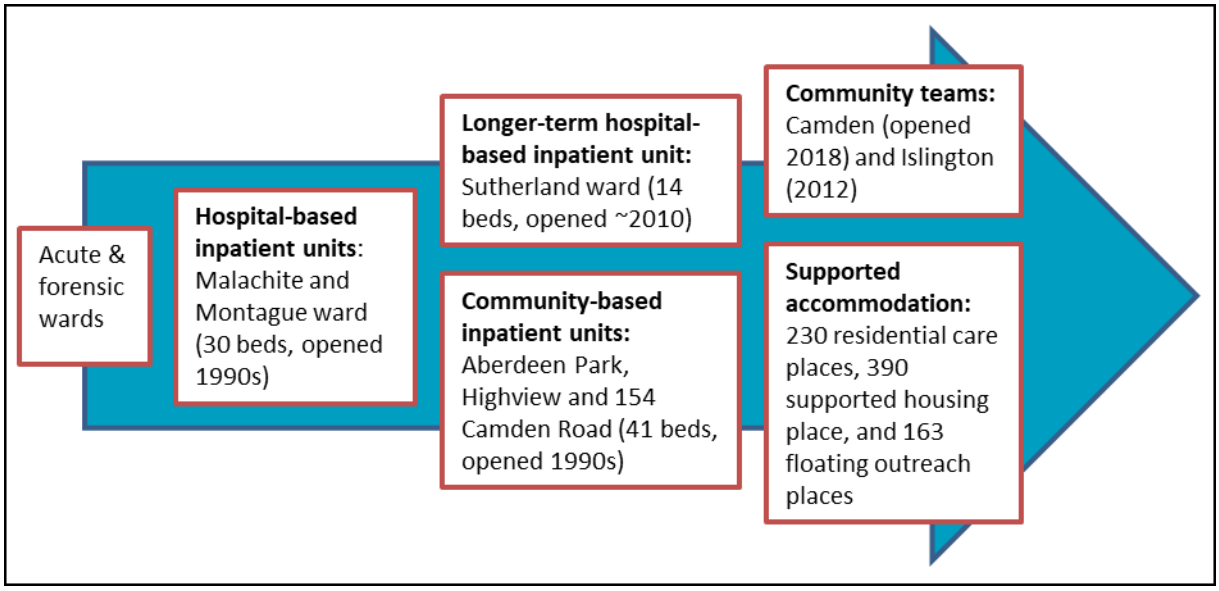
Mental health rehabilitation services and the rehabilitation pathway in Camden and Islington are relatively well established. There are two hospital-based high dependency rehabilitation inpatient units: Montague Ward, which opened in the 1990s and has 14 beds, and Malachite Ward, which opened in 2004 and has 16 beds. There is also Sutherland Ward, a hospital-based longer term high dependency rehabilitation unit with 14 beds, which opened in 2010, plus three community rehabilitation units: Aberdeen Park, Highview and 154 Camden Road, which have all been operating since the 1990s (154 Camden Road was based at Daleham Gardens until 2005) and have a combined total of 41 beds. These are not registered as inpatient services but can take patients subject to CTO.

The QuEST programme of research in 2017 (4, 5) (mentioned in Section 2.8.3) identified the local mental health supported accommodation (12 residential care services providing 230 places, 34 supported housing services providing 390 places, and nine floating outreach services providing 163 places). Although the level of provision remains relatively constant, new services are often commissioned to replace older ones, and therefore the names of these services often change.

There is a community rehabilitation team in each borough. The team in Islington was set up in 2012, and the Camden team in 2018. Both services care co-ordinate people with psychosis

who live in 24-hour supported accommodation, providing specialist clinical input and supporting them with their transitions through the rehabilitation pathway. The inpatient units and community rehabilitation teams are provided by Camden and Islington NHS Foundation Trust (CIFT). The mental health supported accommodation services are provided by several different voluntary sector organisations. Figure 1 illustrates the Camden and Islington mental health rehabilitation pathway.

Figure 1: The Camden and Islington mental health rehabilitation pathway



2.11 Summary

Mental healthcare in England today has evolved from a system based on large, remote, long-stay mental hospitals to a system that is a balance between inpatient and community-based services, with specialisation for supporting people with different types of mental health problem. The contemporary approach to supporting people with long term, complex, and treatment resistant mental health problems is an integrated pathway of rehabilitation services which consist of a range of inpatient rehabilitation units, community rehabilitation teams, and supported accommodation.

3 Chapter 3: The Clinical Records Interactive Search (CRIS)

3.1 Introduction

This chapter describes the development and function of the Clinical Records Interactive Search (CRIS), a tool which de-identifies and structures electronic health records (EHRs) so that they can be used in secondary mental health research. CRIS was used to carry out three of the four studies reported in this thesis. Before the development and function of CRIS is detailed, this chapter starts with an explanation of what is meant by the term 'secondary research' and how electronic health records (EHRs) can be used in mental health research.

3.2 Secondary research and the use of health records in mental health research

A study can be categorised as either being primary or secondary research. Primary research studies are studies where the data used has been collected specifically for the purpose of addressing a specific research question. The main advantage of primary research is that the study design can be tailored to address the research question, which should ensure that the data collected are useful and relevant. A classic example of a primary research study is where the data are collected via interviews with participants and includes the use of standardised measures e.g. in a clinical trial evaluating an intervention. Other examples of primary research would be a survey of the general public measuring self-reported mental health problems, or a qualitative study where a small number of purposively selected participants are interviewed to better understand their experience of a new intervention. However, recruiting participants, often in the hundreds and sometimes in the thousands, and then collecting data from them, often at multiple points over a period spanning months and often years, requires a considerable amount of resource, both in terms of time and finance. For example, the QuEST project which investigated the quality and effectiveness of mental health supported accommodation in England, took five years to complete at a cost of around £1.6 million (102).

Another disadvantage to primary research, especially trials, is that they are typically conducted under very strict conditions and are not representative of real-world settings. In other words, the study may lack ecological validity and one should be cautious in generalising the findings to other settings which may be quite different to that of the study.

Secondary research uses existing data, i.e. data which have been collected for another purpose. Whilst the data have not been collected to answer the specific research question, they provide researchers with the opportunity to investigate research questions using far less resource than primary research. Data used in secondary research can come from a range of sources, including data collected as part of another study, and data recorded routinely for another purpose, such as delivering healthcare.

The medical history and healthcare of individuals was routinely documented on paper throughout the 20th century (103). Health records, or medical records as they are sometimes referred to, developed into a fundamental aspect of how healthcare was organised and administered (104). Typically, every healthcare contact an individual has will be recorded. Over time, this produces prospective, longitudinal data regarding the individual's health, changes in health, and the healthcare they receive during their life course. Such data have the potential to be of great value in research and the evaluation of real-world healthcare. For example, they can be used to corroborate outcomes in primary research studies which relate to health, such as hospitalisations, or used as the source of data for a secondary research study evaluating the implementation of a new service design or treatment. They can also be used in epidemiological studies of populations that are difficult to study and screen in the general population, including people with rare health conditions. However, there are limitations to using healthcare records in research, for example, they will only provide information about people who use healthcare services and not about individuals who use other methods to manage their conditions and symptoms. This potential source of bias may be of particular relevance to mental health research where worldwide there are many different approaches to treatment which do not involve the healthcare system, such as spiritual and religious communities. As with any research, the appropriateness of the study design and data source in addressing the research question should be considered.

Historically, healthcare records were exclusively recorded on paper and filed in cabinets. This started to change in the late 20th and early 21st century with more and more healthcare providers switching from paper to electronic record systems. In the United Stated, the Obama administration invested $30 billion into promoting and improving EHRs, and by 2017 96% of hospitals in the US had access to EHRs (105). Healthcare is increasingly being recorded and

stored using computers at the office, and on laptops and other devices away from the office, rather than on paper. The switch from paper to EHRs has evolved with the way healthcare is delivered, and the way health records can be used in research. Records are no longer handwritten and often ineligible, nor do they need to be physically copied to be accessed in more than one location, causing problematic version control issues and increased risk to confidentiality. With well-established EHR systems, the appropriate healthcare staff involved in an individual's care, including emergency staff, can access an individual's most up to date health records. This enables clinicians to be able to check for known allergies, medications, and healthcare histories, without first having to contact other clinicians, greatly improving the safety and efficiency of healthcare.

EHRs are stored as either structured or free text records. Structured records hold a range of demographic and clinical information (such as sex, date of birth, diagnosis, etc.) completed by selecting from a list of options (e.g. male or female) or by using a specific format (e.g. date). Although structured fields provide data that easily lends itself to quantitative analysis, their utility in research is limited by the types of data available in structured records and their sometimes poor completion rates owing to the preference of clinicians to record data in natural language (106). Free text fields include any entered text and typically comprise clinical notes and uploaded documents, such as discharge summaries. The proportions vary between record systems but they represent around 60% to 70% of the data stored in EHR databases (2, 106) and are a rich source of clinical information, ranging from psychiatric assessments to logs of clinical appointments and referrals. However, it is not as simple to use them in quantitative research as structured records, and they often require extra levels of processing.

The benefits of the switch from paper to EHRs have been recognised around the world. For example, the UK Government's aim to create a paperless NHS (107), and the US Congress introducing incentives to switch from paper to EHR and penalties for not switching (108). Although the switch from paper to EHRs has evolved the way they are used in research, due to their sensitive and confidential nature, access to them for research purposes usually requires information governance permissions and the informed consent of individual patients. Gaining informed consent for each individual may not be an issue for primary research using health records to corroborate data collected from participants, as informed

consent from participants would have to be collected anyway, and consent forms can include items specific to accessing the participant's health records. However, it is an issue for secondary research aiming to use health records, where individuals are not recruited and therefore do not provide informed consent. To address this, techniques have been developed to de-identify EHRs so that they can be used in secondary research without requiring the informed consent of individuals the records pertain to.

The Nordic registers have been described as a "potential goldmine for clinical research" (p.132 (109)). Citizens of Denmark, Sweden, Norway, Finland, and Iceland, all have personal identity numbers (PINs) allowing for linkage between various national registers. This means that a wide range of longitudinal data, such as healthcare, education, and income, recorded at the individual-level from birth or immigration until death or emigration, can be linked and used in research. These data have been used to address research questions which would be unfeasible, unethical, and/or too expensive to address using primary research methods. For example, they have been used to study the association between birth characteristics and the development of cardiovascular disease (110), the risk of foetal death where the mother is vaccinated against influenza (111), the risk of substance use and psychotic disorders for people with epilepsy (112), and the association between migrant status and compulsory admission at the first diagnosis of a psychotic disorder (113). Researchers wishing to use these data must submit an ethics application to the appropriate ethics committee. There are some variations between the Nordic countries, but typically, following an approved ethics application, the researcher will be granted access to a pseudonymised dataset (114).

Pseudonymisation is the process of assigning individuals with a study code and removing the identifiable information in the dataset so that someone who just has access to the dataset should not be able to identify any individual in the dataset, but re-identification is still possible with access to the codebook. The codebook is a data file which links the study code to the identity of the individual (e.g. the individual's name or other identifiable information such as the PIN in the Nordic registers). It is held by the appropriate authority (the government in the case of the Nordic registers), and it can be used to validate, link to another dataset to create a larger dataset, or update the records. True anonymisation is where there is no codebook and re-identification is not possible, which can be limiting for register-based research as it

does not allow for records to be validated, linked, or updated. The distinction between anonymised and pseudonymised is often overlooked in the description of datasets, and pseudonymised dataset are often falsely described as anonymised datasets.

3.3 Health records in England

In England there are hundreds of healthcare providers, each with their own system for organising records. Healthcare is organised regionally and into primary care, secondary care, and tertiary care. Primary care is comprised of local general practices that primarily serve as the initial point of contact for healthcare, and where appropriate, will refer patients on to secondary healthcare services. Secondary care is comprised of inpatient and community services which provide treatment or support for specific health conditions and are organised at the regional level. For example, Camden and Islington NHS Foundation Trust (CIFT), introduced in Chapter 2 (see Section 2.10), is a provider of secondary care mental health services. Tertiary care is comprised of highly specialist services for rare and/or complex health conditions; a single tertiary care service will provide healthcare to a much larger geographical area than a secondary care service.

The Clinical Practice Research Datalink (CPRD), formerly known as the General Practice Research Database (GPRD), is a non-profit research service provided as part of the UK Government's Department of Health and Social Care and contains the pseudonymised health records of a network of UK primary care services. The database currently contains records for 60 million people including 16 million currently active patients (115). It has proven to be of immense value to health research, and as of September 2021, has been used in over 2,800 peer-reviewed publications (116). The CPRD can be utilised for mental health research, for example, it has recently been used to investigate the incidence of depression in people with obesity (117). However, the CPRD does not include health records of secondary care, the principal provider of specialist mental healthcare in England, especially for people with longer term complex mental health problems.

3.4 Development of the CRIS system

The Clinical Records Interactive Search (CRIS) de-identifies and structures the EHRs of NHS mental healthcare trusts (1). Individuals are assigned codes which can be used by the Trust to

re-identify individuals, and so it is a pseudonymised database. However, in this thesis CRIS databases are described as de-identified databases as this better represents the process of how CRIS removes and masks identifiable information from the EHR (this process is described below in Section 3.5).

CRIS was developed by a collaboration between the South London and Maudsley NHS Foundation Trust (SLaM) and the Institute of Psychiatry at King's College London, funded by a Biomedical Research Centre award from the National Institute for Health Research (1-3). SLaM is the largest provider of mental health services in the UK, and one of the largest in Europe. They provide over 230 inpatient and community services (i.e. secondary care) for people residing in the London boroughs of Lambeth, Southwark, Lewisham and Croydon, a combined population of around 1.2 million people. They also provide specialist national services (i.e. tertiary care), including a psychiatric intensive care unit and a psychiatric forensic unit for children and adolescents. SLaM was amongst the pioneers in the switch from paper-based health records to EHRs. Between October 2005 and October 2006, SLaM deployed a bespoke Trust wide EHR system called the Electronic Patient Journey System (ePJS). Patient records from 1999 onwards were migrated onto ePJS, and it was this database of EHRs which was used to develop CRIS in 2008. In the same year, CRIS was granted approval by the Oxford Research Ethics Committee as a de-identified database of EHRs to be used in secondary research (reference number: 08/H0606/71+5). As of January 2020, the SLaM CRIS database contained de-identified records for over 340,000 individual patients (3, 118). Since it was granted ethical approval, CRIS has been used in hundreds of peer-reviewed published studies on a range of topics.

3.5 How CRIS de-identifies EHRs

CRIS de-identifies records by using 'patient identifiers', as defined by the Caldicott Code on Confidentiality, to construct a dictionary of potentially identifiable character strings for each individual patient. Patient identifiers include the patient's NHS identification number, their Trust specific identification number, name, date of birth, address, contact details (telephone numbers and email addresses), and any details of personal contacts (e.g. relative's name and address). These identifiers are sourced from the fields used by clinicians to specifically record this information. For example, there are dedicated fields in the Trust's EHR system where

clinicians record the patient's name and date of birth. Once this information has been used to construct the dictionary, this information is removed, except for date of birth which is truncated so that only the month and year remain, and address which is also truncated so that only the first three characters of the postcode remain. Finally, the dictionary is used to find instances where patient identifiers are recorded elsewhere in the patient's records (e.g. the patient's name in a GP letter), and any matches found are masked (2).

The dictionary does not just include the string of characters recorded in the dedicated source fields, but also other ways that this string of characters might be recorded. The dictionary can generate these other character strings because the dictionary also stores what type of data the character string is. For example, if a patient's date of birth is recorded as '04/10/1980', the dictionary stores this character string as a date and using programmed rules, CRIS will mask any instances of '04/10/1980', but will also mask other ways of recording this same information, such as '4th October 1980', '4th of Oct 1980', '4.10.1980', etc. Similarly, CRIS will mask telephone numbers recorded in the dedicated source fields whether they are recorded with or without spaces. Consider the following fictitious clinical note:

John attended his appointment today and told me that he has a new telephone number, it is 07825 172 265.

The potentially identifiable information in this record is the patient's first name and their telephone number. If this information has been correctly entered in the dedicated source fields used to construct the potentially identifiable information for this patient, CRIS will transform this record so that it appears as:

ZZZZZ attended his appointment today and told me that he has a new telephone number, it is ZZZZZ.

The potentially identifiable information has been masked. It does this for both historical and current records, so CRIS will also mask any instances of John's old telephone numbers. However, if the source fields were not correctly completed (e.g. a misspelling or the record is out of date) or the patient identifier in the clinical note included an error (e.g. a misspelling or typo), this information would not have been masked. Similarly, if a nickname was used

somewhere in the records but not recorded in the source fields, this would also not be masked. This issue was considered during the early development stages of CRIS (2). Through discussions with a stakeholder group – setup specifically for the purpose of overseeing the development of CRIS (and then monitoring its use by researchers following its development) and includes service users, carers, clinicians, and members of the public – it was agreed that a single patient identifier alone is unlikely to identify an individual. This agreement is consistent with the overarching approach taken by the development team to de-identification: there is a risk of re-identification following de-identification, but all efforts should be made to reduce this risk as far as it is feasible whilst aiming for minimal loss of information which may be valuable to research (1). This approach is exemplified by the truncation of a patient's date of birth and home address. The exact date is removed but the month and year is retained so that an approximate age can be derived, and the full home address is removed but the first part of the postcode is retained so that some geographical information is still available.

Another possible issue relating to the reliance of specific fields within the EHR system to create the dictionary of potentially patient identifiable information is the completion rate of these source fields. This was also considered during development, and as it transpires, was not a critical issue. At the time of the check, there were more than 200,000 individuals with records on the SLaM database. All patients had a first and last name recorded (these fields are mandatory), 99.7% had a recorded date of birth, and 98.5% had at least one address recorded (2).

3.6 How effective is CRIS at de-identifying EHRs

The CRIS de-identification process was evaluated by Fernandes and colleagues in 2013 (2). They tested recall (out of all the patient identifiers, how many were de-identified) and precision (out of all the instances CRIS masked a character string, how many were actually patient identifiers which were correctly masked) for a random set of 500 'event notes' (free text fields clinicians use to record contacts with patients and any event regarding the healthcare of the patient e.g. a completed referral) containing 3,603 patient identifiers. CRIS correctly identified and masked 3,573 patient identifiers producing a recall rate of 97.6%, and

incorrectly masked 30 character strings which were not patient identifiers producing a precision rate of 98.8%.

In the same evaluation, the authors also investigated the potential for breaches and inferring information (2). They defined a breach as the presence of three or more patient identifiers, including misspelled patient identifiers, occurring in a single record or series of records pertaining to a single patient. This was carried out by manually screening the same 500 event notes tested for recall and precision, in addition to manually screening sequentially recorded event notes for 50 patients. On average, 20 records were screened per patient. Out of the 500 records, only one potential breach was reported. For a single patient, their third line of address, postcode and last name appeared in de-identified records, and all occurred because of misspellings. The authors judged that there was a 'low' chance of re-identification of this patient because the information was outdated, the information could not be verified, and because of the incorrect spellings. Out of the 50 patients whose notes were screened sequentially, there was not a single breach recorded. The authors noted that whilst there may be a threat to patient anonymity where patient information has not been successfully masked, this threat is highly contingent on the intention of the researcher. A researcher whose intention is to re-identify a patient may be able to do so whereas re-identification is unlikely if the researcher is not motivated to do so and is aware of their responsibility to avoid incidentally re-identifying a patient.

3.7 CRIS as a framework for accessing EHRs for research

The efforts to prevent the possibility of re-identification are not limited to the technical processes which lie behind de-identification but also includes the central role of the stakeholder group in the development and implementation of CRIS, and the security protocols put in place (1). In this sense, CRIS is best understood as a framework for making EHRs accessible to researchers rather than just as a tool which de-identifies and structures EHRs. The security protocols include specification of who can access the CRIS database and how the database should be accessed. Researchers seeking to use the CRIS database must first have a letter of access or an honorary/substantive contract with the NHS trust and have an approved CRIS project application. See Section 3.11 for further details regarding this process and what is required in the project application. Approved researchers can then only

access the database from within the Trust network and firewall and must not remove any data from within this network. Also, database searches are routinely monitored to ensure that they fall within the remit of what the researcher specified in their project application.

3.8 Patient and public perception of health records use in research

CRIS operates within the laws which allow and regulate the processing of personal data (the General Data Protection Regulation (119) and Data Protection Act 2018 (120)). CRIS also complies with the national data opt-out (NDOO) service (121), introduced by the NHS in England in 2018 (122). By default, an individual's EHRs is included in the CRIS dataset, but the NDOO service means that patients can have their records withdrawn and not used in CRIS research, or any other research which uses healthcare records and does not have the explicit consent of the individual (individuals who have used the NDOO service and opted for their records not to be used in research, can still consent to their records being used for specific studies).

Atkin and colleagues recently investigated public awareness of the NDOO, and perceptions of anonymised patient data in research (123). The participants were recruited locally from the West Midlands area and the study was conducted on behalf of the PIONEER Health Research Data Hub. PIONEER is a framework similar to CRIS in that it de-identifies EHRs but for acute medical care not mental healthcare. The study included a series of workshops and a questionnaire with a total of over 350 participants, including patients, members of the public, and healthcare staff. They found that less than a third of participants were aware of the NDOO system (32%). However, the vast majority were happy for their healthcare records to be used for research by NHS trusts (94%), academic institutions (85%), and healthcare companies (68%), but less than half were happy for their data to be used by non-healthcare organisations (41%). The main concerns participants raised were unauthorised data re-use, the potential of re-identification, discrimination, and for their records to be used in research which does not benefit patients. The findings from this study suggest that there is a lack of awareness on how individuals can control the use of their EHRs in research, but that there is general public support for research using de-identified medical records when it is properly regulated and carried out by the NHS or academic institutions with the aim of benefitting patients.

Another study, conducted by Adanijo et al., investigated the views of 22 mental health service users on the use of de-identified mental health care records in research (124). Qualitative data were collected via four focus groups conducted online. Prior to the focus groups, the participants were provided with a summary of CRIS and then asked open ended questions about sharing clinical data and how data sharing systems should be developed to ensure they are efficient and ethical. Thematic analysis was used to identify themes from these focus groups and participants were included in this process. The purpose of data sharing was important to participants, they expressed concern about whether the research was for the public good or not, and for profit or not. This aligns with the finding by Atkin et al. on how the proportion of participants that were happy with their records being used varied depending on the type of organisation they were being used by (123). Adanijo et al. also reported concerns on the potential of discrimination through misattribution of physical health symptoms to a mental health diagnosis and discrimination of individuals or groups in society. Other issues raised by participants were safeguarding data and ensuring data were anonymous and confidential; accuracy and informed consent, including transparency in how data was shared and used; and incorporating service user involvement in data sharing systems and the governance of these systems.

Encouragingly, the areas and themes identified by Atkin et al. (123) and Adanijo et al. (124) are at least in part addressed by the CRIS framework. The CRIS framework is a joint venture between NHS Trusts and academic institutions. All proposals to use CRIS must explain how the research will benefit patients, and service user involvement is incorporated into the oversight and governance of CRIS. As previously described in Section 3.4 and Section 3.5, there is a CRIS stakeholder group which is composed of people using local mental healthcare services, carers, mental healthcare professionals, and members of the public. This stakeholder group had a central role in the initial development of CRIS and continues to have a central role in its implementation by acting as on oversight committee. The role of the committee includes reviewing applications, monitoring how the database is being used, and involvement in discussions and decision-making regarding its continued development (1, 125).

3.9 Patient and public involvement in CRIS

Stakeholder groups like the CRIS oversight committee are an example of patient and public involvement (PPI) in research, where patients and the public are involved in the design, planning and execution of research. PPI is recognised as an important aspect to healthcare research in the UK (126) and internationally (127), and is very often a requirement by research funders (128). Broadly, improving PPI in research is part of an imperative which empowers people, by transforming research so that it is something which is done 'by' or 'with' patients and the public rather than done 'for' or 'to' them (126). Furthermore, including PPI at various stages in the research lifecycle has been shown to improve the quality and relevance of research (129).

As CRIS continues to develop, a new PPI group has been set-up to specifically inform decision-making and future research regarding database linkages (125). For example, the SLaM CRIS database has been linked to the Hospital Episodes Statistics (HES) database, which includes details on all NHS hospital admissions (including medical admissions) and mortality (130).

Although PPI appears to have a central role in many aspects of CRIS, the degree of patient and public awareness of CRIS is unclear. The studies by Atkin et al. (123) and Adanijo et al. (124) suggests that there may be general support from the public on not-for-profit research which aims to improve healthcare, but further research is needed to understand how widespread this support may be. It is unknown what the general consensus is on the use of de-identified mental healthcare records in research, and Atkin et al.'s study indicates a lack of public awareness of the NDOO service in the UK and their rights on how their healthcare records are used (123). The next section of this Chapter describes the CIFT CRIS database which is the database used in the studies reported in Chapters 4, 6, and 7.

3.10 The CIFT CRIS database

As previously described, CRIS was developed on the SLaM EHR database, and SLaM uses a system called ePJS (see Section 3.4). It has since been developed and deployed at several other NHS Trusts in England using different health record systems, including the Camden and Islington NHS Foundation Trust (CIFT). The catchment area for CIFT and the local mental health rehabilitation pathway were described in the previous Chapter (Section 2.10), as were

the sociodemographic characteristics and mental health morbidity of the area (Section 2.9). Regarding the Trust's health records, CIFT switched from a paper-based records system to an electronic-based records system in 2008 using a system called RiO. In 2015, they switched to another EHR system, called Carenotes. A number of studies using the CIFT CRIS database have been conducted and published in peer-reviewed journals, demonstrating the viability of the deployment of CRIS at other NHS Trusts and with other EHR systems. For example, a study by Werbeloff et al. used CIFT CRIS to investigate delays in diagnosis and treatment for bipolar affective disorder (9) and produced similar results to a similar study using SLaM CRIS (131).

Werbeloff et al. in the same study also reported sociodemographic characteristics of individuals with records on the CIFT CRIS database as of 31st August 2015 (9). In total, the database contained records for 108,161 individuals. There were slightly more females (55,718, 51.5%) than males (52,243, 48.4%), with only 0.1% (159) of individuals missing information for sex; almost a quarter were between 35- and 44-years old (24,665, 22.8%), which was higher than any other age band; and almost half were of White ethnicity (51,713, 47.8%). As of 21st July 2022, the number of individuals with records on the CIFT CRIS database was 168,045. The proportion of females (86,669, 51.6%) and males (80,967, 48.2%) were similar to 2015; there was a similar proportion aged 35- to 44-years-old (34,880, 20.8%), again, this was the age band with the highest proportion of individuals; and there was a lower proportion of people with White ethnicity (66,644, 39.7%). However, there was also a higher rate of missing data for ethnicity in the more recent database (36,991, 34.2% vs. 72,954, 43.4%). Therefore, the difference in the proportion that are White may not be as large as it seems. Table 2 provides further details on the sociodemographic characteristics of the CIFT CRIS database in 2015 and 2022.

Table 2: The sociodemographic characteristics of individuals on the 2015 and 2022 CIFT CRIS database

		31 August 2015 (N=108,168) (9)	21 Jul 2022 (N=168,045)
Sex	Male	52,243 (48.4%	80,967 (48.2%)
	Female	55,718 (51.5%)	86,669 (51.6%)
	Missing	159 (0.1%)	292 (0.2%)
Age	24 and under	5,302 (4.9%)	8,515 (5.1%)
	25 to 34	19,854 (18.4%)	28,695 (17.1%)
	35 to 44	24,665 (22.8%)	34,880 (20.8%)
	45 to 54	22,295 (20.6%)	31,215 (18.6%)
	55 to 64	12,725 (11.8%)	24,038 (14.3%)
	65 to 74	7,838 (7.2%)	13,464 (8.0%)
	75 to 84	6,266 (5.8%)	10,115 (6.0%)
	85 and over	9,175 (8.5%)	17,006 (10.1%)
	Missing	48 (0.1%)	117 (0.1%)
Ethnicity	Asian or Asian British	4,136 (3.8%)	6,062 (3.6%)
	Black African, Black Caribbean or Black British	7,620 (7.0%)	10,610 (6.3%)
	Mixed or multiple ethnic groups	1,923 (1.8%)	3,071 (1.8%)
	White	51,713 (47.8%)	66,644 (39.7%)
	Other	5,737 (5.3%)	8,704 (5.2%)
	Missing	36,991 (34.2%)	72,954 (43.4%)

3.11 Research ethics

As previously described in this Chapter (Section 3.4), the SLaM CRIS database has been granted ethical approval as a de-identified database of EHRs to be used in secondary research (Oxford Research Ethics Committee: reference number 08/H0606/71+5). The CIFT CRIS database has also been granted ethical approval to be used in secondary research (National Research Ethics Service (NRES) Committee East of England—Cambridge Central: reference number 14/EE/0177). As explained in Section 3.7, to be granted access to the SLaM CRIS database, researchers are required to have a letter of access or an honorary/substantive contract with the NHS Trust and have an approved CRIS project application. The project application includes sections on rationale for the project, the useful knowledge which would be gained from the results and how this will benefit patients, and the type of records the

researcher plans on using to define groups and use in their results. The application is reviewed by the SLaM CRIS oversight committee with consideration for the potential of patient identification via searches that are too specific or are likely to return a small number of patients. The SLaM CRIS project application form is completed online via the Trust website (132). Similar criteria and process must be met and followed by researchers wishing to gain access to the CIFT CRIS database. Further information regarding the CIFT CRIS database and the process for submitting project applications is available on the Trust website (133).

I have an honorary contract with CIFT. I submitted two separate project applications for: i) a study assessing the feasibility of using CRIS to evaluate mental health supported accommodation services at CIFT (Chapter 4); ii) two studies using CRIS at CIFT to a) compare inpatient service use pre- and post-inpatient rehabilitation (Chapter 6), and b) explore the viability of using propensity score matching to establish a valid comparison group for an inpatient rehabilitation group (Chapter 7). Both applications were approved by the CIFT CRIS oversight committee.

3.12 Summary

Secondary research methods can be used to address research questions which may be unethical or require much greater resources if it were conducted as a primary research study. For some research questions, secondary research may also produce findings with greater ecological validity. However, there are limitations to secondary research. The data used in secondary research has not been collected for the purpose of the study, and therefore, the suitability of the data to address the research question and the quality of the data needs to be considered when any findings are interpreted.

Data from primary research studies are often used as a source for secondary research, as are electronic health records (EHRs). For studies evaluating healthcare services or an intervention that is already being deployed, EHRs are a valuable source of longitudinal, real-world data which can be used to inform future healthcare. As they contain personal and sensitive information, for EHRs to be used in research the individual the records pertain to needs to provide their informed consent or the records need to first be de-identified. Gaining consent

for this is often done in primary research to corroborate the data they collect but it is usually not feasible in secondary research.

The Clinical Records Interactive Search (CRIS) de-identifies EHRs of NHS mental health Trusts. CRIS has been granted ethical approval to be used in secondary research and has been deployed in several NHS Trusts in England, including Camden and Islington NHS Foundation Trust (CIFT).

4 Chapter 4: The feasibility of using CRIS to evaluate mental health supported housing services

A modified version of this chapter was published as a peer reviewed article in PLoS One:

Dalton-Locke C, Thygesen JH, Werbeloff N, Osborn D, Killaspy H (2020). Using de-identified electronic health records to research mental health supported housing services: A feasibility study. PLoS ONE 15(8): e0237664. doi: 10.1371/journal.pone.0237664

4.1 Introduction

It was around the start of my studentship, October 2017, when the CIFT CRIS database was established and being suggested as a potential resource for research evaluating mental health services. I attended a seminar by Dr Nomi Werbeloff, who at the time was the manager of the CIFT CRIS database and first author on a study demonstrating the viability of using the database in mental health research (9). Following the seminar, I contacted Dr Werbeloff to arrange a meeting to discuss the potential of using the CIFT CRIS database to evaluate mental health supported accommodation services. I also met with the academic lead for the CIFT CRIS database, Prof. David Osborn. We concluded that there was sufficient potential and so I discussed project ideas with my supervisor, Prof Helen Killaspy. We agreed on a project that would explore the feasibility of using the CIFT CRIS database to evaluate mental health supported housing services.

In Chapter 3, I detailed the development of CRIS, how it works, and its implementation with the CIFT EHR system. A description of mental health supported accommodation and supported housing, and its important role within the mental health rehabilitation pathway, was provided in Chapter 2 Section 2.8.3. Mental health supported accommodation is a challenging area to research as demonstrated by the QuEST project.

The QuEST project (previously described in Section 2.8.3), a NIHR-funded programme of research investigating mental health supported accommodation in England, included a randomised control feasibility trial (6). This trial was designed to investigate the feasibility of randomising individuals to supported housing or floating outreach (another type of supported accommodation, also described in Section 2.8.3). This was based on a previous study in the QuEST project, a national survey, which found that the level of needs of individuals living in supported housing were similar to the needs of individuals using floating outreach services

(4). Most people graduate from supported housing to floating outreach but if people could go straight to floating outreach, it would reduce the number of moves. Moving home is a major life event for anyone and it is therefore unsurprising that repeated moves from one type of supported accommodation to another have been reported by users of mental health supported accommodation as a source of stress (8). However, the feasibility trial revealed a number of barriers to recruitment and randomisation. Out of 1,432 people screened, only eight were recruited to the study and randomised. The main barriers were staff and patients' preference for a particular supported accommodation service or for a particular service type, the perception that supported housing and floating outreach did not provide the same level of support, and staff feeling that randomisation compromised their professional judgement. In addition, the QuEST project required a large amount of resource, costing a total of £1.6 million pounds and taking five years to complete, primarily due to the primary research methods utilised.

There is a need to identify alternative methods for researching mental health supported accommodation. Therefore, the aim of this study was to explore the feasibility of using the CIFT CRIS database as a means to evaluate mental health supported accommodation services. I chose to focus on supported housing services because there are more supported housing services in Camden and Islington than there are residential care or floating outreach services, and to make the study feasible in the time available.

The specific objectives were to:

I. Explore the CIFT CRIS database for structured fields regarding accommodation status and investigate their potential use in identifying a sample of people who have lived in a supported housing service
II. Develop a search of free text records to identify a sample of people who have lived in a supported housing service
III. Test the validity of both the structured fields and free text search approaches in identifying a sample of people who have lived in a supported housing service

IV. Describe the sample in terms of their sociodemographic and clinical characteristics, and compare this to a national survey carried out as part of the QuEST project in 2014 (4)

4.2 Methods

4.2.1 Setting

This study used the CIFT CRIS database, which as described in Chapter 3, contains the de-identified EHRs of CIFT, the NHS Trust which provides the residents of Camden and Islington with secondary mental healthcare, including a range of inpatient and community services. Camden and Islington are inner city London boroughs situated towards the north of London. CIFT transitioned from paper to an electronic record-based system called RiO in 2008, and the CIFT CRIS database contains the records recorded since the implementation of the electronic records system.

The sociodemographic characteristics and mental health morbidity of both boroughs were described in Chapter 2 (Section 2.9). Also reported in Chapter 2 are details of the Camden and Islington local mental health rehabilitation pathway, including the provision of supported housing and further details about the mental health rehabilitation services provided by the Trust (Section 2.10). To briefly recap, as of 2017 there were 34 supported housing services providing 390 places in Camden and Islington. These services are provided by several different voluntary organisations and housing associations. Although services are often decommissioned and new services commissioned, the level of provision has remained relatively constant.

4.2.2 Search approach

The potential utility of two approaches were explored to obtain a sample of de-identified individuals who have used a supported housing service: i) using structured fields relevant to the individual's accommodation; and ii) developing a free text search of clinical notes. I also compared these two approaches to see if they identified the same individuals. Finally, I investigated whether it was possible to describe the sample in terms of their sociodemographic and clinical characteristics using structured fields provided in the CRIS database. Records between 1 January 2008 and 31 December 2017 were examined.

4.2.3 Structured fields search

Two structured fields relevant to an individual's accommodation were identified in the sections of the EHR where the clinician is expected to record and update Care Programme Approach (CPA) meeting outcomes (named in the database as 'cpa_accommodation_desc') and demographic details ('accommodation_status_desc'). Both these fields had values (pre-determined options for the clinician to enter) representative of mental health supported accommodation services. Values representative of all types of supported accommodation were included, not just supported housing services, because of the heterogeneity in the terminology used to describe supported housing, and the likelihood that different terms may be used by different clinicians to record different types of service, or the same term may be used differently by different clinicians. The included values were: 'Supported accommodation', 'Supported lodgings', 'Supported group home', 'Mental Health Registered Care Home', and 'Other accommodation with mental healthcare and support'. A full list of all the response options (values) available to clinicians for both structured fields is available in the Appendices (Appendix A). All entries using either of these fields are stored in CRIS, so it is possible to identify previous as well as current accommodation status.

4.2.4 Free text search

Figure 2 is a flow diagram illustrating the iterative process for developing the free text search of clinical notes. First, a list of all supported housing services in the area was generated, based on a previous audit of supported accommodation services in Camden and Islington I carried out in 2016 as part of the QuEST project (134). The final list comprised 35 services. A series of single service searches were developed for each service based on the name of the service. As there were four pairs of services with similar names, 31 single service searches were developed. These single service searches were then combined into an 'all service search'. The search started at a simplistic level, by using the most distinctive word from the name of the service so that all clinical notes with a mention of this word were returned. The data extraction from each search included the unique identification number randomly assigned by CRIS to each individual on the database, the text of clinical notes that contained the search term, and the date the note was recorded. The data were ordered by identification number and note date, to facilitate manual review, which is described later in this Section.

Refinement of the search process was iterative and based on the goal of increasing the number of notes each data extraction contained and the number of individuals they pertained to, whilst keeping the positive predictive value as high as possible. The positive predictive value was defined as the ratio of true positives (i.e. the number of individuals included in the search where there was sufficient evidence to suggest they either currently live or previously lived in a supported housing service) to all the individuals included in the data extraction (true positives plus false positives, i.e. the number of individuals included in the search where there was insufficient evidence to suggest they either currently live or previously lived in a supported housing service), and can be expressed as a percentage. The positive predictive value was estimated by carrying out a manual notes review to identify true and false positives.

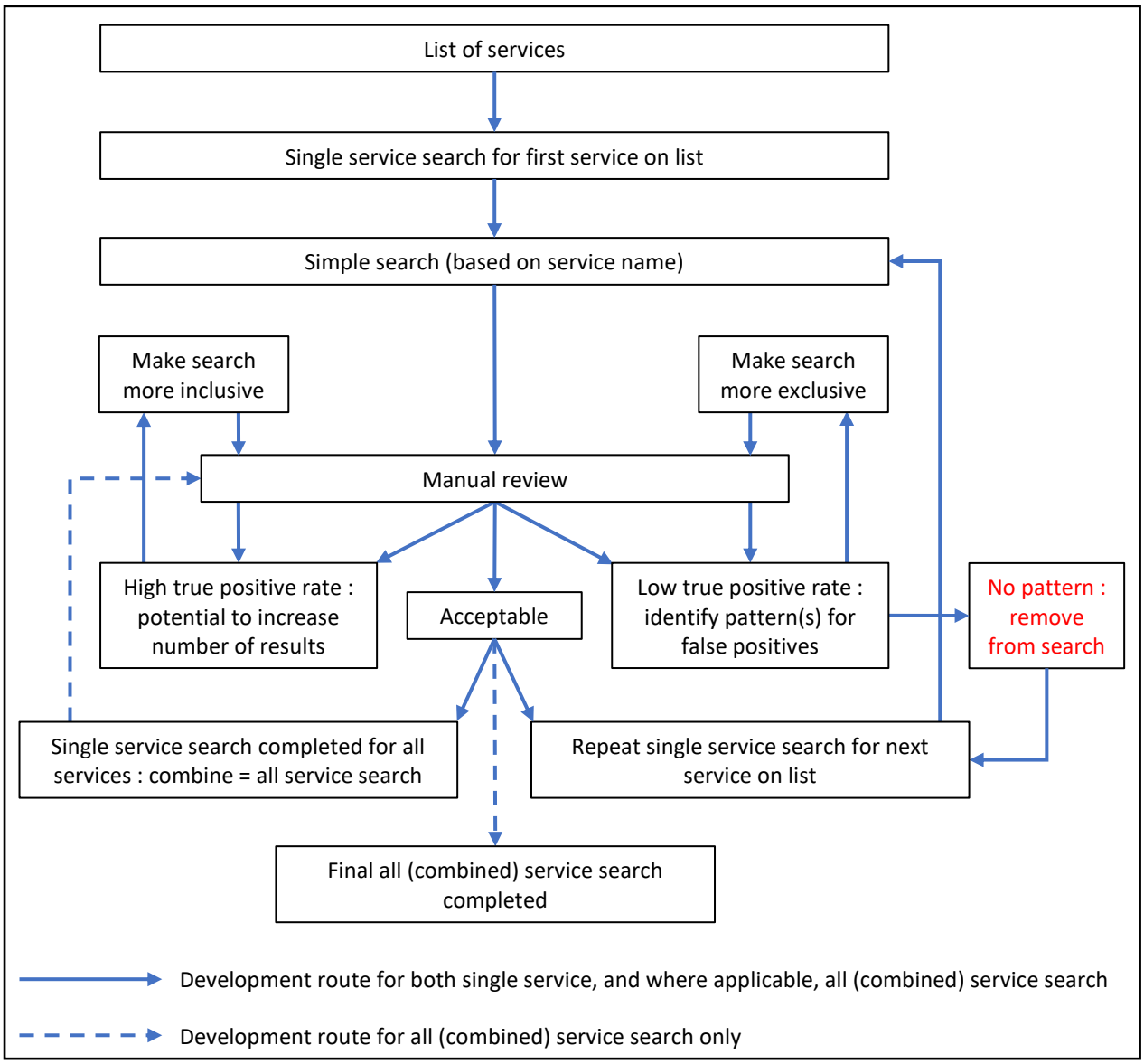
For each data extraction (i.e. each iteration of the single service searches and all services searches), clinical notes pertaining to the first 10% of individuals listed were manually reviewed. Because individuals were listed in order of their random identification numbers, the sample of clinical notes reviewed were random. If it was clear from the individual's note(s) that they had previously used or were currently using a supported housing service, the individual (not individual notes) was designated as a true positive. A typical example would be a note documenting a clinician's visit to a service to see the individual. An individual was assigned as false positive if the notes pertaining to that individual were not actually referring to a supported housing service, or if a service was being referred to but it was unclear if the individual had ever actually used the service (e.g. a referral to a service was being discussed but it was unclear if the referral was ever submitted and accepted).

Reasons for false positives were noted and if any pattern(s) emerged, they were used to improve the search term. For example, a search for a fictitious service named 'Forward View' may initially be based on the search term FORWARD, which would return clinical notes including mentions of Forward View but also any other mention of the word 'forward'. If the extraction for this search included a high number of false positive individuals, and a number of the clinical notes assigned to these false positives contained the term 'forward thinking' or 'forward planning', then the search could be improved by changing the search term to FORWARD V or adding terms so that the notes could not contain the terms FORWARD THINKING or FORWARD PLANNING.

Patterns to false positives were not limited to text included in the clinical note but could also include patterns such as the number of notes returned per individual. For example, if a false positive was more likely than a true positive to only have a single note returned by the search, then the search could be refined to only include individuals which have more than one note pertaining to them.

This process was repeated until there was no longer a consistent pattern to the false positives and the positive predictive value was acceptable, i.e. over 25%. If the positive predictive value was high, i.e. over 75%, the search was revised to see if a higher number of returns could be achieved whilst maintaining a high positive predictive value. The process was therefore a matter of attempting to achieve the optimal balance between specificity (not over inclusive and lacking in accuracy) and sensitivity (not over exclusive and lacking in sample size). If a pattern to the false positives did not appear and the positive predictive value was not acceptable, development of this single service search ceased and it was not included in the all service search. Finally, the all service search was refined using the same approach applied to each single service search, aiming for the optimal balance between specificity and sensitivity. True and false negatives (i.e. the number of individuals not included in the search where there was sufficient evidence to suggest they did not either currently live or previously lived in a supported housing service, or the number of individuals not included in the search where there was sufficient evidence to suggest they did either currently live or previously lived in a supported housing service, respectively) were not estimated.

Figure 2: Flow diagram of free text search development



4.2.5 Ethics

This study was granted the necessary ethical approvals. See Section 3.11 for details.

4.3 Results

4.3.1 Structured fields search

Values representative of mental health supported accommodation in the CPA and demographics accommodation status structured fields were recorded for a total of 1,635 and 882 individuals, respectively. A large majority of the total 126,769 individuals in the database did not have any record for either of these structured fields. There was a total of 59,408

records using the CPA accommodation field and 65,065 records using the demographics accommodation field; in both instances multiple records can pertain to the same individual as historical records are stored and not overwritten by new records in the same field. There was a total of 50 possible values (i.e. response options) in each structured field, with some slight differences between the two fields. These 50 values were grouped into seven categories. Appendix A provides the full list of values for each structured field and how they were categorised, and Appendix B and Appendix C show how many individuals there were in each group for the CPA accommodation field and the demographics accommodation field, respectively.

4.3.2 Free text search of clinical notes

Table 3 presents the development of the free text search of clinical notes, the number of clinical notes and individuals included, and the true positive rate, for the first search, the first iteration of each search, and the final version of each search. Of the 31 single service searches, 28 attained acceptable positive predictive values, the remaining three were removed and not included in the all service search. Half (14) of the single service searches had an acceptable positive predictive value after the first search, the most iterations required to develop an acceptable single service search was nine (single service search 13).

The final combined all service search returned a total of 21,103 clinical notes pertaining to 1,105 individuals. Notes for 116 individuals (10.5%) were reviewed with a positive predictive value of 77/116 (66.4%). Extrapolating this rate to the remainder of the results produced an estimated positive predictive value of 733/1,105 (66.4%).

In the initial all services search, one of the key differences between true positive and false positives was the number of clinical notes for each individual: false positives were much more likely to have only a single clinical note. Therefore, a condition was added to the search whereby individuals were removed if they only had a single note matching the search term. This largely explains the reduction in the number of individuals relative to the number of clinical notes between the first search (1,822 individuals and 23,501 notes) and the first iteration of the all service search (1,076 individuals and 22,755 notes, a reduction of 746 individuals and also a reduction of 746 notes). This was the only search condition applied that

accounted for frequency patterns, and the only pattern/condition not based on the text content of notes. A full log of the search term development, including the identification of false positive patterns and the SQL search code, is archived on the CIFT CRIS database and is available to CRIS-approved researchers.

Table 3: Free text search development: The returned results for the first search, the first iteration, and the final search, for each single service search and the all service search

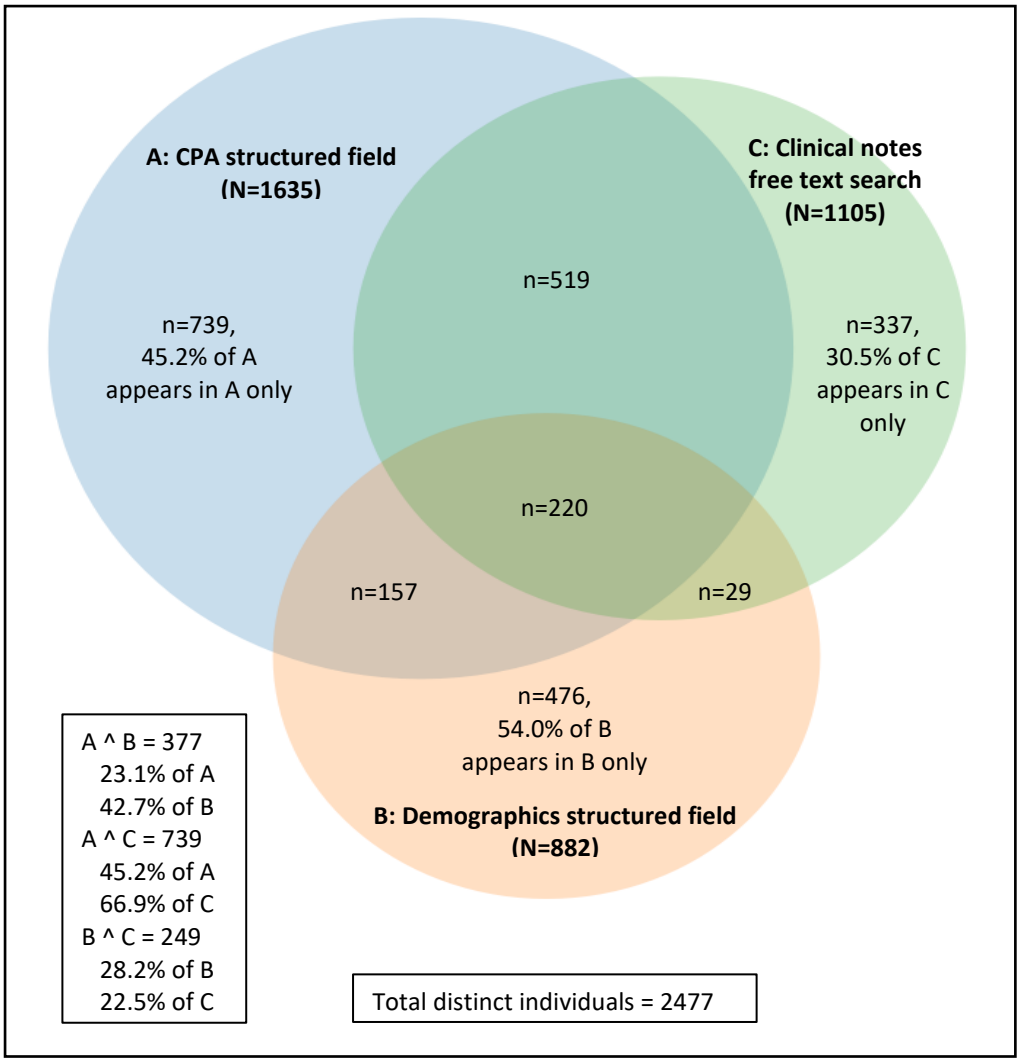
Search		First search			First iteration			Final search			
		Clinical notes	Individuals	True pos. rate	Clinical notes	Individuals	True pos. rate	Search number	Clinical notes	Individuals	True pos. rate
Single serv.	1	1,582	266	58%	179	73	82%	1st	1,582	266	58%
	2	1,856	439	25%	1,677	340	33%	5th	233	88	67%
	3	410	107	36%	42	27	…	1st	410	107	36%
	4	824	108	50%	13	8	…	1st	824	108	50%
	5	293	74	36%	31	17	…	1st	293	74	36%
	6	749	245	0%	711	217	7%	4th	256	47	86%
	7	7,256	1774	0%	1,851	938	0%	5th	410	117	100%
	8	1,979	842	0%	595	262	11%	6th	268	108	100%
	9	1,039	284	14%	982	241	7%	4th	96	36	100%
	10	255	57	86%	1,003	173	86%	2nd	1,003	173	86%
	11	119	40	39%	1,181	100	67%	2nd	1,181	100	67%
	12	155	45	82%	266	73	86%	2nd	266	73	86%
	13	1,472	637	0%	965	464	0%	10th	160	84	63%
	14	423	91	33%	161	52	40%	3rd	54	33	42%
	15	2,923	191	64%	441	86	…	1st	2,923	191	64%
	16	1,573	212	36%	…	…	…	1st	1,573	212	36%
	17	7,110	305	50%	6,560	288	…	3rd	4,487	244	83%
	18	2,224	612	25%	1,018	250	18%	3rd	1,005	240	…
	19	1,758	897	…	1,643	823	17%	7th	447	198	44%
	20	431	73	44%	28,114	…	…	1st	431	73	44%
	21	752	344	0%	81	17	15%	REMOVED			
	22	217	74	71%	217	75	…	2nd	217	75	…
	23	798	124	33%	33	20	…	1st	798	124	33%
	24	1,107	315	0%	1,078	304	0%	REMOVED			
	25	56	39	…	8,151	1587	…	7th	1,046	345	29%
	26	2,111	175	67%	…	…	…	1st	2,111	175	67%
	27	319	101	67%	267	117	33%	1st	319	101	67%
	28	28,592	…	…	…	…	…	REMOVED			
	29	1,178	704	…	39	…	…	6th	22	13	100%
	30	150	32	38%	…	…	…	1st	150	32	38%
	31	222	61	60%	…	…	…	1st	222	61	60%
All serv.	1	23,501	1822	…	22,755	1076	59%	3rd	21,103	1,105	66%

Pos. = Positive. Serv. = Service.

4.3.3 Comparing the structured fields and free text search approach

Figure 3 shows how many individuals appeared in each of the three searches (the free text search of clinical notes and the two structured field searches), and the overlap between them. Of the 1,105 identified in the free text search, 739 (67%) were also identified in the CPA structured field, but only 249 (23%) also appeared in the demographics structured field. Of the 1,105 identified in the free text search, 768 (70%) were also identified by one of the two structured field searches. The structured fields combined identified 2,140 unique individuals. All sources combined identified a sample of 2,477 unique individuals in total. Overall, 925 (37%) appeared in at least two of the searches and 220 (9%) appeared in all three. A total 337 individuals appeared only in the free text search.

Figure 3: A Venn diagram showing the overlap of individuals between the free text search and structured fields



4.3.4 Sociodemographic variables and diagnosis

Table 4 shows the sociodemographic variables and diagnosis of the individuals identified from each search approach, extracted from structured fields within the CIFT CRIS database, compared to participants of the national survey of supported accommodation in England carried out as part of the QuEST study in 2014 (4). Over a half to two-thirds in each sample were male (59% to 67%), the mean age was between 41.7 and 47.1 years, most were single (66% to 84%), and the most frequently recorded diagnosis was schizophrenia or another form of psychosis (39% to 64%). The samples identified from CRIS differed most from the QuEST national sample in ethnicity; in the CRIS sample 54% to 60% were recorded as White compared to 81% in the QuEST survey. This reflects the greater proportion of people from Black and ethnic minority groups in Camden and Islington compared to the rest of England (see Section 2.9).

Table 4: Sociodemographic variables and diagnosis of the individuals identified by the different approaches, compared to a 2014 national survey

		CRIS CPA structured field (N=1635)	CRIS Demo-graphics structured field (N=882)	CRIS Clinical notes free text search (N=1105)	National survey: Supported housing only (N=251)*
Sex - n (%)	**Male**	1051 (64%)	521 (59%)	738 (67%)	167 (67%)
	Unknown/Missing	2 (0.1%)	4 (0.5%)	1 (0.1%)	0 (0%)
Age†	**Mean (SD)**	47.1 (16.3)	41.7 (15.8)	43.7 (14.4)	40.6 (12.3)
	Unknown/Missing	0 (0%)	2 (0.2%)	0 (0%)	0 (0%)
Ethnicity - n (%)	**Asian**	88 (5%)	43 (5%)	63 (6%)	-
	Black	419 (26%)	175 (20%)	324 (29%)	-
	Mixed	70 (4%)	35 (4%)	65 (6%)	-
	White	988 (60%)	492 (56%)	593 (54%)	185 (74%)
	Unknown/Missing	70 (4%)	137 (16%)	60 (5%)	-
Marital status‡ - n (%)	**Divorced/Separated/ Widowed**	211 (13%)	91 (10%)	108 (10%)	-
	Married/Civil partner	86 (5%)	48 (5%)	44 (4%)	-
	Single	1311 (80%)	619 (70%)	927 (84%)	195 (78%)
	Unknown/Missing	27 (2%)	124 (14%)	26 (2%)	-
Diagnosis§ - n (%)	**Schizophrenia or schizoaffective disorder**	921 (56%)	344 (39%)	703 (64%)	171 (69%)
	Bipolar, depression, or anxiety disorder	209 (13%)	113 (13%)	120 (11%)	49 (27%)
	Personality disorder	139 (9%)	77 (9%)	71 (6%)	-
	Other	229 (14%)	133 (15%)	113 (10%)	66 (11%)
	Unknown/Missing	137 (8%)	215 (24%)	98 (9%)	3 (1%)

*National survey of supported accommodation services in England 2014 (4).
†Calculated from the median date within the search parameters (01-January-2008 to 31-December-2017, median date: 31-December-2012) and date of birth.
‡The most frequently recorded marital status for individuals.
§The most recently recorded diagnosis.

4.4 Discussion

Two structured fields for accommodation status were identified in the CIFT CRIS database, located in the demographics and CPA section. In these structured fields, there were 882 and 1,635 individuals recorded as living or having lived in a mental health supported accommodation service, respectively. I also developed a free text search of clinical notes to identify individuals who were currently or had previously lived in supported housing. This search identified a total of 1,105 individuals, with an estimated positive predictive value of 66.4%. Therefore, it is estimated that around 733 of these 1,105 (66.4%) individuals were currently or had previously lived in supported housing.

The estimated positive predictive value indicates that around a third of individuals from the free text search were false positives and had not lived in supported housing. Therefore, any study of supported housing that used this approach would require the researcher to manually review the free text notes of all 1,105 individuals to ascertain the true and false positives. This is relatively resource demanding. Another way to validate the sample would be by comparing the overlap of individuals appearing in the structured field searches and free text search, as was done in this study. Fewer than two-in-five of the total unique individuals identified appeared in more than one of the three searches (925 out of 2,477, 37.3%), fewer than one-in-five individuals appeared in all three searches (406 out of 2,477, 16.4%), and around one-in-three individuals appeared in the free text search and at least one of the structured field searches (768 out of 2,477, 31.0%). Of note is that the proportion of individuals identified in the free text search who only appeared in the free text search (30.5%) was similar to the estimated proportion of the free text search that were false positives (33.6%). It is unknown to what degree individuals from these two proportions overlap, but the similarity of the proportions suggest that the group of individuals who appear in both the free text search and at least one of the structured field searches may be an effective approach to validation. A manual review similar to the review performed on a 10% sample of the free text search results, on the proportion which only appeared in the free text search and on the proportion which appeared in the free text search and one of the two structured fields, would be a way of testing this assumption.

Bearing these considerations in mind, the sample size of 768 compares well with the QuEST study which had a sample size of 619 (5). These 619 individuals took 12 months to recruit and required a team of four full-time researchers, a project manager, and a chief investigator. The same team was required to carry out the 30-month prospective observational study. However, this was a study which used primary research methods and therefore specifically collected data to address their specific research question, investigating the rate of successful move-on from supported accommodation. Also, there are substantial limitations in the methods used to obtain the sample in the current study.

4.4.1 Limitations

There was a high rate of missing data in both structured fields which recorded accommodation status. Although most NHS Trusts have a health records policy that emphasises the importance of staff ensuring that certain records are kept up to date to facilitate best practice and patient safety, poor completion rates of structured fields is a well-recognised issue (9, 106). It would stand to reason those individuals with records without a CPA would have missing records in the CPA accommodation field as the field is effectively not applicable to these individuals, but this would need to be verified and is unlikely to explain all the missing values. Also, this cannot explain the high missing rates on the demographics accommodation field as this field is applicable to all individuals with records. If there are reasons staff are more likely to complete either field for some individuals rather than others, then a sample based on either field would be affected by selection bias. A possible reason for incomplete healthcare records may be that the individual is receiving poorer healthcare, or at least it may be that missing data is correlated with poorer healthcare.

There are also issues with the free text search developed in this study, in addition to the evidence that a third are likely to be false positives. First, there may be selection bias in that individuals with greater clinical contact are likely to have more records and are therefore more likely to be returned by the search. This greater level of contact with mental health services and a greater number of records is likely to reflect people with more severe mental health problems. In other words, the false negatives may have less severe mental health problems than the true positives. Further compounding this issue is that the number of false negatives were not estimated. This could perhaps be estimated in future studies by reviewing the records of a sample of individuals who did not appear in the search to determine whether they are a true negative or a false negative. However, most people living in supported accommodation have complex and longer term mental health problems (4) and are therefore likely to have an extensive history of contact with NHS mental health services. Second, an unforeseen issue in the development of the free text search was that the names of supported housing services often included part of the address. As explained in Chapter 3 (Section 3.5), home address is classified as a patient identifier and is masked by CRIS in the free text records. Therefore, where an individual lived in a supported housing service and the name of that service was included in the address, and that address was recorded as the individual's home

address, they would not appear in the free text search. This may have substantially reduced the number of true positives returned. The third and final issue, which is perhaps the foundation for all the other issues including those related to the structured fields, is that the supported housing services in Camden and Islington were not provided by CIFT and the use of these services are not systematically recorded using the CIFT EHR system. Most people living in these supported housing services will have a level of mental health need that means they are also in contact with local NHS mental health services and are therefore on the CIFT CRIS database. However, because the use of these services is not systematically recorded on this database, it is challenging to reliably ascertain a group of supporting housing service users using this approach.

4.5 Summary

Mental health supported accommodation is a key component in the contemporary mental health rehabilitation pathway. It is however a challenging area for primary research and other methods of evaluation are needed. The study reported in this Chapter suggests that it may be feasible to identify a sample of individuals who have used a mental health supported housing service using the CIFT CRIS database, but there are a number of substantial limitations and reasons to doubt the reliability of the approach. Chief among them is that supported housing services in Camden and Islington are not provided by CIFT and therefore the use of these services is not systematically recorded in CIFT EHRs. Prior to any studies investigating mental health supported accommodation using CRIS and the search approaches developed in this study, further work needs to be done to address the limitations highlighted in this Chapter.

5 Chapter 5: Systematic review and narrative synthesis on the effectiveness of mental health rehabilitation services

A modified version of this chapter was published as a peer reviewed article in Frontiers in Psychiatry:

Dalton-Locke C, Marston L, McPherson P and Killaspy H (2021). The Effectiveness of Mental Health Rehabilitation Services: A Systematic Review and Narrative Synthesis. Frontiers in Psychiatry 11:607933. doi: 10.3389/fpsyt.2020.607933

5.1 Introduction

In Chapter 1, I explained how the aim and objectives of my PhD were revised following the findings in my MSc project where I explored the feasibility of using the CIFT CRIS database to research mental health supported housing services (Chapter 4). I concluded from my MSc project that although it was possible to identify a reasonably sized sample of supported housing service users using CIFT CRIS, there were substantial limitations to using it for this purpose, which were mainly due to the use of these services not being systematically recorded on CIFT CRIS. I therefore considered whether to use CIFT CRIS to investigate another component within the mental health rehabilitation pathway.

Unlike supported accommodation services, inpatient mental health rehabilitation units in Camden and Islington are provided by CIFT and the use of these services is systematically recorded on CIFT CRIS. Through discussion with my supervisors, we concluded that I should conduct a study using the CIFT CRIS database comparing inpatient service use before and after admission to an inpatient mental health rehabilitation unit. From our knowledge of the literature in this field, we believed such a study would add a meaningful contribution to the field. However, to confirm this, I decided to first conduct a systematic review of the published literature reporting on the effectiveness of mental health rehabilitation services. In this Chapter I report the methods, results, and discussion of the findings from this systematic review.

5.2 Background

To date, there has not been a systematic review which investigates the effectiveness of all components in the mental health rehabilitation pathway. There has however been a systematic review which investigated the effectiveness of mental health supported

accommodation (135). McPherson and colleagues looked at a range of mental health and psychosocial outcomes in their review and categorised the included studies into three types: studies which evaluated deinstitutionalisation programmes (i.e. studies which examined the outcomes for people discharged from long term hospital admission to specialist community services; please see Chapter 2 for a description of the deinstitutionalisation of mental healthcare); studies evaluating services for homeless people with severe and complex mental health problems; and studies of services for people with complex longer term mental health problems who were not necessarily homeless (i.e. mental health supported accommodation, as described in Chapter 2 Section 2.8.3).

The most robust evidence was for services designed for the population of people with mental health problems who were homeless, most of which evaluated the "Housing First" approach (135). The review found these services helped stabilise housing and, over time, reduce clinical service use. Unlike other supported accommodation systems, where people progress from higher to lower supported settings after demonstrating adequate ability in independent living skills (the 'train and place' approach), Housing First provides people with a permanent tenancy, and then offer them intensive, flexible support from a visiting community team (the 'place and train' approach). The review also found that services for deinstitutionalised populations reduced inpatient service use over time but that the evidence base for mental health supported accommodation was lacking.

The aim of the systematic review reported in this Chapter was to evaluate the international quantitative evidence for the effectiveness of mental health rehabilitation services, in terms of their effect on inpatient service use and the rate of move-on to settings with less support. The types of rehabilitation service included were hospital-based inpatient rehabilitation units, community-based rehabilitation units, community rehabilitation teams, and supported accommodation services. The objectives of the were to:

I. Develop a comprehensive search strategy based on the PICOS (Population, Intervention, Comparison, Outcome, and Study design) framework (136) to identify peer reviewed publications reporting quantitative studies on populations who had used a mental health rehabilitation service, and that reported on 'move-on'

(successful discharge) from these services and/or inpatient service use before, and after the period of rehabilitation

II. Register the search strategy on The International Prospective Register of Systematic Reviews (PROSPERO)

III. Execute the search, review the search returns, and select which articles to include and exclude using pre-specified eligibility criteria

IV. Assess the quality of the included studies using a standardised and validated quality assessment tool

V. Carry out meta-analyses if the extracted data from the included studies allowed such an analysis (i.e. the included studies were sufficiently homogenous)

VI. Carry out a narrative synthesis of the included studies if meta-analyses were not feasible

5.3 Methods

5.3.1 Inclusion criteria

This review included quantitative studies in the English language that reported on at least one of two outcomes: (1) inpatient service use, and (2) move-on from the mental health rehabilitation service to another setting. These two outcomes were selected as they are objective measures of the effectiveness of rehabilitation services and have been used in previous studies of these services (5, 65, 70). The inclusion and exclusion criteria were designed using the PICOS framework (136).

5.3.2 Population

The population of interest was adults with a diagnosis of a severe mental health problem, including schizophrenia, schizoaffective disorder, and bipolar disorder. These diagnostic groups were selected as the vast majority of users of mental health rehabilitation services have previously been diagnosed with one of these disorders (86). Studies were excluded if they focused on participants with first episode psychosis (as they were unlikely to be at the stage in their illness where they had developed long term problems requiring rehabilitation), organic psychosis, substance induced psychosis, dementia, personality disorder, depression, or anxiety. Studies were included where more than 49% of participants had one of the included diagnoses, and where the mean age of the sample was between 18 and 65.

5.3.3 Intervention

The term 'rehabilitation' has been used to describe a wide range of services and interventions in mental health. For the purpose of this review, a mental health rehabilitation service was considered to be a service which provided longer term care (at least 6 months) to individuals with longer term and complex mental health problems, was staffed by a multidisciplinary team (three or more disciplines) and used a biopsychosocial and person-centred approach that aimed to enable the person to gain skills for independent living and community integration. This included hospital- and community-based inpatient rehabilitation units, community rehabilitation teams, and supported accommodation services. These types of service are recommended by NICE as essential components in the local mental health rehabilitation pathway (86), and are described in detail in Chapter 2 (Section 2.8). Studies which solely evaluated community services delivering assertive community treatment or intensive case management were excluded on the basis that these approaches tend to focus on people living in independent rather than staffed supported accommodation and these models of care have already been extensively evaluated (137). However, studies which investigated a specific intervention, for example, cognitive behavioural therapy (CBT), were included if the treatment consisted as part of the treatment being delivered in one of the above types of rehabilitation service.

5.3.4 Comparison

There were no inclusion or exclusion criteria relating to the type of comparison carried out in the study.

5.3.5 Outcomes

Studies were only included if they reported on inpatient service use and/or move-on to other settings. Move-on included discharge from the rehabilitation unit to the community or from a supported accommodation service to another type of supported accommodation or independent accommodation. Where available, the setting (type of accommodation) the individual was discharged to or moved on to was extracted.

5.3.6 Study design

All quantitative studies were eligible, including prospective and retrospective observational studies, quasi-experimental studies and randomised controlled trials (RCTs) published since 1st January 2000. This date was selected in an attempt to keep the review focussed on studies investigating contemporary mental health rehabilitation services. Qualitative studies and case studies were excluded.

5.3.7 Search strategy

Six online databases were searched: CINAHL Plus, Embase, MEDLINE, PsycINFO, The Cochrane Library and Web of Science, using subject terms and free text searches relevant to the review population (e.g., 'severe mental illness', 'psychosis', 'schizophrenia'), intervention (e.g., 'rehabilitation' and 'supported accommodation'), and outcomes (e.g., 'admission', 're-admission', 'move-on', 'discharge'). The searches were carried out on 14 June 2019 and the results exported to EndNote (version X9) (138) for de-deduplication. The searches were updated on 9th July 2020. The titles and abstracts of all studies were screened in parallel. The full texts of studies included after this stage were then screened for final inclusion. 10% of articles at both the title/abstract and full text stages were independently screened by a second reviewer (another PhD student in the field of mental health rehabilitation). Discrepancies were discussed, and any that could not be resolved were adjudicated by my primary supervisor. Forward and backward citation searches were carried out on all studies included after the full text screening. The full search strategy is available in the Appendices (Appendix D).

5.3.8 Data extraction

A bespoke data extraction form was used to collate data from all the included studies. Meta data were extracted in addition to other study details, including the year the study was published, the country where the study was conducted, the study design, and the sample selection method. The study setting was also extracted and categorised as: inpatient rehabilitation unit, community rehabilitation unit, community rehabilitation team, or supported accommodation service. Study details relevant to the review outcomes were also extracted, including the number of participants at baseline (in each group if the study was comparing between groups), the follow-up period, the number of participants who

completed follow-up, any reported detail on psychiatric hospitalisations (e.g. mean number of inpatient days), and move-on to other settings. Where reported or where it could be derived, the proportion of participants with a specific outcome (e.g., the proportion of participants who moved to a more independent setting or who had a hospitalisation during the follow-up period) was also extracted.

5.3.9 Quality assessment

Kmet's standardised quality assessment criteria were used to assess all the included studies (139). This tool was selected because it can be used with quantitative studies of various study designs. It includes 14 criteria for RCTs and 11 criteria for non-RCTs, with each criterion scored as being met fully (=2), partially (=1) or not at all (=0). The scores for each item are summed, divided by the total possible score and multiplied by 100 to produce a linear score out of 100. Initially, a randomly selected 10% of included studies were independently assessed by me and another PhD student. We then compared and discussed our ratings before independently assessing a second set of studies, again a randomly selected 10%. The agreement rate on the second set was 91% (89/98 ratings). For four of the seven studies double rated, there was no difference in the total score. For the remaining three studies, two studies had a difference of 4.5 and one study had a difference of 3.8. Given the agreement rate and the minor effect the disagreements had on the total quality score, I assessed the remaining 80% of included studies without a second rater.

5.3.10 Data synthesis

Discharge from an inpatient rehabilitation service to the community or, for people in supported accommodation services, moving from higher to lower levels of supported accommodation or to an independent tenancy, are markers of successful rehabilitation. However, remaining at the same level of supported accommodation is an indicator of stability and can also be regarded as a positive outcome, albeit a less positive one than a move to a lower level of supported accommodation. Meta-analyses were therefore planned on the following three outcomes:

1. Positive move-on (number of people who moved to a more independent setting during the follow-up period as a proportion of the total number followed-up)

2. Maintained community placement (number of people during the follow-up period who either stayed at the same community placement, moved to a setting with a similar level of support, or moved to a more independent setting, as a proportion of the total number followed-up)
3. Hospitalisation (number of people who were hospitalised during follow-up as a proportion of the total number followed-up)

Most of the included studies were observational in design and reported the review outcomes as frequencies and/or proportions. These proportions were pooled using the "metaprop_one" command (140) with a random-effect model, in Stata 14 (141). However, heterogeneity, calculated using the I^2-test (142), was high in each meta-analysis (i.e. > 50%) (143). The included studies were examined by service type and by length of follow-up to see whether doing so would sufficiently reduce the level of heterogeneity, but high levels of heterogeneity persisted. There are several other possible explanations for the high level of heterogeneity, including variation between the studies in study design, quality score, and the different healthcare systems operating in the countries where included studies were conducted. It was therefore decided that a narrative synthesis would be conducted and this would be reported as the primary form of data synthesis. The results of the meta-analyses are reported in the Appendices (Appendix E).

The narrative synthesis was carried out following the guidelines by Popay et al. (144). There were three stages to this. The first stage was a preliminary synthesis of the included studies focussing on the type of service studied and the remit of the service. The second stage explored consistencies in the results between studies, with consideration of the study design, country, sample size, follow-up period and quality assessment score (greater emphasis was placed on studies with larger samples and of higher quality). In the third and final stage, the robustness of the synthesis was reviewed by checking the main findings and the strength of these findings.

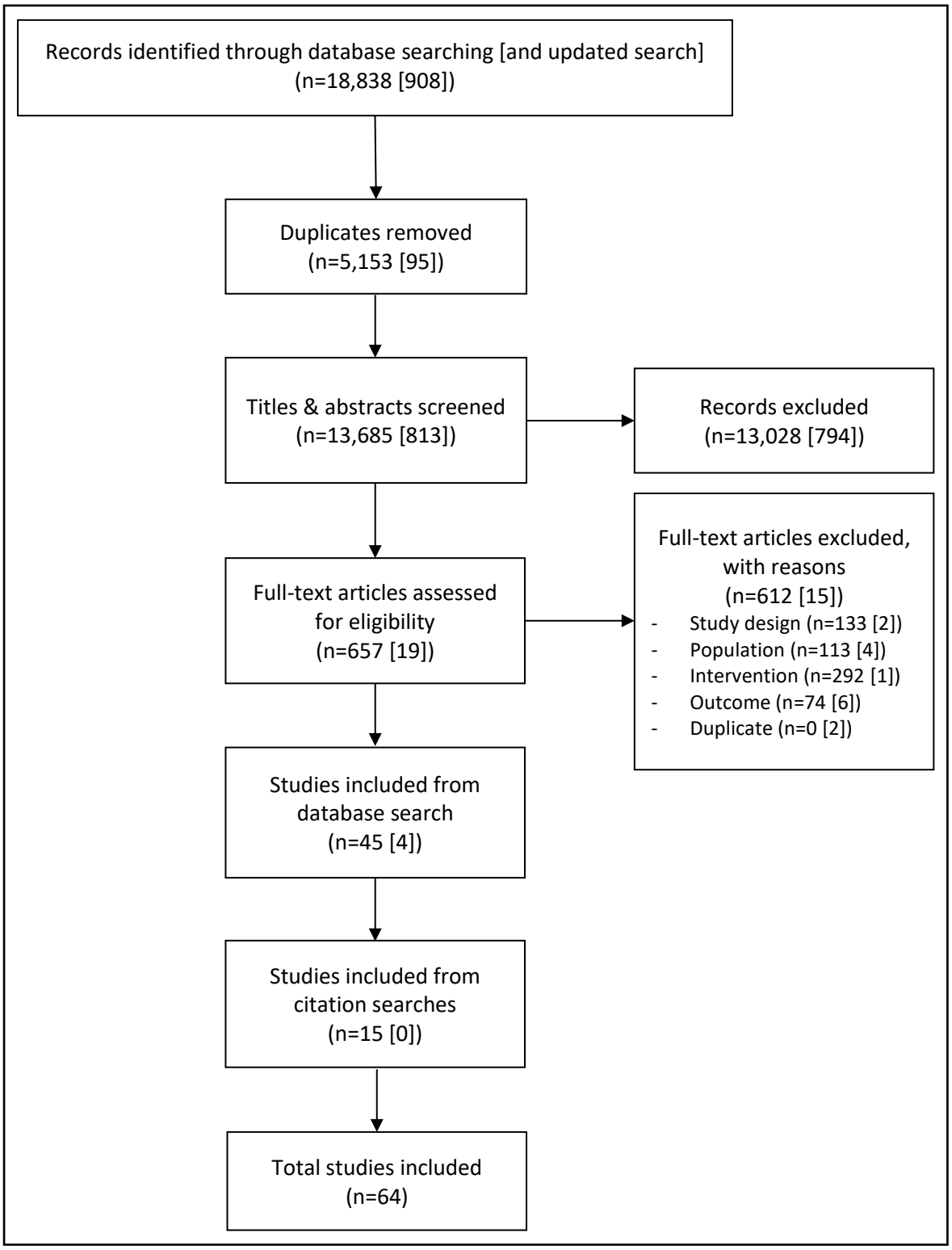
5.3.11 Review registration

This review was prospectively registered on PROSPERO (reference number: CRD42019133579).

5.4 Results

The initial database searches returned a total of 18,838 studies, which was reduced to 13,685 after de-duplication. Following screening of titles and abstracts, 13,028 studies were excluded. The full texts of the remaining 657 studies were screened, of which a further 612 were excluded. Almost half of these studies (292) were excluded because the service or intervention which was being investigated was not adequately described, or because it was not a rehabilitation service. The number of studies included from the initial database searches was therefore 45. The updated database search in July 2020 identified a further 908 studies, and out of these studies four were included producing a sub-total of 49 included studies. The reference lists and citations of these 49 studies were screened, adding a further 15 studies and producing a final total of 64 included studies. Figure 4 shows the number of studies at each stage.

Figure 4: PRISMA flow diagram



The studies were conducted in 14 different countries: 24 in Europe (11 in UK, four in Italy, three in Netherlands, three in Denmark, and one each in Ireland, Spain and Sweden), 19 in the United States (US), seven in Australia, five in Japan, four in Canada, three in Israel and one each in Singapore and Turkey. Most of the studies were observational in design (24 prospective and 25 retrospective), the remainder were RCTs (15). The mean quality score was 78.4 (SD 16.1). The lowest score was 40.9 and 11 studies scored the highest possible score, 100. Regarding settings, 20 studies evaluated inpatient rehabilitation services (11 hospital based and nine community based), eight studies investigated community rehabilitation teams, 35 studies investigated supported accommodation services (one of which also investigated inpatient rehabilitation units and community rehabilitation units), and one study investigated outcomes for people who had used a rehabilitation service without specifying the setting.

The included studies could be broadly categorised as evaluating services with one of three remits. The first category, and largest in terms of the number of studies included with more than half the total (33), comprised studies investigating contemporary mental health rehabilitation services. These were services designed for people with complex and longer term mental health problems with the specific aim of supporting them to live in more independent settings. The second category were studies investigating services for people who were homeless and had a severe mental health problem. There were 13 of these studies, all of which were conducted in the US or Canada. The third category accounted for 18 of the included studies and focused on deinstitutionalisation programmes and services designed to provide a less institutional setting for patients discharged from long stay hospitals. These studies were mainly published prior to 2010. Table 5 shows details of all the included studies, including the category as just described, country, setting, study design, review outcomes and quality score.

Table 5: Characteristics and review outcomes of the included studies

First author, Year published	Country	Primary setting	Main aim	Design	Sample selection	N (by group)	Follow-up (FU) in months	Ratio (%) moved to higher supportive setting	Ratio (%) moved to lower supportive setting	Inpatient service use	Quality rating
Contemporary rehabilitation studies											
Anderson, 2001 (145)	US	Supported accom.	To characterise residents (their socio-demographics and service utilisations) of intermediate care facilities	Obs., retro.	Random selection amongst residents with schizophrenia or schizoaffective disorder	179	12	NR	NR	Proportion with an admission during FU 80/179 (45%)	77.3
Awara, 2017 (146)	Canada	Hospital rehab. unit	Describe characteristics of inpatient rehab. unit inpatients, investigate hospital days pre- and post-admission	Obs., retro.	All discharges from single inpatient unit	80	6	7/58 (12.1%)	48/58 (82.8%)	Proportion with an admission six months pre-rehab. = 48/53 (90.6%); six months post-rehab. = 10/53 (18.9%)	81.8
Blow, 2000 (147)	US	Hospital rehab. unit	Investigate effects on service utilisation of four treatment programmes: STAR-II (an intensive inpatient rehabilitation programme), day treatment aiming to support and train for living in the community, assertive community treatment (ACT), and TAU	Obs., pros.	Patients enrolled on treatment programme	861 (STAR II=405, day treatment=173, ACT= 123, TAU= 160)	36	NR	NR	Mean (SD) hospitalised days one-yr before baseline vs. one-yr before 3-yr FU: STAR-II: 274.0 (101.7) vs. 149.1 (157.6); Day treatment: 221.4 (102.7) vs. 74.5 (104.0); ACT: 258.4 (109.4) vs. 104.2 (133.3); TAU: 246.6 (136.9) vs. 185.5 (163.3)	68.2

First author, Year published	Country	Primary setting	Main aim	Design	Sample selection	N (by group)	Follow-up (FU) in months	Ratio (%) moved to higher supportive setting	Ratio (%) moved to lower supportive setting	Inpatient service use	Quality rating
Contemporary rehabilitation studies											
Bota, 2007 (148)	US	Supported accom.	Does boarding home reduce inpatient use	Obs., retro.	Patients discharged from boarding home (BH)	20	37	NR	NR	Pre-BH = mean 3.3 days per month; During-BH = 0.33; Post-BH = 0.24	68.2
Bradshaw, 2000 (149)	US	Community rehab. team	Investigate effectiveness of CBT for schizophrenia compared to day treatment programme (DTP)	RCT	Patients consecutively referred to day treatment programme following discharge from inpatient admission who met study criteria	24	36	NR	NR	CBT&DTP (n=8) = Yr1: Mean 5.0 (SD 7.87), Yr2: 0 (0), Yr3: 0 (0); DTP (n=7) = Yr1: 2.57 (3.82), Yr2: 2.71 (4.86), Yr3: 2.29 (4.27).	57.7
Bunyan, 2016 (150)	UK	Hospital rehab. unit	Investigate clinical and economic effectiveness of inpatient rehab. units	Obs., retro.	Sequential discharges	22	24	1/21 (4.8%)	19/21 (90.5%)	Mean inpatient days: Pre (24 months): 379.45 (standard error (SE) 56.26) Post (24 months): 110.59 (SE 52.45)	77.3
Chan, 2020 (151)	UK	Community rehab. team	Investigate individual characteristics that predict successful progress	Obs., retro.	All transfers to service within study period	193	51	NR	45/193 (23.3%)	NR	100.0

First author, Year published	Country	Primary setting	Main aim	Design	Sample selection	N (by group)	Follow-up (FU) in months	Ratio (%) moved to higher supportive setting	Ratio (%) moved to lower supportive setting	Inpatient service use	Quality rating
Contemporary rehabilitation studies											
Dalum, 2018 (152)	Denmark	Community rehab. team	Investigate effectiveness of IMR compared to TAU in Denmark	RCT	Schizophrenia and bipolar disorder patients at one of three community services	198 (IMR=99; TAU=99)	12	NR	NR	Mean number of admissions (SD): IMR=0.6 (1.1), TAU=0.6 (1.7)	96.2
D'Avanzo, 2004 (153)	Italy	Supported accom.	Identifying factors that predict discharge from res. services	Obs., pros.	All patients of res. facilities in Lombardy during study period	1792 (low-staffed=133; medium-staffed=126; high-staffed=1042; res. care=491)	13	49/1792 (2.7%)	191/1792 (10.7%)	NR	100.0
de Girolamo, 2014 (154)	Italy	Supported accom.	To describe res. facility patients and investigate associations with discharge at one-yr FU	Obs., pros.	All patients staying in 23 medium-long-term res. facilities provided by St John of God Order with a primary psychiatric diagnosis	403	12	6/403 (1.5%)	64/403 (15.9%)	NR	86.4

First author, Year published	Country	Primary setting	Main aim	Design	Sample selection	N (by group)	Follow-up (FU) in months	Ratio (%) moved to higher supportive setting	Ratio (%) moved to lower supportive setting	Inpatient service use	Quality rating
Contemporary rehabilitation studies											
de Girolamo, 2016 (155)	Italy	Supported accom.	Compare demographics and outcomes of persons in services with history of violence vs controls	Obs., pros.	Patients living in res. facilities at four different sites	139	12	1/139 (0.7%)	20/139 (14.4%)	NR	81.8
de Mooij, 2016 (156)	Netherlands	Supported accom.	Track changes in residence and care settings	Obs., pros.	Random selection from patients treated by outpatient teams, sheltered housing or inpatient care	59	72	NR	NR	NR	100.0
Färdig, 2011 (157)	Sweden	Community rehab. team	Evaluate effectiveness of IMR program	RCT	Patients from study sites meeting inclusion criteria	41 (IMR=21; TAU (psych outpatient rehab. centre)= 20)	12	NR	NR	12m at baseline: IMR = 4/21 (19.0%); TAU = 5/20 (25.0%); 12m at 21m FU: IMR = 0/19 (0%); TAU = 2/19 (10.5%)	88.5
Hanrahan, 2001 (158)	US	Supported accom.	Examining resident satisfaction with community integrated living arrangement facilities and compare hospital days before and after	Obs., pros.	Resident at randomly selected community integrated living arrangement facility, with at least one-yr residence	74 (Integrated=43; Continuous=31)	12	NR	NR	Mean = 5.3 (SD 17) in first yr at community living arrangement facilities vs 47.7 (SD 103) in 1yr prior to facility	72.7

First author, Year published	Country	Primary setting	Main aim	Design	Sample selection	N (by group)	Follow-up (FU) in months	Ratio (%) moved to higher supportive setting	Ratio (%) moved to lower supportive setting	Inpatient service use	Quality rating
Contemporary rehabilitation studies											
Incedere, 2019 (159)	Turkey	Community rehab. team	Investigate outcomes of a hybrid case management model for patients with schizophrenia	Obs., pros.	Patients living with caregivers and unable to live independently, treated with case management	30	24	NR	NR	24-month pre mean number of admissions = 1.33 (SD 1.06); 24-month during treatment/FU = 0.23 (0.56)	59.1
Jensen, 2019 (160)	Denmark	Community rehab. team	Effectiveness of IMR in Denmark	RCT	Patients at three community services	198 (IMR=99; TAU 99)	12	NR	NR	Mean difference in hospital days reported only (not means of groups) between IMR and TAU = 19.4 (95% CI: -0.76-0.5)	100.0
Kavanagh, 2009 (161)	Ireland	Hospital rehab. unit	Describe characteristics and progress of inpatient rehab. patients	Obs., retro.	First patients admitted to service	50	60	0	17/46 (37.0%)	NR	83.3
Killaspy, 2013 (162)	UK	Hospital rehab. unit	Investigate five-yr outcomes for rehab. service users	Obs., retro.	All patients at selected services were potentially approached for participation	141 (47 inpatient unit, 44 community unit, 50 supported accom)	60	41/124 (33.1%)	50/124 (40.3%) (Inpatients: 19/47 (40.3%); Community & supported accom.: 31/94 (33.0%)	NR	95.5

First author, Year published	Country	Primary setting	Main aim	Design	Sample selection	N (by group)	Follow-up (FU) in months	Ratio (%) moved to higher supportive setting	Ratio (%) moved to lower supportive setting	Inpatient service use	Quality rating
Contemporary rehabilitation studies											
Killaspy, 2016 (70)	UK	Community rehab. unit	Longitudinal outcomes for services users of inpatient rehab. units	Obs., pros.	All patients of selected services	362 (339 FU)	12	0	187/339 (55.2%)	NR	100.0
Killaspy, 2020 (5)	UK	Supported accom.	Investigate 30-month outcomes for users of supported accommodation	Obs., pros.	Randomly selected services users from nationally representative, randomly selected services	619 (159=RC; 251=SH; 209=FO)	30	NR	243/586 (41.5%) (RC 15/146 (10.3%); SH 96/244 (39.3%); FO 132/196 (67.3%))	Proportion with any admission during FU: 110/586 (18.8%): RC 27/146 (18.5%); SH 60/244 (24.6%); FO 23/196 (11.7%)	100.0
King, 2000 (163)	UK	Community rehab. unit	Investigate variables predictive of difference in outcome and explore patterns of change over time	Obs., pros.	All residents during study period	20	26	5/20 (25.0%)	8/20 (40.0%)	NR	59.1
Lascorz, 2018 (164)	Spain	Supported accom.	Evaluate 'evolution' of patients in first 10 years of a res. service	Obs., retro.	Residents with minimum of 2yr stay at service	93	60	14/93 (15.1%)	19/93 (20.4%)	Mean number of hospital days at one-yr prior to residence = 101, during 1st yr = 6.2, 2nd yr = 8.6, 3rd yr = 7.2, 4th yr = 2.3, 5th yr = 6.8, 6th yr = 9.5, 7th yr = 12.9, 8th yr = 12.1, 9th yr = 10.1, 10th yr = 14.1 (n not reported for each time-point)	54.5

First author, Year published	Country	Primary setting	Main aim	Design	Sample selection	N (by group)	Follow-up (FU) in months	Ratio (%) moved to higher supportive setting	Ratio (%) moved to lower supportive setting	Inpatient service use	Quality rating
Contemporary rehabilitation studies											
Lee, 2009 (165)	US	Supported accom.	Investigate individual and housing characteristics associated with positive and negative programme discharge	Obs., retro.	Residents with minimum of 6m stay at service	237	30	41/237 (17.3%)	32/237 (13.5%)	NR	63.6
Lichtenberg, 2008 (166)	Israel	Community rehab. team	Assess effectiveness of clinical case management in 'revolving door' patients compared to TAU and no treatment	RCT	Patients identified via the national psychiatric case registry as having had three admissions during 1996-97.	370 (CCM=122; TAU=95; NT=153)	12	NR	NR	Proportion with any admission during FU: 248/370 (67.0%) (CCM=87/122, 71.3%; TAU=75/95, 78.9%; NT=86/153, 56.2%)	80.8
Macpherson, 2017 (167)	UK	Hospital rehab. unit	Evaluate outcomes of two inpatient recovery units	Obs., retro.	All patients at selected services	43	12	5/43 (11.6%)	38/43 (88.4%)	NR	81.8

First author, Year published	Country	Primary setting	Main aim	Design	Sample selection	N (by group)	Follow-up (FU) in months	Ratio (%) moved to higher supportive setting	Ratio (%) moved to lower supportive setting	Inpatient service use	Quality rating
Contemporary rehabilitation studies											
Malinovsky, 2013 (168)	US	Supported accom.	Track a range of recovery indicators after an organisation-wide implementation of the recovery model	Obs., pros.	All residents of service by provider	627	12	NR	NR	Does not distinguish psychiatric and physical hospitalisation. Mean (SD) number of hospital days for month before recovery model = 9.79 (26.68) and month after 5.52 (19.74). Total number of hospital days one-yr pre recovery model = 4994, and one-yr post = 2970	95.5
Muir, 2008 (169)	Australia	Supported accom.	Evaluate Mental Health Housing and Accommodation Support Initiative	Obs., pros.	Resident at service during two-yr study period	110	12	NR	NR	For n=67: Mean number of hospitalised days per person per year pre-HASI = 88.7 and during-HASI = 16.8. Mean number of days hospitalised per admission pre-HASI = 29.9 and during-HASI = 6.7	63.6

First author, Year published	Country	Primary setting	Main aim	Design	Sample selection	N (by group)	Follow-up (FU) in months	Ratio (%) moved to higher supportive setting	Ratio (%) moved to lower supportive setting	Inpatient service use	Quality rating
Contemporary rehabilitation studies											
Nordentoft, 2012 (170)	Denmark	Supported accom.	Exploring the population residing in psychiatric supported housing facilities in Denmark	Obs., retro.	From national register: resident at service with previous psychiatric contact, matched with controls without any history of supported accommodation	5722=cases; 28,085=control	12	NR	NR	Mean hospitalised days in one-yr pre admission to residence / matching: 167 for both groups; one-yr post admission to residence / matching: 26.9 (cases) and 101.6 (control)	95.5
Parker, 2020 (171)	Australia	Community rehab. unit	To investigate predictors of positive outcomes for users of community care units	Obs., retro.	Discharge from service with one-yr pre-admission and one-yr post-discharge administrative records	501	12	NR	NR	Mean number of hospital days one-yr pre-admission mean = 101.54 (SD 113.01); one-yr post-discharge mean = 70.39 (SD 118.33)	100.0
Sakiyama, 2002 (172)	Japan	Supported accom.	Identifying conditions where use of supported housing is effective	Obs., pros.	Discharged from service between April 1992 and October 1998	55	38	25/55 (45.5%)	30/55 (54.5%)	NR	77.3

First author, Year published	Country	Primary setting	Main aim	Design	Sample selection	N (by group)	Follow-up (FU) in months	Ratio (%) moved to higher supportive setting	Ratio (%) moved to lower supportive setting	Inpatient service use	Quality rating
Contemporary rehabilitation studies											
Shadmi, 2018 (173)	Israel	N/A	To investigate whether PROMs can be used to predict rehospitalisation for people with schizophrenia	Obs., retro.	All schizophrenia patients in surveyed areas (central and north Israel) who have used psychiatric rehab. services were approached	2842	12	NR	NR	Proportion with any admission during FU: 379/2842 (13.3%)	100.0
Tan, 2017 (174)	Singapore	Community rehab. team	Compare IMR with TAU on symptoms, rehospitalisation and social functioning	RCT	Patients referred to service who met study criteria (including >2 admissions in previous yr)	50 (IMR=25; TAU=25)	24	NR	NR	Mean number of hospital days at 12-month FU: IMR = 0.00 (SD 0.00); TAU = 25.68 (24.11); and at 24-month FU (12 months post treatment): IMR = 0.08 (SD 0.40); TAU = 21.64 (20.01)	73.1
Wong, 2008 (175)	US	Supported accom.	Investigate patterns and reasons for residents leaving supported independent living	Obs., retro.	All residents	452	21	63/452 (13.9%)	52/452 (11.5%)	Proportion with any admission during FU: 86/452 (19.0%)	85.0

First author, Year published	Country	Primary setting	Main aim	Design	Sample selection	N (by group)	Follow-up (FU) in months	Ratio (%) moved to higher supportive setting	Ratio (%) moved to lower supportive setting	Inpatient service use	Quality rating
Services for homeless people with long term and complex mental health problems											
Aubry, 2015 (176)	Canada	Supported accom.	Effectiveness of Housing First (HF) compared to TAU	RCT	People with severe mental illness who were homeless or precariously housed. Referral into study by health and social service agencies	950 (HF=469; TAU=481)	12	HF= 60/450 (13.3%); TAU= 121/406 (29.8%)	NR	NR	100.0
Aubry, 2016 (177)	Canada	Supported accom.	Effectiveness of HF with assertive community treatment compared to TAU (extension of Aubry 2015)	RCT	People with severe mental illness who were homeless or precariously housed. Referral into study by health and social service agencies	950 (HF=469; TAU=481)	24	NR	NR	Number of days hospitalised across both groups reduced by 62%, a similar reduction for both groups (NR by group)	100.0
Gilmer, 2010 (178)	US	Supported accom.	Recovery, service utilisation and cost outcomes of Full Service Partnership (FSP)	Obs., retro.	Admission between October 2006 and December 2007	363 (FSP=209; Control= 154)	12	NR	NR	NR	90.9

First author, Year published	Country	Primary setting	Main aim	Design	Sample selection	N (by group)	Follow-up (FU) in months	Ratio (%) moved to higher supportive setting	Ratio (%) moved to lower supportive setting	Inpatient service use	Quality rating
Services for homeless people with long term and complex mental health problems											
Gilmer, 2014 (179)	US	Supported accom.	Compare service use and costs of FSP clients with matched controls	Obs., retro.	Participants identified from Health Records database, enrolled on FSP between Jan 2005 and June 2009. Matched to participants on demographics and clinical characteristics, and health service use	20462 (FSP= 10231; Control= 10231)	12	NR	NR	Mean (standard error) number of hospital days for: FSP: 12-month pre = 12.2 (0.3), 12-month post = 7.8 (0.2); Control: 12-month pre = 11.6 (0.3), 12-month post = 7.2 (0.2)	95.5
Gilmer, 2014 (180)	US	Supported accom.	Fidelity of FSP to HF and res. outcomes	Obs., retro.	Patients enrolled on FSP for at least 180 days between January 2005 and June 2009	6584 (High fidelity=1858, Moderate=3481, Low=1245)	12	NR	NR	NR	100.0
Gulcur, 2003 (181)	US	Supported accom.	Comparing HF with supported housing (SH)	RCT	Recruited from streets and hospitals	225 (HF=99; SH=126)	24	NR	NR	NR	65.4

First author, Year published	Country	Primary setting	Main aim	Design	Sample selection	N (by group)	Follow-up (FU) in months	Ratio (%) moved to higher supportive setting	Ratio (%) moved to lower supportive setting	Inpatient service use	Quality rating
Services for homeless people with long term and complex mental health problems											
Lipton, 2000 (182)	US	Supported accom.	To study long-term effectiveness of housing approaches for homeless persons with severe mental illness	Obs., retro.	Residence at high/moderate/ low-intensity service during study period	2937 (High=873, Moderate=540, Low=1524)	30	NR	NR	NR	85.0
McHugo, 2004 (183)	US	Supported accom.	Comparing two approaches to linking housing with mental health services (integrated: housing and support provided by the same service, and parallel: provided by separate services)	RCT	Recruited from various sources. Current or risk of homelessness and severe mental illness	121 (Integrated=61, Parallel=60)	18	NR	NR	NR	80.8
Stefancic, 2007 (184)	US	Supported accom.	Access and retention of housing in HF and TAU	RCT	Referral to study for randomisation to HF or TAU (chronic shelter users with psychiatric disabilities)	260 (HF=209; TAU=51)	47	NR	NR	NR	58.3

First author, Year published	Country	Primary setting	Main aim	Design	Sample selection	N (by group)	Follow-up (FU) in months	Ratio (%) moved to higher supportive setting	Ratio (%) moved to lower supportive setting	Inpatient service use	Quality rating
Services for homeless people with long term and complex mental health problems											
Stefancic, 2007 (184)	US	Supported accom.	Access and retention of housing in HF and TAU	RCT	Referral to study for randomisation to HF or TAU (chronic shelter users with psychiatric disabilities)	260 (HF=209; TAU=51)	47	NR	NR	NR	58.3
Tsemberis, 2003 (185)	US	Supported accom.	Present initial results for a longitudinal study evaluating housing stability for HF programme	RCT	Referral to study, mainly by services in contact with chronic homelessness and severe mental illness	225 (HF=99; Control=126)	6	NR	NR	NR	73.1
Tsemberis, 2004 (186)	US	Supported accom.	Examine longitudinal effects of HF (extension of Tsemberis, 2003)	RCT	Two sub-samples: 1. Street homeless 2. Psychiatric hospital (and homeless before hospitalisation)	225 (HF=99; Control=126)	24	NR	NR	NR	65.4

First author, Year published	Country	Primary setting	Main aim	Design	Sample selection	N (by group)	Follow-up (FU) in months	Ratio (%) moved to higher supportive setting	Ratio (%) moved to lower supportive setting	Inpatient service use	Quality rating
Services for homeless people with long term and complex mental health problems											
van Kranenburg, 2020 (187)	Netherlands	Hospital rehab. unit	Investigate relationship between clinical changes during treatment and long-term outcomes from SuRe (Sustainable Residence)	Obs., retro.	All admissions to SuRE, with minimum four-yr length of admission by study end (Jan 2015)	165	48	26/165 (15.8%)	70/165 (42.4%)	NR	86.4
Deinstitutionalisation programmes											
Baloush-Kleinman, 2003 (188)	Israel	Community rehab. unit	Outcomes of a deinstitutionalisation programme in Israel	Obs., retro.	All admissions to service	205	60	16/205 (7.8%)	138/205 (67.3%)	Proportion with any admission during FU: 16/205 (7.8%)	50.0
Barbato, 2004 (189)	Italy	Supported accom.	Reporting four-yr outcomes of all patients discharged from hospital to community residence	Obs., pros.	All patients discharged from hospital to community residence	163	42	NR	NR	Proportion with any admission during FU: 35/163 (21.5%)	72.7
Bartholomew, 2018 (190)	US	Community rehab. unit	Evaluation of a programme for long-stay patients difficult to discharge to community	Obs., retro.	All admissions within first yr of service opening	22	7	5/22 (22.7%)	11/22 (50.0%)	NR	50.0

First author, Year published	Country	Primary setting	Main aim	Design	Sample selection	N (by group)	Follow-up (FU) in months	Ratio (%) moved to higher supportive setting	Ratio (%) moved to lower supportive setting	Inpatient service use	Quality rating
Deinstitutionalisation programmes											
Chan, 2007 (191)	Japan	Supported accom.	Effect of supported group residence compared to continued long-stay hospital admission	RCT	Patients in a private psychiatric hospital which met study criteria	28 (supported group residence=14; continued admission=14)	24	NR	NR	Proportion with any admission during FU: 3/14 (21.4%)	84.6
Chopra, 2011 (192)	Australia	Supported accom.	Investigate long-term outcomes for ex-long-stay patients who moved to a residential psychiatric service	Obs., retro.	All patients who moved to Footbridge Community Care Unit (CCU)	18	84	NR	1/18 (6%)	NR	68.2
Duurkoop, 2003 (193)	Netherlands	Supported accom.	13-yr FU of patients discharged from long-stay hospital to two levels of community residence	Obs., pros.	All clients at the two study sites (Kempering and Surinemeplain)	174 (Kemp.=84; Surin.=90)	121	7/174 (4.0%) (Kemp.=5/84 (6.0%); Surin.=2/90 (2.2%))	16/174 (9.2%) (Kemp.=15/84 (17.9%); Surin.=1/90 (1.1%))	NR	40.9
Gamble, 2011 (194)	US	Hospital rehab. unit	Evaluation of a preparation for discharge programme	Obs., pros.	Long-stay patients at several hospitals, did not select people with risk issues or complex needs	10	24	0	8/10 (80%)	NR	43.8

First author, Year published	Country	Primary setting	Main aim	Design	Sample selection	N (by group)	Follow-up (FU) in months	Ratio (%) moved to higher supportive setting	Ratio (%) moved to lower supportive setting	Inpatient service use	Quality rating
Deinstitutionalisation programmes											
Hallam, 2002 (195)	UK	Community rehab. unit	Cost effectiveness of rehab. services for difficult-to-place long-stay patients	Obs., pros.	Difficult-to-place patients from Friern Hospital moved to one of four rehab facilities	67	60	6/56 (10.7%)	24/56 (42.9%)	NR	63.6
Hobbs, 2000 (196)	Australia	Supported accom.	Investigating outcomes of ex-long stay patients discharged to community res. services	Obs., pros.	All patients discharged from long-stay hospital (closure) to community residences	43	24	7/42 (16.7%)	3/42 (7.1%)	Proportion with any admission during FU: 20/43 (46.5%)	72.7
Hobbs, 2002 (197)	Australia	Supported accom.	Six-yr follow-up of ex-long stay patients (extension to Hobbs, 2000)	Obs., pros.	All patients discharged from long-stay hospital (closure) to community residences	47	72	7/44 (15.9%)	26/44 (59.1%)	NR	59.1
Macpherson, 2004 (198)	UK	Supported accom.	Examine treatment outcomes of hostels in Gloucester	Obs., retro.	All patients admitted to any of the four hostels from open (between 1983 and 1993) and 1999	58	120	21/58 (36.2%)	10/58 (17.2%)	Proportion with any admission during FU: 19/58 (32.8%)	81.8

First author, Year published	Country	Primary setting	Main aim	Design	Sample selection	N (by group)	Follow-up (FU) in months	Ratio (%) moved to higher supportive setting	Ratio (%) moved to lower supportive setting	Inpatient service use	Quality rating
Deinstitutionalisation programmes											
McCrone, 2006 (199)	UK	Community rehab. unit	Compare the service use and costs of 'difficult to place' patients discharged from Warley and Friern Hospital	Obs., pros.	Difficult to place' patients from both hospitals	84 (Friern=63; Warley= 21)	12	NR	NR	Proportion with any admission during FU: Friern: 5/63 (7.9%); Warley: 3/21 (14.3%)	86.4
Meehan, 2011 (200)	Australia	Supported accom.	Evaluate clinical and social outcomes of a group discharged from long-stay hospitals into supported accom.	Obs., pros.	All patients discharged from long-stay hospital to community residences	181	84	NR	NR	Proportion with any admission during FU: 112/181 (60.2%)	77.3
Noda, 2004 (201)	Japan	Hospital rehab. unit	Evaluating outcomes of an inpatient rehab. discharge programme	Obs., retro.	Patients enrolled on programme	224	84	47/224 (21.0%)	172/224 (76.8%)	NR	68.2
Ryu, 2006 (202)	Japan	Supported accom.	Evaluate outcomes of long-stay patients discharged to residential facility	Obs., pros.	All patients transferred to Sasagawa Village	78	24	0	0	Proportion with any admission during FU: 4/78 (5.1%)	81.8

First author, Year published	Country	Primary setting	Main aim	Design	Sample selection	N (by group)	Follow-up (FU) in months	Ratio (%) moved to higher supportive setting	Ratio (%) moved to lower supportive setting	Inpatient service use	Quality rating
Deinstitutionalisation programmes											
Tanioka, 2013 (203)	Japan	Hospital rehab. unit	Examine factors associated with discharge from long-stay hospital enrolled in a rehab. programme	Obs., retro.	All patients enrolled in programme with >1yr inpatient admission	70	12	NR	NR	NR	70.0
Trauer, 2001 (204)	Australia	Community rehab. unit	To follow all patients admitted to CCU from long-stay ward and investigate 1yr outcomes	Obs., pros.	All patients on long-stay ward nominated for CCU	125	12	14/99 (14.1%)	4/99 (4.0%)	Proportion with any admission during FU: 11/70 (15.7%)	54.5
Trieman, 2002 (49)	UK	Hospital rehab. unit	Study long-term outcome of long-stay inpatients regarded unsuitable for community placement	Obs., pros.	'Difficult-to-place' long-stay patients	72	60	0	29/72 (40.3%)	NR	81.8

Accom. = accommodation, ACT = assertive community treatment, BH = boarding home, BPR = Boston Psychiatric Rehabilitation, CBT = cognitive behavioural therapy, CCM = clinical case management, CCU = community care unit, DTP = day treatment programme, FSP = Full Service Partnership, FU = follow-up, HF = Housing First, IMR = Illness Management and Recovery, Kemp. = Kempering, NR = not reported, Obs. = observation study, Pros. = prospective study, QoL = quality of life, RCT = randomised controlled trial, Rehab. = rehabilitation, Res. = residential, Retro. = retrospective study, SH = supported housing, SuRe = Sustainable Residence, Surin. = Surinemeplain, TAU = treatment as usual, Yr = year.

5.4.1 Studies of contemporary mental health rehabilitation services

This group of studies was the most varied regarding setting and findings. Of the 33 studies in this category, almost half (15 studies) investigated supported accommodation services, nine studies investigated community rehabilitation teams, six studies investigated inpatient rehabilitation units, two studies investigated community rehabilitation units, and one study did not specify the type of rehabilitation service investigated. Most of the studies (27) used an observational design, the remainder were RCTs (6). All six RCTs in this category investigated the effectiveness of community rehabilitation teams. Almost half of the studies were based in the US (eight) or the UK (seven), three were based in Denmark, three in Italy, two in Australia, two in Israel, and one each in Canada, Ireland, Japan, Netherlands, Singapore, Spain, Sweden, and Turkey. Therefore, the studies were conducted in a range of different healthcare systems and contexts. The mean Kmet quality score was 82.5 (SD 15.1) with eight studies scoring 100. Table 5 provides more details regarding these studies, including a brief description of the aim of each study and the results from each study that are relevant to this review.

The most consistent outcome was a reduction in inpatient service use after an inpatient rehabilitation admission compared to before the admission. However, the magnitude of the reduction did vary between studies, as did the quality scores. Parker and colleagues (171) (quality score 100) compared inpatient days 12 months before admission with 12 months after discharge for 501 patients from five inpatient rehabilitation units in Australia. The mean inpatient days reduced from 101.54 (SD 113.01) before the admission to 70.39 (SD 118.33) afterwards. Bunyan and colleagues (150) (quality score 77.3) compared inpatient days over a longer period; 24 months before and after, but with a much smaller sample; 24 individuals from three units in South London. They reported a much larger reduction in inpatient service use, the mean inpatient days reduced from 379.45 (standard error (SE) 56.26) to 110.59 (SE 52.45). Blow and colleagues (147) evaluated an inpatient rehabilitation programme in the US deployed during the 1990s. For 405 individuals, they reported inpatient days reduced from a mean of 274.0 (SD 101.7) in the 12 months before the programme to 149.1 (SD 157.6) in the 12 months before the three-year follow-up. The study however did have a low quality score (68.2). The final study reporting this outcome only looked at the period six months before and after an admission to a single Canadian inpatient rehabilitation unit for 80 individuals (146)

(quality score 81.8). They reported the number of individuals with no inpatient admissions before the rehabilitation admission was five (9.4%) compared to 43 (81.1%) in the period after the rehabilitation admission.

A few studies reported length of inpatient rehabilitation admission before successful discharge, but the findings were inconsistent. For example, Killaspy et al. (70) conducted a large, high quality cohort study (quality score 95.5) involving 50 rehabilitation units across England and 339 patients and, found that most patients (55%) had been discharged without subsequent re-admission or community placement breakdown within 12 months. However, three smaller studies with lower quality scores reported variable rates of successful discharge. One of these studies included 43 participants from two inpatient units also in England and found that 88% were discharged at 12-month follow-up (quality score 81.8). A study based in Ireland with 50 participants from a single inpatient unit reported 37% were discharged at five-year follow-up (quality score 83.3), and another study conducted in England but with only 20 participants from a single inpatient unit found 60% were discharged at 6.5-year follow-up (quality score 59.1).

Studies evaluating supported accommodation reported good outcomes in terms of reduced inpatient service use. Nordentoft and colleagues (170) carried out a study with a high quality score (95.5) using the Danish national health register to investigate inpatient days before and after a move to a supported accommodation service, and found a large reduction (mean 167 days in the 12 months prior to move vs. 27 days in the 12 months after). However, the authors were critical of the quality of care provided in supported accommodation and described these services as the “new asylums in the community” (p. 1251), with poorly defined treatment, variable staffing levels, and a similar cost per day to long-stay hospitals. It should be noted that this study did not formally assess the quality of care in these services. Concerns about the content of care in supported accommodation services in the US were also made by Anderson et al. (145) (quality score 77.3), who found only half the residents in their sample received interventions other than medication. This was however one of the older studies published (it was published in 2001) and may not be representative of current services or of services beyond the studied sample. Four other studies also reported reduced inpatient

service use after a move to a supported accommodation service (quality scores 63.6, 68.2, 72.7, 95.5) (148, 158, 168, 169).

As explained in Chapter 2 (Section 2.8.3), a national cohort study of mental health supported accommodation in England (the QuEST study) found that less than half moved on to more independent settings over a 30-month period (5), this is despite most services in England having a remit to move residents on within two years. The rate of move-on did vary by service type. Only 10% of participants in residential care services moved on (15/146), around a third of supported housing participants (96/244), and around two-thirds of floating outreach participants (132/196) (for a description of these three types of supported accommodation, please see Section 2.8.3). After taking account of differences in clinical characteristics of participants, the adjusted odds ratio for move-on from floating outreach compared to residential care was 7.96 (95% CI 2.92 to 21.69) and 2.74 (95% CI 1.01 to 7.41) when compared to supported housing. This study was included in this review and received a Kmet quality score of 100.

Limited 'forward' moves in supported accommodation were also found in other studies included in this review, including studies conducted in Italy (quality scores 100, 81.8, 86.8) (153-155), the state of Philadelphia in the US (quality scores 85.0, 63.6) (165, 175), and in a single low quality study conducted in Spain (quality score 54.5) (164). This does not necessarily mean these participants had stable accommodation as 'sideways' moves (i.e. moves to supported accommodation with similar levels of support) or 'backwards' moves (i.e. moves to higher levels of support) were not reported. A study by de Mooij and colleagues (156) (quality score 100) that tracked changes in address of 262 people in the Netherlands with severe mental health problems over a six-year period, found that 204 (78%) changed address at least once, and 68 (26%) changed address at least four times. However, only 59 (23%) of these 262 people were living in supported accommodation at baseline.

Four studies investigated predictors of successful move-on from inpatient rehabilitation units and/or supported accommodation. A large, high quality Israeli study (N=2,842, quality score 100) found that higher self-reported quality of life amongst patients of inpatient rehabilitation services was associated with lower rates of re-admission (173). Two studies by Killaspy and

colleagues found that the degree to which inpatient rehabilitation services (quality score 100) (70) and supported accommodation services (quality score 100) (5) adopted a recovery orientation was associated with successful discharge and move-on, respectively. They also found that supported accommodation services with greater promotion of human rights had higher rates of successful move-on (5). A study in Japan found that shorter hospital admissions prior to moving into supported accommodation predicted successful move-on from supported accommodation (172). However, this study was of low quality (quality score 77.3).

Results of studies evaluating community rehabilitation teams (149, 151, 157, 159, 160, 166, 174) were mixed, and all except one of these studies were RCTs. Most of these studies investigated the effectiveness of a specific rehabilitation programme taking place in the community, known as Illness Management and Recovery (IMR) (152, 157, 160, 174). The IMR programme primarily consists of psychoeducation and promotion of personal recovery, delivered via weekly group sessions over the course of nine months. None of the included studies found the intervention to be associated with a reduction in inpatient service use. A high quality (quality score 100) RCT involving 198 participants comparing IMR with treatment as usual (TAU) also found no difference at 12-month follow-up in terms of functioning, symptoms, or emergency room visits (160).

Four of the included studies that investigated community rehabilitation teams did not evaluate IMR. Two of these studies were published recently (151, 159) but differed considerably in quality scores (59.1 and 100). The high quality study reviewed health records to look at outcomes for 193 patients of an inner-city community rehabilitation team in England that supported people living in 24-hour supported accommodation (151). The authors found that fewer than one-in-four (n=45, 23%) patients moved on to more independent accommodation with a median follow-up period of 4.25 years (interquartile range 2.67 to 5.25 years). The study with the lower quality score looked at the outcomes of 30 patients supported by a case management model based on rehabilitation principles in Turkey (159). They found that the psychiatric hospital admission rate for participants reduced from a mean of 1.33 (SD 1.06) in the two-year period before case management, to 0.23 (SD 0.56) over the same length of time whilst receiving case management.

The other two studies that evaluated community rehabilitation teams were published in 2000 (149) and 2008 (166), and were both carried out in Israel. The 2000 study had a very small sample (n=8) and a low quality score (57.7). It examined the effectiveness of cognitive behavioural therapy (CBT) for people with a diagnosis of schizophrenia participating in a day treatment programme based on psychiatric rehabilitation principles, by randomising them to CBT (day treatment plus CBT) or TAU (day treatment only). They found no difference in the number of hospital admissions between groups. The 2008 study had a much larger sample size (n=370) and a higher quality score (80.8). It investigated the effectiveness of clinical case management for "revolving door patients", which included training of skills necessary for daily living tasks. They did not find that clinical case management was any more effective at reducing hospital admissions than TAU.

Only one study included more than two components of the rehabilitation pathway (as described in Chapter 2 Section 2.8). Killaspy and Zis (162) (quality score 95.5) reviewed healthcare records to investigate the outcomes of 141 patients of three inpatient rehabilitation units, two community rehabilitation units and four supported accommodation services, all located in two inner city London boroughs. Over five years, 40% of those with complete follow-up data (50/124) had progressed in a forward direction along the rehabilitation pathway, 27% (33/124) had maintained their community placement, and 38% (41/124) had a 'backwards' move.

5.4.2 Studies of services for homeless people with severe mental health problems

This group of studies recruited participants who were either homeless or at risk of homelessness and had a severe mental health problem. The mean Kmet quality score was 83.8 (SD 14.3) with three studies scoring 100. The majority (8/13) of these studies were RCTs and all except one evaluated models of supported accommodation. This study investigated a long-term inpatient unit based in the Netherlands designed specifically for people who were homeless and had a treatment resistant severe mental health problem and a substance misuse problem (187). All the other studies in this category were conducted in North America (nine in the US and three in Canada) and most (10/13) investigated either the 'Housing First' (176, 177, 181, 184-186, 205) or the 'Full Service Partnership' (178-180) programme.

Table 5 provides more details regarding these studies. The Full Service Partnership model is very similar to the Housing First approach (described previously in this Chapter, Section 5.2), and Gilmer et al. describes it as a Housing First program that does "whatever it takes to improve residential stability and mental health outcomes" (p.646) (178). Gilmer and colleagues (quality score 100) (180) found that the Full Service Partnership programmes with higher fidelity to the Housing First model were more effective in reducing the number of days spent homeless, but the low fidelity programmes were still effective. Low fidelity programmes resulted in a mean reduction of 34 days per year spent homeless (95% CI -55 to -13) whereas high fidelity programmes had a mean reduction of 87 days (95% CI -109 to -64).

All the Housing First (176, 177, 181, 184-186, 205) and Full Service Partnership studies (178-180) reported the intervention to be effective at reducing homelessness and improving housing stability. The strongest evidence was reported by Aubry et al. (quality score 100) (177). They conducted a multi-centre RCT in Canada, allocating 950 participants to Housing First or TAU (access to all the locally available housing services, except for Housing First) and tracked their housing status and health outcomes over two years. At the final two-year follow-up, 74% (95% CI 69% to 78%) of Housing First clients were in stable housing compared to only 41% (95% CI 35% to 46%) of those receiving TAU. Housing First clients were also housed quicker and rated their accommodation as better quality.

There were two studies in this category which did not evaluate the Housing First or Full Service Partnership model. Lipton and colleagues (182) (quality score 85.0) studied the effectiveness of supportive housing in New York City for homeless people with severe mental health problems. They defined the term 'supportive housing' to describe all housing services with integrated support for people with a severe mental health problem. At two-year and five-year follow-up, 64% and 50% of their 2,937 participants, respectively, had remained in stable housing for the entire follow-up period. McHugo and colleagues (183) (quality score 80.8) compared a non-integrated model of care (housing and mental health support provided by two separate agencies) with an integrated approach (where the two components were provided by the same agency) and found participants randomised to the integrated approach at 18-month follow-up had spent more days in stable housing.

The one study in this category which did not focus on supported accommodation, instead investigated a long-term compulsory inpatient ward based in the Netherlands, and tracked the outcomes of 165 patients for four years from the point of their admission (quality score 86.4) (187). At the end of the four-year period, 69 patients (42%) had not been discharged, 70 (42%) had been discharged to more independent settings (including voluntary psychiatric wards and supported housing), and 26 (16%) had been transferred to settings with greater support.

5.4.3 Studies of deinstitutionalisation programmes

The deinstitutionalisation of mental healthcare was described in Chapter 2, and included a section detailing the influential TAPS studies (Section 2.5). Some of the TAPS studies were published before 2000 and therefore did not meet the eligibility criteria for the systematic review reported in this Chapter. The main consensus of the 18 studies included in the category of studies looking at deinstitutionalisation programmes was consistent with the main conclusion drawn in Chapter 2: the process of closing the large institutions and discharging long stay patients to specialist community services was successful.

All except one of the 18 studies were observational. There was one study which was an RCT which randomly allocated patients to continued hospitalisation or to a group home (191) (quality score 84.6). This study was carried out in Japan and found that the group of patients discharged to a group home improved in comparison to the continued hospitalisation group in terms of positive symptoms, and the number of social and recreational activities they engaged in. However, the patients discharged to a group home did fare worse on a measure of physical health. Three other studies in this category were conducted in Japan, five studies in Australia, four in the UK, two in the US, and one each in Israel, Italy and the Netherlands. All but two of the studies had follow-up periods of at least two years, but the overall level of quality was low (mean quality score 67.1 (SD 14.5), and none of the studies scored 100). Further details regarding these studies are available in Table 5.

Most patients were clinically stable in the community (49, 189, 195, 196, 200, 201, 204) (quality scores 54.5, 72.7, 63.6, 72.7, 77.3, 68.2, and 81.8) with improvement in positive symptoms of psychosis (191, 196, 202) (quality scores 84.6, 72.7, and 81.8), social functioning

(191, 202, 204) (quality scores 84.6, 54.5, and 81.8), and challenging behaviours (195) (quality score 63.6), at final follow-up. One study reported greater improvements in social functioning and clinical symptoms in patients who were more severely unwell at recruitment (193), but this study had a very low quality score (40.9). Importantly, patients were also more satisfied with their living arrangement in the community when compared to hospital (192, 196) (quality scores 72.7 and 68.2). Following their initial discharge to the community, a substantial proportion of patients subsequently moved to more independent settings with less than 24-hour staff supervision (188, 195, 197, 198) (quality scores 63.6, 59.1, 81.1, 50.0). However, Chopra et al.'s small study of 18 people reported patients were less satisfied with their accommodation following the subsequent move, and were often still living in restrictive settings and unhappy about making recurrent moves (192) (quality score 68.2).

Two studies found older patients were less likely to do as well (203, 204) (quality scores 70.0 and 54.5). This may partly be explained or conflated with the finding that a longer stay in hospital is associated with unfavourable outcomes (199) (quality score 86.4) and the fact that older patients of the institutions were more likely to have more severe, longer term mental health problems than younger patients. Trieman et al. (49) (quality score 81.8) tracked the 'difficult to place' patients who were the last to be discharged from a north London asylum (one of the TAPS studies mentioned in Chapter 2 Section 2.5). At five-year follow-up they had similarly positive outcomes to those who had been discharged earlier, including clinical stability and a reduction in challenging behaviour. Many had moved on from their initial community placement to a more independent setting. Similar findings were reported by two smaller studies in the US with lower quality scores (190, 194) (quality scores 50.0 and 43.8).

5.5 Discussion

The 64 included studies were too heterogeneous for meta-analyses, therefore a narrative synthesis was carried out. Heterogeneity was mainly due to a lack of specificity in studies that reported on 'mental health rehabilitation' and that they were conducted across different countries with different healthcare systems and contexts. The included studies were categorised into three groups based on the broad remit of the service or intervention which the study evaluated.

5.5.1 Contemporary mental health rehabilitation

The included studies in the group which evaluated contemporary mental health rehabilitation services were the most relevant to the aim and objectives of this thesis (Chapter 1 Section 1.1). The most consistent finding from these studies was reduced inpatient service use after an inpatient rehabilitation admission or after a move to a supported accommodation service compared to the period before the admission (146, 147, 150, 171) or move (148, 158, 168-170). However, the magnitude of the reduction was variable, the length of time before and after was relatively short, and the studies were observational and did not include valid comparison groups. The capacity to infer causality from these studies is therefore limited. Study design and inference of causality is discussed further in Chapter 7 (Section 7.1), but in brief, as RCTs in this area are in most instances unfeasible (6), further observational studies that account for confounding and/or have valid comparison groups are needed.

It was also consistently found that move-on in mental health supported accommodation to more independent settings (including other levels of supported accommodation) was limited, and most did not move within the expected timeframe of around two years (5, 153-155, 165, 175). This finding suggests that these timeframes require review and that services should be commissioned to provide more flexible and individually tailored support, with the understanding that an individual may continue to require the current level of support in the longer term. Alternatively, this finding may suggest that there is a lack of appropriate accommodation for people to move-on to. This was considered in one of the included studies (5), which found that around a third of residents in supported housing who had not moved-on were ready to move-on (30.5%); this figure was lower for participants in residential care (9%) or receiving floating outreach services (7%).

The provision of more, appropriately resourced, floating outreach or Housing First services may help address this by providing more appropriate options for people leaving supported housing. Alternatively, the visiting support provided to people in their own homes through the floating outreach approach can be tailored according to fluctuations in the individual's needs and, if resourced appropriately, may provide an alternative to the stepped supported housing pathway that necessitates recurrent moves for people as they progress in their recovery.

However, it ought to be acknowledged by service planners and commissioners that some individuals have a high level of support need which only settings with staff based on site (i.e. supported housing or residential care) are able to meet. In addition, some individuals prefer to live in congregate settings with staff on-site rather than individual tenancies as it can protect against isolation and loneliness which are often experienced in non-congregate settings (8, 98). A variety of supported accommodation models will therefore be required within a local area, and the level of provision should be based on the needs of the local population, as recommended by the NICE guideline on rehabilitation for adults with complex psychosis (86).

A possible implication of limited 'forward' move-on from supported accommodation is that services are encouraged to make 'sideway' moves, especially if services are commissioned and measured on the basis of their move-on rate. Sideway moves are likely to be disruptive to the individual and detrimental in their progress towards their optimal level of independence (8, 98). Most of the studies included in this review did not report sideway moves but the study by D'Avanzo and colleagues in Italy did (153). They reported that around a quarter (24%) of all moves were sideway moves. However, this study was conducted in 2004 and may not be representative of the rate of sideway moves now and in other countries. Further research on the rate of sideway moves should be conducted but it is worth noting that there are various reasons why a sideways move can be in the best interest of the individual. For example, someone wanting to move to a service which is closer to their family.

5.5.2 Services for homeless people with severe mental health problems

Almost all the included studies which investigated services for the homeless population were trials of the Housing First model, or of a similar type of model, and they all reported positive outcomes with regard to housing stability (176-181, 184-186, 205). A recent systematic review and meta-analyses of the Housing First approach also reported this finding but found less clear evidence for other outcomes including mental health symptoms, substance misuse, and employment (206). This was consistent with the largest trial included in our review which found no difference between Housing First and TAU in mental health symptoms (177). This study also reported no difference in inpatient days, number of emergency department visits, or arrests (177).

There is strong evidence Housing First does address homelessness amongst people with severe mental health problems, but further research is required on other important outcomes and on other populations. If found effective for non-homeless people with complex longer term mental health problems, then it should be considered how this approach could be implemented within the mental health rehabilitation pathway.

5.5.3 Deinstitutionalisation programmes

The included studies which looked at deinstitutionalisation programmes or services for people with previous long stay in psychiatric institutions, were consistent with the main conclusion drawn in Chapter 2 (Section 2.5); deinstitutionalisation can be successful if carefully planned and when the resource saved from closing the long stay psychiatric institutions is appropriately redirected to services and accommodation in the community. Most individuals in the included studies were successfully discharged from long stay hospitals to community settings without any clinical deterioration (49, 189, 195, 196, 200-202, 204). There were however a substantial minority who required higher levels of community support over a longer period and a more gradual approach to rehabilitation (49, 188, 199). Perhaps this is in keeping with the findings from the cohort studies included in the contemporary rehabilitation category that showed a relatively low rate of move-on to more independent settings (5, 153-155, 165, 175), and that there are people with higher levels of complex needs that require longer term supported accommodation.

5.5.4 Strengths and limitations

The main strength of this systematic review is its comprehensiveness. Six online databases were searched, which returned 14,498 articles including the articles returned in the updated search and after deduplication. This was supplemented by forward and backward citation searches of included studies. The search strategy was prospectively registered, and the reliability of the screening procedure and quality assessments were assured by independent second reviewers.

The main limitation of this review is that the included studies covered a broad range of rehabilitation services from several different countries with different healthcare systems, and the studies were, unfortunately, too heterogeneous for meta-analyses. The included studies

were broadly grouped into three categories for the narrative synthesis but within these categories are studies which investigate different types of intervention from different countries and settings. Therefore, even within these categories there still exists a great deal of heterogeneity. The term 'rehabilitation' has been used in mental health to describe a range of different approaches, and depending on how the intervention was described, it was not always possible to distinguish a mental health rehabilitation service from a general mental health service. Therefore, relevant studies may have been excluded. Future synthesis of research in this field would benefit from clearer description of the intervention or service being evaluated.

Although there was a broad range of approaches to mental health rehabilitation included, the review outcomes were narrow. This review only looked at inpatient service use and move-on but there are many other outcomes that are important to people using mental health rehabilitation services, such as social functioning, occupational actives, and general wellbeing. Also, the review only included quantitative research. Qualitative research in this field may provide important contextual and experiential evidence which is missing from the present review. Such research could be used to understand rehabilitation services in ways which could be used to improve them. For example, better understanding what is it about these services that people find helpful or unhelpful. However, a review of quantitative research which delves deeper into the structure and content of rehabilitation services (e.g. what are the services aiming to achieve, what are the services providing, and what training have practitioners received), may also help inform researchers and practitioners what it is about rehabilitation interventions that helps (or hinders) individuals. Finally, grey literature, trial registers, and non-English language studies were not searched, and therefore relevant studies from these sources were not included.

5.6 Summary

The field of mental health rehabilitation research is heterogenous and lacking in some areas. There is reasonable evidence to suggest that inpatient service use is reduced after an admission to an inpatient rehabilitation service or a move to a supported accommodation service. However, studies which address potential confounding, and studies which include comparison groups, are lacking, and therefore the capacity to infer causality is limited. It was

also found that the proportion of people who moved on from higher to lower supported accommodation was lower than what is widely expected by policy makers and therefore such timeframes may require adjustment. Finally, the review found strong evidence for the Housing First model in reducing homelessness but its effectiveness regarding other important outcomes and when targeting people with complex mental health problems who are not homeless remains unclear.

6 Chapter 6: Using CIFT CRIS to compare inpatient service use before and after an inpatient rehabilitation admission

6.1 Introduction

In this chapter I report on the study I conducted using the CIFT CRIS database to compare inpatient service use before and after an inpatient rehabilitation admission. Admission to an inpatient rehabilitation unit is usually the entry point for individuals on the rehabilitation pathway. Patients are usually referred to these services following a series of repeated admissions to acute inpatient units. Inpatient mental health rehabilitation units, and their role within the rehabilitation pathway, was described in further detail in Chapter 2 Section 2.8.2.

The research on the effectiveness of inpatient rehabilitation units was also described in Chapter 2 Section 2.8.2. The most relevant study for my purposes for the study described in this chapter was conducted by Bunyan and colleagues (150) (this study was also included in my systematic review reported in Chapter 5). They compared inpatient service use for 22 individuals admitted to one of three inpatient rehabilitation units provided by Oxleas NHS Foundation Trust in southeast London, in the two years before and two years after their rehabilitation admission. They found a reduction in inpatient service use after the rehabilitation admission compared to before. In the study reported in this Chapter, the aim is to corroborate Bunyan and colleagues' findings, by using the CIFT CRIS database to investigate a larger cohort over a longer before and after period, whilst adjusting for potential confounding variables. I also aimed to investigate patient characteristics associated with successful discharge.

The objectives of the study were to:

I. Use the CIFT CRIS database to identify a cohort of individuals with an admission to an inpatient mental health rehabilitation unit between 1st January 2010 and 30th April 2019
II. Extract sociodemographic, clinical characteristics, and inpatient service use from the CIFT CRIS structured records for each individual in the cohort
III. Validate the accuracy of the CRIS structured records relating to inpatient service use using free text records
IV. Compare mental health inpatient service use for the identified cohort of users of inpatient rehabilitation units before and after their rehabilitation admission
V. Compare sociodemographic and clinical characteristics of patients discharged from the inpatient rehabilitation unit to the community with those who were transferred to another inpatient service
VI. Compare sociodemographic and clinical characteristics of patients re-admitted to hospital within 12 months of discharge from the inpatient rehabilitation unit with those who were not re-admitted within 12 months

6.2 Methods

6.2.1 Design, cohort criteria, and setting

This study utilised an observational design, using longitudinal data from the CIFT CRIS database. The cohort was defined as any individual with a recorded admission to one of the trust's two high dependency inpatient rehabilitation units between 1st January 2010 and 30th April 2019, where the admission was for at least 84 days and the individual had at least 365 days of records available before and after this admission. The patient's first admission fulfilling these criteria was treated as their 'index' admission. The minimum of 365 days of records before and after the index admission was required to compare inpatient service use before and after the inpatient rehabilitation admission. Therefore, this study utilised records pertaining to the period between 1st January 2009 and 30th April 2020. The start of records for each patient was defined as the entry date for their first recorded 'progress note' (a free text record used by clinicians to record details of any contact with the service user) or the start date of their first recorded inpatient admission, whichever was recorded first. The patient's end of records was defined as the study end date (30th April 2020), or, if the individual died during the study period, their date of death as recorded on the CRIS database.

The year 2009 is the first full year of records available on the CIFT CRIS database, hence why 1st of January 2009 was selected as the start date for this study. The study end date refers to the date of the last update of the CIFT CRIS database prior to data extraction (30th April 2020).

Further details regarding the two high dependency inpatient rehabilitation units used in this study, and how they fit within the local mental health rehabilitation pathway in Camden and Islington, are reported in Chapter 2 Section 2.10. A 'high dependency inpatient rehabilitation unit' is a specific type of inpatient rehabilitation unit classified by the Royal College of Psychiatry's Rehabilitation Faculty in their typology of inpatient rehabilitation services (83). This typology is described in Chapter 2 Section 2.8.2. Henceforth in this chapter, these units are referred to simply as inpatient rehabilitation units. The sociodemographic and mental health morbidity of Camden and Islington are reported in Chapter 2 Section 2.9, and the development and function of CRIS is described in Chapter 3.

6.2.2 Data extraction

Data were initially extracted from structured fields in the CRIS database. For each individual in the cohort, gender, date of birth, ethnicity, ICD-10 diagnosis and date of diagnosis were extracted (the mental health diagnosis recorded nearest to the index admission start date was treated as the primary mental health diagnosis), as well as the start date, end date, and ward name for each inpatient admission. Inpatient data were initially extracted from the 'episodes table' (a section of the database for records which report the start and end date of when a patient was using a service, including inpatient and community services) but the data corresponded poorly with free text records. Admission data from the 'ward stay table' (like the episodes table but only for inpatient services) appeared to better correspond with the free text records and were therefore used instead of the episodes table. A sample of the records from the ward stay table were subsequently validated against free text records. The procedure for this validation is described below (Section 6.2.4). Each admission was classified as an acute admission, a psychiatric intensive care admission, a forensic admission, or a rehabilitation admission. This was done by creating a list of all the ward names recorded in the admission data, and together with my primary supervisor who is a consultant psychiatrist at CIFT and is familiar with all the inpatient services, we allocated each ward as an inpatient service type. Admissions were also noted as being within or outside CIFT. Transfers between

inpatient services (instances where an admission end date matched the admission start date of the next recorded admission) of the same type were coded as continued admissions, whereas transfers to a different type of inpatient service was coded as a new admission. For example, if an individual had an acute admission recorded as ending on 5th January 2012 and another acute admission recorded as starting on 5th January 2012, this would be coded as a single continued admission. However, if an individual had an acute admission ending on 5th January 2012 and a rehabilitation admission starting on 5th January, then the rehabilitation admission would be coded as a new admission.

Data from clinical assessments using the Health of the Nation Outcome Scale (HoNOS; (207)) were also extracted. The HoNOS is a clinician rated clinical and social functioning assessment scale with good psychometric properties which is used nationally and internationally (208-210). It consists of 12 items (1. aggression and overactivity, 2. self-harm, 3. problem drinking and drugs, 4. cognitive impairment, 5. physical impairment, 6. hallucinations and delusions, 7. depressed mood, 8. other mental health problem, 9. relationship problems, 10. daily living skills, 11. living conditions, and 12. occupation/activities), each rated from 0 to 4, with a score of 0 indicating that there is no problem in this area affecting health or functioning and a score of 4 indicating a very severe problem. The HoNOS is recorded routinely by NHS staff at admission and discharge from inpatient and community care and at least annually. HoNOS assessments were extracted for four time-points:

1. The first recorded assessment
2. Assessment recorded within three months of the index rehabilitation admission start date
3. Assessment recorded within three months of the index rehabilitation admission end date
4. The last recorded assessment

As there are no time constraints around the first and last recorded assessments, it is possible that for any individual one of these assessments could be the same assessment recorded at one of the other time-points. For example, if an individual had their first recorded HoNOS assessment within three months of their index rehabilitation admission start date, and there

were no other assessments recorded closer to the index start date, then for this individual the same HoNOS assessment was extracted for both these time-points.

6.2.3 Validation of referrals to the index inpatient rehabilitation admission from the community

As previously described (Section 6.2.2), inpatient service use data were extracted from structured fields, including admission start and end dates. Although some patients are referred to an inpatient rehabilitation service from the community, the vast majority are referred from another inpatient service (65). Therefore, free text records of any patient without an admission recorded immediately prior to their index admission were reviewed to confirm if the patient was indeed admitted from the community or whether details of an admission were missing from their structured records. This was done by reviewing 'progress notes' and relevant 'uploaded documents' recorded on or near the index admission start date. Progress notes are free text records used to describe healthcare contacts with patients or any changes in their healthcare. Uploaded documents include any document which has been uploaded to the individual's healthcare record, for example, GP letters, psychiatric assessments, and discharge summaries. When a 'missing' admission was discovered using this method (i.e. the admission prior to the index rehabilitation admission was reported in the free text records, but was missing in the structured records), the details of the admission (inpatient service type, start date, and end date) were added to the extracted dataset.

6.2.4 Validation of inpatient service use data

To validate the extracted structured data relating to inpatient service use, the start and end dates of admissions for a random 10% of the cohort were validated. The cohort was ordered by their randomly generated database identification number and the first 10% listed was selected for this validation. Similar to the process described above (Section 6.2.3), progress notes recorded on or near the admission start and end date recorded in the structured fields were reviewed for any mention of the admission. On the rare occasion there were no progress notes recorded on or near the start or end date, or these progress notes did not refer to an admission, any uploaded documents recorded around the start or end date were reviewed. Where a start or end date extracted from the structured records was inaccurate according to the free text records (progress notes or uploaded documents), the date was corrected in the

extracted dataset. It was agreed with my supervisors that if 5% or more of the admission dates checked did not match within one day of the corresponding date extracted from the free text records, then the remainder of the admissions pertaining to the cohort would also be checked.

6.2.5 Statistical methods

Data management and analyses were carried out using Stata 16.0 (211). Pre- and post-index rehabilitation admission inpatient service use were analysed using paired t-tests and negative binomial regression models. Five t-tests were conducted, comparing the number of inpatient days during the one, two, three, four, and five year(s) before the index admission with the same period of time after the index admission. These t-tests were reported as two-tailed tests. Histograms showing the distribution of the difference between pre- and post-index inpatient days were used to examine normality. This is a similar approach to the analysis conducted by Bunyan at al. (150).

Two negative binomial regression models were planned: an unadjusted model and a model adjusted for potential confounder variables. Negative binomial regression was selected over a linear regression model as the outcome data were count (i.e. a number of events over a period of time), and selected over a Poisson regression model as the outcome was over-dispersed (i.e. the variance was greater than the mean). To compare inpatient service use before and after the index admission whilst accounting for the variance in the exposure period before and after the index admission, inpatient days were entered as the response variable and the exposure period was entered as the exposure variable (the period of time pre- and post-index admission for which records were available), with a binary time variable added to the model (pre-index admission or post-index admission) (212). The regression coefficient was computed as an incident rate ratio to facilitate interpretation. The following variables were added as potential confounder variables to the adjusted model:

- age
- gender
- ethnicity (entered as a binary variable: White or non-White, as there were too few individuals from Asian, Black, mixed, and other minority ethnic groups)

- co-morbidity (an ICD-10 mental health or physical health diagnosis recorded during the study period which was different to the primary mental health diagnosis)
- the length of the index rehabilitation admission in days (this variable was entered as quartiles, with the second and third quartile combined to create the reference group on the basis that the first quartile may be an indicator of the rehabilitation admission being too short to provide an adequate 'dose' of rehabilitation, and the fourth quartile representing individuals who may be progressing slower than most)
- the calendar year in which the index rehabilitation admission commenced (as a proxy for policy or system changes over time, e.g. a new community rehabilitation service opening during the study period which facilitates discharge from inpatient rehabilitation services)
- whether the patient was admitted to the inpatient rehabilitation service from a forensic ward or not
- whether the patient was discharged from the index rehabilitation admission under a Community Treatment Order (CTO) or not
- The three HoNOS items most relevant to this patient group – 6. hallucinations and delusions, 9. relationship problems, and 10. daily living skills – recorded within three months of the index admission end date and entered as binary variables: no to mild problem (item score 0–2) or moderate to severe problem (3–4)

Finally, the sociodemographic and clinical characteristics of patients discharged from the index rehabilitation admission to the community were compared with patients transferred to another inpatient service. The same comparison was made between patients without any inpatient re-admission within 12 months following the index rehabilitation admission with patients re-admitted within 12 months (re-admitted patients included patients who were transferred from the rehabilitation unit to another inpatient service). Both comparisons were conducted using two-tailed chi-squared tests and t-tests.

6.2.6 Ethics

This study was granted the necessary ethical approvals. Further details are provided in Chapter 3 Section 3.11.

6.3 Results

6.3.1 Sociodemographic and clinical characteristics

Table 6 shows the sociodemographic and clinical characteristics of the study cohort. It comprised 172 individuals, with a mean age of 44 years (SD 14), most of whom were male (n=101, 59%), of White ethnicity (n=98, 57%), and single (n=155, 91%). Almost three-quarters had a primary mental health ICD-10 diagnosis of schizophrenia disorder (n=126, 73%), and around half had a mental or physical health co-morbidity (n=97, 56%). Sixteen individuals (9%) died during the study period at a mean age of 65 years (SD 12).

Table 6: Sociodemographic and clinical characteristics (N=172)

	n	%*
Age at the start date of the index admission (mean, SD)	44.2	13.8
Male	101	59
Ethnicity	-	-
White - British/Irish/Other	98	57
Asian	9	5
Black	51	30
Mixed or Other ethnicity	14	8
Marital status	-	-
Single	155	91
Divorced/Separated/Widowed	10	6
Married/Civil partner	6	4
Primary mental health ICD-10 diagnosis†	-	-
Schizophrenia disorder (F20-F24 & F26-F29)	126	73
Schizoaffective disorder (F25)	28	16
Manic episode (F30) or bipolar affective disorder (F31)	11	6
Other mental health disorder	7	4
Co-morbid mental health diagnosis‡	-	-
Substance misuse disorders (F10-F19)	44	26
Depression and anxiety disorders (F32-F48)	10	6
Disorders of adult personality and behaviour (F60-F69)	15	9
Co-morbid physical health diagnosis‡	-	-
Endocrine, nutritional and metabolic diseases (E00-E90)	41	24
Diseases of the nervous system (G00-G99)	8	5
Diseases of the circulatory system (I00-I99)	21	12
Diseases of the respiratory system (J00-J99)	10	6
Any other diagnosis (C00-D89, H00-H95 & K00-Q99)	24	14
Any co-morbidity§	97	56
Multiple co-morbidity**	55	32
Died during the study period	16	9
Age at death (mean, SD)	64.5	11.8

*Percentages are of the non-missing total, unless the percentage is for missing.

†The ICD-10 mental health diagnosis with a recorded date closest to the index rehabilitation admission start date (median distance from index start date: 101 days, first quartile and third quartile 26 – 211).

‡Whether this ICD-10 diagnosis has ever been recorded during the study period (01 January 2009 to 30 April 2020) for this individual, in addition to the 'Primary mental health ICD-10 diagnosis'.

§Any co-morbidity does not include 'Any other physical health diagnosis (C00-D89, H00-H95 & K00-Q99)' or ICD-10 codes: R00-Z99.

**More than one co-morbidity.

6.3.2 Validation of referral from the community to the index inpatient rehabilitation admission

Of the 172 patients identified in the cohort, 50 (29%) did not have an admission recorded immediately prior to their index rehabilitation admission in their structured records (i.e. the discharge date of the admission immediately prior to the index admission did not match the start date of the index admission), suggesting they were referred to the inpatient rehabilitation service from the community. However, through reviewing the free text records of these patients, it transpired 39 of the 50 (78%) in fact were transferred from another inpatient service to the inpatient rehabilitation unit (i.e. they had an admission which ended the same day the index rehabilitation admission started). Of these 39 patients, the admission they were transferred from was recorded in the structured fields but the end date of this admission or the start date of the index admission were inaccurate for 13 (39%) of the patients. 23 of the 39 patients (59%) were transferred to the index admission from an inpatient service not provided by CIFT. The remaining three individuals (8%) were transferred to the inpatient rehabilitation service from another inpatient service within the Trust but there was no record of the admission in the structured fields.

6.3.3 Validation of inpatient service use

The validation of start and end dates of inpatient admissions recorded in the structured fields was conducted for 18 individuals in the cohort (10%), by reviewing their free text records. For these 18 patients a total of 211 admissions were recorded in the structured fields, and therefore there were 422 start and end dates to validate. Of these 422 dates, 351 matched exactly (83%) and 409 matched within one day (97%). This met the threshold for an acceptable matching rate and so the inpatient service use dates pertaining to the remainder of the cohort were not checked.

6.3.4 Inpatient service use: The index rehabilitation admission, and pre- and post-index admission

Table 7 shows the length of time that CRIS records were available before and after the index rehabilitation admission, inpatient service use before and after the index admission, and the length of the index admission. The mean time that records were available before the index rehabilitation admission was 4.4 years (SD 2.2), and the median was 4.1 years (interquartile

range (IQR) 2.6 to 6.2). The mean inpatient days per person pre-index admission was 519 (SD 400), and the median was 420 days (IQR 262 to 653). The mean time that records were available post-index admission was 5.2 years (SD 2.4), and the median was 5.4 days (IQR 3.1 to 7.0). The total mean post-index admission inpatient days per person was 411 (SD 595) and the median was 153 days (IQR 0 to 583), indicating a positively skewed data distribution. There were 64 patients without any inpatient days during the post-index admission period (37%). This was the case for only one patient in the pre-index admission period (0.6%). The mean length of the index rehabilitation admission was 354 days (SD 223) and the median was 318 days (IQR 191 to 455).

Considering the study period (1st January 2009 to 30th April 2020) and the fact that the index rehabilitation inpatient admission had to be at least 84 days in length, with 365 days of records available before and after to be eligible for inclusion, the earliest possible start date of an index admission was 1st January 2010, and the latest possible start and end date was 5th February 2019 and 30th April 2019 respectively. This meant that there was less chance for an index admission starting in 2018 or 2019 compared to other years in the study period. This is demonstrated in Table 7 which shows that there were only six patients in the cohort with an index admission starting in 2018, and there were zero patients with an index admission which started in 2019. The number of patients with an index admission start date between 2010 and 2014 was consistent (between 22 and 25), but there were fewer between 2015 and 2017 (between 15 and 18).

Table 7: Index rehabilitation admission length, and pre- and post-index inpatient service use (N=172)

			Mean (SD)		Median (IQR)
Pre-index admission inpatient days			519 (400)		420 (262 to 653)
Pre-index admission number of admissions			3.8 (3.0)		3 (1.5 to 5)
***Pre-index admission period, in years**			4.4 (2.2)		4.1 (2.6 to 6.2)
Pre-index admission period proportion as an inpatient			40% (31%)		29% (18% to 52%)
Index rehabilitation admission inpatient days			354 (223)		318 (191 to 455)
Index rehabilitation admission start date calendar year (n, (%))			-	-	-
2010	**2011**	**2012**	22 (13)	22 (13)	24 (14)
2013	**2014**	**2015**	23 (13)	25 (15)	15 (9)
2016	**2017**	**2018**	18 (10)	17 (10)	6 (3)
2019	**-**	**-**	0 (0)	-	-
Post-index admission inpatient days			411 (595)		153 (0 to 583)
Post-index admission number of admissions			1.9 (2.4)		1 (0 to 3)
****Post-index admission period, in years**			5.2 (2.4)		5.4 (3.1 to 7.0)
Post-index admission period proportion as an inpatient			20% (26%)		8% (0% to 31%)

SD = standard deviation, IQR = interquartile range.
*The start date used to calculate the pre-index admission period is the date their first progress note is recorded or on the start date of their first recorded admission, whichever comes first within the study period (1 January 2009 to 30 April 2020).
**The end date used to calculate the post-index admission period is the date records are available up until (30 April 2020) or their date of death if one is recorded.

6.3.5 Pre- and post-index rehabilitation admission

Table 8 shows where individuals were before and after their index rehabilitation admission (i.e. the referral source and discharge location). The vast majority were transferred from another inpatient service (n=161, 94%) and only a few were admitted directly from the community (n=11, 6%). Three-quarters were discharged to the community (n=130, 76%), and the rest were transferred to another inpatient service (n=42, 24%). Around half were made subject to a Community Treatment Order (CTO) at the point of discharge from the index rehabilitation admission (n=96, 56%).

Table 8: Pre- and post-index rehabilitation admission location, and Community Treatment Order status at index admission discharge (N=172)

	n	%
Location immediately prior to the index rehabilitation admission	-	-
Other inpatient service	161	94
Acute inpatient (including psychiatric intensive care unit)	133	83
Forensic inpatient	17	11
Other inpatient	11	7
Community	11	6
Location immediately after the index rehabilitation admission	-	-
Other inpatient service	42	24
Community	130	76
Placed on Community Treatment Order at index rehabilitation admission discharge	96	56

6.3.6 HoNOS scores

Table 9 shows the HoNOS scores for each item at four-time points: the first HoNOS assessment during the study period; the start of the index rehabilitation admission (within three months of the start date); the end of the index rehabilitation admission (within three months of the end date); the last recorded HoNOS assessment during the study period. There was a high rate of missing data at the start and end of the index admission time-points, with total HoNOS scores missing for 75 (44%) and 71 (41%) patients, respectively. The completion rate was much higher for the other two timepoints. For the first and last time-points, total HoNOS scores were only missing for four (2%) patients and one (1%) patient, respectively. The total score was highest at the index admission start date (mean 33.1, SD 14.8), but remained stable across the other time-points (mean 27.4 to 27.5, SD 13.2 to 16.6). The three HoNOS items; 6. hallucinations and delusions, 9. relationship problems, and 10. daily living skills, tended to be scored as 3 (moderately severe problem) or 4 (severe to very severe problem) more often than other items across the time points. For example, in the first recorded HoNOS, 6. hallucinations and delusions, 9. relationship problems, and 10. daily living skills, 37%, 31%, and 28% of patients scored 3 or 4, respectively, whereas the next highest scoring item was 8. other mental health problems where 23% of patients scored 3 or 4.

Table 9: HoNOS scores (N=172)

First recorded HoNOS*	Score (n (%†))					Missing
Item	0	1	2	3	4	-
1. Aggression and overactivity	79 (47)	25 (15)	41 (25)	14 (8)	8 (5)	5 (3)
2. Self-harm	141 (85)	13 (8)	6 (4)	5 (3)	0 (0)	7 (4)
3. Problem drinking and drugs	104 (62)	18 (11)	21 (13)	19 (11)	6 (4)	4 (2)
4. Cognitive impairment	87 (52)	42 (25)	22 (13)	10 (6)	5 (3)	6 (3)
5. Physical impairment	106 (64)	21 (13)	23 (14)	13 (8)	3 (2)	6 (3)
6. Hallucinations and delusions	47 (28)	18 (11)	40 (24)	44 (26)	19 (11)	4 (2)
7. Depressed mood	94 (56)	43 (26)	19 (11)	8 (5)	4 (2)	4 (2)
8. Other mental health problem	76 (47)	16 (10)	33 (20)	28 (17)	10 (6)	9 (5)
9. Relationship problems	48 (29)	26 (15)	42 (25)	34 (20)	18 (11)	4 (2)
10. Daily living skills	36 (21)	24 (14)	60 (36)	44 (26)	4 (2)	4 (2)
11. Living conditions	85 (51)	22 (13)	31 (18)	18 (11)	12 (7)	4 (2)
12. Occupation/activities	77 (46)	34 (20)	26 (15)	24 (14)	7 (4)	4 (2)
Total standardised score‡ (mean, SD)	27.5	14.6	-	-	-	4 (2)
HoNOS at index start date§	**Score (n (%†))**					**Missing**
Item	**0**	**1**	**2**	**3**	**4**	**-**
1. Aggression and overactivity	33 (34)	25 (26)	19 (20)	15 (15)	5 (5)	75 (44)
2. Self-harm	87 (90)	2 (2)	5 (5)	2 (2)	1 (1)	75 (44)
3. Problem drinking and drugs	59 (61)	10 (10)	11 (11)	6 (6)	11 (11)	75 (44)
4. Cognitive impairment	58 (60)	8 (8)	21 (22)	9 (9)	1 (1)	75 (44)
5. Physical impairment	51 (53)	16 (16)	24 (25)	5 (5)	1 (1)	75 (44)
6. Hallucinations and delusions	16 (16)	9 (9)	24 (25)	37 (38)	11 (11)	75 (44)
7. Depressed mood	44 (46)	24 (25)	18 (19)	9 (9)	1 (1)	76 (44)
8. Other mental health problem	41 (43)	9 (9)	18 (19)	21 (22)	7 (7)	76 (44)
9. Relationship problems	17 (18)	13 (13)	29 (30)	29 (30)	9 (9)	75 (44)
10. Daily living skills	14 (14)	5 (5)	35 (36)	31 (32)	12 (12)	75 (44)
11. Living conditions	46 (47)	9 (9)	14 (14)	15 (15)	13 (13)	75 (44)
12. Occupation/activities	43 (44)	5 (5)	16 (16)	22 (23)	11 (11)	75 (44)
Total standardised score‡ (mean, SD)	33.1	14.8	-	-	-	75 (44)

HoNOS at index end date**	Score (n (%†))					Missing
Item	0	1	2	3	4	-
1. Aggression and overactivity	40 (40)	31 (31)	18 (18)	8 (8)	4 (4)	71 (41)
2. Self-harm	91 (90)	7 (7)	2 (2)	0 (0)	1 (1)	71 (41)
3. Problem drinking and drugs	61 (60)	16 (16)	14 (14)	8 (8)	2 (2)	71 (41)
4. Cognitive impairment	55 (54)	23 (23)	16 (16)	7 (7)	0 (0)	71 (41)
5. Physical impairment	55 (54)	18 (18)	19 (19)	6 (6)	3 (3)	71 (41)
6. Hallucinations and delusions	21 (21)	9 (9)	38 (38)	23 (23)	10 (10)	71 (41)
7. Depressed mood	48 (48)	19 (19)	27 (27)	7 (7)	0 (0)	71 (41)
8. Other mental health problem	44 (44)	12 (12)	26 (26)	16 (16)	2 (2)	72 (42)
9. Relationship problems	24 (24)	12 (12)	25 (25)	39 (39)	1 (1)	71 (41)
10. Daily living skills	15 (15)	20 (20)	39 (39)	25 (25)	1 (1)	72 (41)
11. Living conditions	58 (57)	12 (12)	14 (14)	14 (14)	3 (3)	71 (41)
12. Occupation/activities	47 (47)	17 (17)	22 (22)	14 (14)	1 (1)	71 (41)
Total standardised score‡ (mean, SD)	27.5	13.2	-	-	-	71 (41)
Last HoNOS recorded* **	**Score (n (%†))**					**Missing**
Item	**0**	**1**	**2**	**3**	**4**	**-**
1. Aggression and overactivity	93 (54)	34 (20)	26 (15)	11 (6)	7 (4)	1 (1)
2. Self-harm	153 (89)	10 (6)	4 (2)	4 (2)	0 (0)	1 (1)
3. Problem drinking and drugs	120 (70)	15 (9)	17 (10)	8 (5)	11 (6)	1 (1)
4. Cognitive impairment	83 (49)	34 (20)	30 (18)	19 (11)	5 (3)	1 (1)
5. Physical impairment	96 (56)	22 (13)	22 (13)	20 (12)	11 (6)	1 (1)
6. Hallucinations and delusions	55 (32)	19 (11)	42 (25)	44 (26)	11 (6)	1 (1)
7. Depressed mood	91 (53)	34 (20)	27 (16)	15 (9)	4 (2)	1 (1)
8. Other mental health problem	100 (58)	15 (9)	37 (22)	16 (9)	3 (2)	1 (1)
9. Relationship problems	39 (23)	29 (17)	48 (28)	44 (26)	11 (6)	1 (1)
10. Daily living skills	30 (18)	23 (13)	42 (25)	65 (38)	11 (6)	1 (1)
11. Living conditions	102 (60)	18 (11)	20 (12)	20 (12)	11 (6)	1 (1)
12. Occupation/activities	72 (42)	27 (16)	31 (18)	34 (20)	7 (4)	1 (1)
Total standardised score‡ (mean, SD)	27.4	16.6	-	-	-	1 (1)

*The first recorded HoNOS after the patient entered the cohort. This may also be the same HoNOS recorded as the HoNOS at index start date.

†Score percentages are calculated using the total number of patients with complete data for the corresponding item. Missing percentages are calculated using the total number of patients in the cohort.

‡Total score is out of 100 and standardised so that assessments with 1, 2, or 3 missing items are comparable. HoNOS assessments with more than 3 items missing are treated as missing for total standardised score.

§HoNOS at index start date is the HoNOS with the recorded date closest to their index admission start date, and within 84 days of their index start date. 21 of the 97 (22%) HoNOS assessments at the index start date was the same as the individual's first recorded assessment.

**HoNOS at index end date is the HoNOS with the recorded date closest to their index admission end date, and within 84 days of their index end date.

***The last recorded HoNOS before the patient leaves the cohort. This may also be the same HoNOS recorded as the HoNOS at index end date. 3 of the 171 (2%) last recorded HoNOS assessments was the same assessment recorded at index end date.

6.3.7 Comparing pre- and post-index admission inpatient service use

Table 10 shows the t-test results comparing the number of inpatient days during the one-year, two-year, three-year, and four-year periods before and after the index rehabilitation admission. The five-year comparison was not carried out as too few individuals in the cohort had this length of records before and after their inpatient rehabilitation admission (n=3). Although the cohort size decreased substantially with each additional year used in the comparison, there was a statistically significant difference between the number of inpatient days before and after the rehabilitation admission for each pre-post period, with patients having fewer inpatient days following discharge from the rehabilitation unit. Histograms showing the difference in inpatient days before and after did not suggest that this difference deviated substantially from a normal distribution. These histograms are presented in the Appendices (Appendix F).

Table 10: Pre-and post-index admission inpatient days comparison (N=172)

Pre- and post-exposure period	n	Pre-index admission		Post-index admission		p-value
		Mean	SD	Mean	SD	
One year	172	222.9	114.9	103.7	137.6	<0.001
Two years	123	354.6	203.4	185.5	248.6	<0.001
Three years	82	424.3	307.7	253.5	332.1	0.001
Four years	36	561.4	447.5	305.6	420.2	0.015

6.3.8 Negative binomial regression models

The following results are drawn from the unadjusted and adjusted negative binomial regression models comparing pre- and post-index admission inpatient days. In the unadjusted model, the incident rate ratio comparing the post-index admission period with the pre-index admission period was 0.504 (95% CI 0.358 to 0.710), meaning that inpatient days reduced by 50% in the period after the index admission compared to before. The incident rate ratio increased slightly to 0.555 (95% CI 0.351 to 0.877) when adjusted for potential confounding variables (age, gender, ethnicity, co-morbidity, length of index inpatient rehabilitation admission, the calendar year in which the index rehabilitation admission commenced, whether the patient was admitted to the inpatient rehabilitation service from a forensic ward or not, whether the patient was discharged from the index rehabilitation admission under a CTO or not, and the three HoNOS items most relevant to this patient group: 6. hallucinations

and delusions, 9. relationship problems, and 10. daily living skills). This meant that when accounting for the potential confounding variables, there was an estimated 44% reduction in inpatient days in the post-index admission period compared to the pre-index admission period. However, due to missing HoNOS scores, the adjusted model did not include the full cohort (n=100), whereas the unadjusted model did (n=172). Therefore, a post-hoc regression analysis was also conducted, adjusting for the same potential confounding variables with the exception of the three HoNOS items, so that the full cohort was included in the model (n=172). This model produced an incident rate ratio, 0.520 (95% CI 0.367 to 0.737), which fell between the incident rate ratios estimated by the unadjusted model and the adjusted model which included the HoNOS scores.

6.3.9 Comparing patients discharged from their index admission to the community with patients discharged to another inpatient service

Table 11 shows the comparison of the sociodemographic and clinical characteristics of patients discharged from the index rehabilitation admission to the community (n=130) with patients who were transferred to another inpatient service (n=42). The only evidence of a statistical difference was the mean age of the two groups (p=0.048); those who transferred to another inpatient service were younger at the point of the index rehabilitation admission (mean 40.5, SD 12.7) compared to those who were discharged to the community (mean 45.4, SD 14.0). The apparent lack of differences between these two groups should be interpreted with caution given small cell sizes in some cases and the imbalance in the size of the two groups.

Table 11: The characteristics of patients discharged from their index inpatient rehabilitation admission to the community and patients transferred to another inpatient service (n=172)

	Discharged to community (n=130)		Transferred to another inpatient service (n=42)		p-value
	n	%	n	%	
Age (mean, SD)	45.4	14.0	40.5	12.7	0.048
Female	50	38	21	50	0.187
Male	80	62	21	50	-
Ethnicity	-	-	-	-	-
White - British/Irish/Other	75	58	23	55	0.739
Asian	6	5	*	-	0.523
Black	39	30	12	29	0.860
Mixed ethnicity	6	5	*	-	0.523
Other	*	-	*	-	0.815
Marital status	-	-	-	-	-
Single	115	88	40	95	0.201
Divorced/Separated/Widowed	9	7	*	-	0.274
Married/Civil partner	5	4	*	-	0.653
Primary mental health ICD-10 diagnosis†	-	-	-	-	-
Schizophrenia disorder	96	74	30	71	0.758
Schizoaffective disorder	20	15	8	19	0.576
Manic episode or bipolar affective disorder	8	6	*	-	0.820
Other mental health disorder	6	5	*	-	0.524
Co-morbid mental health diagnosis‡	-	-	-	-	-
Substance misuse disorders	35	27	9	21	0.478
Depression and anxiety disorders	9	7	*	-	0.274
Disorders of adult personality and behaviour	10	8	5	12	0.400
Co-morbid physical health diagnosis‡	-	-	-	-	-
Endocrine, nutritional and metabolic diseases	33	25	8	19	0.402
Diseases of the nervous system	6	5	*	-	0.969
Diseases of the circulatory system	14	11	7	17	0.310
Diseases of the respiratory system	8	6	*	-	0.738
Any other diagnosis	19	15	5	12	0.659
Co-morbidity§	73	56	24	57	0.911
Multiple co-morbidity**	43	33	12	29	0.586
Location prior to index rehab inpatient admission	-	-	-	-	-
Other inpatient service	120	92	41	98	0.221
Community	10	7	*	-	-
Died during the study period	15	12	*	-	0.076
Age at death (mean, SD)	64.9	12.1	*	-	-

*Supressed due to small numbers.

†The ICD-10 mental health diagnosis with a recorded date closest to the index rehabilitation admission start date (median distance from index start date: 101 days, IQR: 26–211).

‡Whether this ICD-10 diagnosis has ever been recorded during the study period (01 January 2009 to 30 April 2020) for this individual, in addition to the 'Primary mental health ICD-10 diagnosis'.

§Any co-morbidity does not include 'Any other physical health diagnosis (C00-D89, H00-H95 & K00-Q99)' or ICD-10 codes: R00-Z99.

**More than one co-morbidity.

Table 12 shows individuals' inpatient service use before and after the index inpatient rehabilitation admission, as well as the length of the index admission and the calendar year in which the index admission started. This information is presented for the group discharged to the community following their index admission and the group transferred to another inpatient service. The proportion of days spent as an inpatient before the index rehabilitation admission was less for those discharged to the community (mean 36%, SD 29%) compared to those transferred to another inpatient service (mean 50%, SD 33%; t=2.6, df=170, p=0.009). The proportion of days spent as an inpatient in the period after the index rehabilitation admission was also lower for those discharged to the community (mean 14%, SD 24%) compared to those transferred to another inpatient service (mean 38%, SD 26%; t=5.5, df=170, p<0.001). Amongst the group discharged to the community, 64 (49%) individuals had no further recorded inpatient service use following their index inpatient rehabilitation admission. There was no difference between the two groups in the calendar year in which the index admission started (χ^2=8.7, df=8, p=0.370), suggesting the differences between the groups cannot be explained by systematic differences (e.g. a change in the local mental health rehabilitation pathway such as a new community service).

Table 12: Index rehabilitation admission length and pre- and post-index inpatient service use of patients discharged from their index inpatient rehabilitation admission to the community, and for patients transferred to another inpatient service (N=172)

	Discharged to community (n=130)		Transferred to another inpatient service (n=42)	
	Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)
Pre-index admission inpatient days	486 (401)	398 (240 to 587)	621 (387)	554 (354 to 755)
Pre-index admission number of admissions	3.7 (2.9)	3 (1 to 5)	3.9 (3.3)	3 (2 to 5)
***Pre-index admission record availability period, in years**	4.5 (2.2)	4.2 (2.7 to 6.1)	4.3 (2.5)	3.9 (2.2 to 6.3)
Proportion of days spent as an inpatient during the pre-index admission period	36% (29%)	27% (16% to 45%)	50% (33%)	37% (23% to 92%)
Index rehabilitation admission length (days)	362 (219)	321 (206 to 475)	331 (237)	295.5 (129 to 375)
Index rehabilitation admission start date calendar year (n, (%))	-	-	-	-
2010 **2011** **2012**	14 (11)	15 (12)	18 (14)	8 (19)	7 (17)	6 (14)
2013 **2014** **2015**	19 (15)	20 (15)	15 (12)	4 (10)	5 (12)	0 (0)
2016 **2017** **2018**	13 (10)	12 (9)	4 (3)	5 (12)	5 (12)	2 (5)
2019 **-** **-**	0 (0)	-	-	0 (0)	-	-
Post-index admission inpatient days	298 (527)	12.5 (0 to 358)	760 (660)	463 (261 to 1066)
Post-index admission number of admissions	1.6 (2.3)	1 (0 to 3)	2.7 (2.5)	2 (1 to 3)
†Post-index admission record availability period, in years	5.0 (2.3)	4.9 (3.0 to 6.8)	5.7 (2.5)	5.8 (3.4 to 7.6)
Proportion of days spent as an inpatient during the post-index admission period	14% (24%)	0% (0% to 19%)	38% (26%)	30% (20% to 50%)

IQR = interquartile range.

*The start date used to calculate the pre-index admission period is the date their first progress note is recorded or on the start date of their first recorded admission, whichever comes first within the study period (1 January 2009 to 30 April 2020).

†The end date used to calculate the post-index admission period is the date records are available up until (30 April 2020) or their date of death if one is recorded.

6.3.10 Comparing patients re-admitted and not re-admitted within 12 months of discharge from their index rehabilitation admission

Table 13 shows the results of comparisons of sociodemographic and clinical characteristics of patients who were (n=83) and were not (n=89) re-admitted within 12 months following their index rehabilitation admission. There was evidence of differences, albeit of varying strength, between the groups regarding several sociodemographic and clinical characteristics. Those who were re-admitted within one year were: more likely to be female (48% vs 35%, p=0.075); less likely to be White (49% vs 64%, p=0.053); more likely to be Black (37% vs 22%, p=0.033); more likely to have a co-morbid disease of the circulatory system (17% vs 8%, p=0.072); more likely to have any co-morbidity (67% vs 46%, p=0.005); and more likely to be admitted to the index rehabilitation admission directly from another inpatient service rather than from the community (98% vs 90%, p=0.039). However, cell sizes were small for some of these comparisons and therefore caution should be applied in the interpretation of these results.

Table 13: The characteristics of patients not re-admitted and re-admitted within one year of their index rehabilitation admission discharge (N=172)

	Not re-admitted within one year (n=89)		Re-admitted within one year (n=83)		p-value
	n	%	n	%	
Age (mean, SD)	45.5	13.7	42.8	14.0	0.200
Female	31	35	40	48	0.075
Male	58	65	43	52	-
Ethnicity	-	-	-	-	-
White - British/Irish/Other	57	64	41	49	0.053
Asian	5	6	*	-	0.814
Black	20	22	31	37	0.033
Mixed ethnicity	5	6	*	-	0.814
Other	*	-	*	-	0.594
Marital status	-	-	-	-	-
Single	80	91	75	90	0.917
Divorced/Separated/Widowed	5	6	5	6	0.909
Married/Civil partner	*	-	*	-	0.931
Unknown/Missing	*	-	*	-	-
Primary mental health ICD-10 diagnosis†	-	-	-	-	-
Schizophrenia disorder	69	78	57	69	0.190
Schizoaffective disorder	11	12	17	20	0.149
Manic episode or bipolar affective disorder	*	-	7	8	0.291
Other mental health disorder	5	6	*	-	0.287
Co-morbid mental health diagnosis‡	-	-	-	-	-
Substance misuse disorders	19	21	25	30	0.188
Depression and anxiety disorders	5	6	5	6	0.909
Disorders of adult personality and behaviour	9	10	6	6	0.503
Co-morbid physical health diagnosis‡	-	-	-	-	-
Endocrine, nutritional and metabolic diseases	18	20	23	28	0.250
Diseases of the nervous system	*	-	5	6	0.409
Diseases of the circulatory system	7	8	14	17	0.072
Diseases of the respiratory system	*	-	6	7	0.444
Any other diagnosis	11	12	13	16	0.532
Co-morbidity§	41	46	56	67	0.005
Multiple co-morbidity**	25	28	30	36	0.258
Location prior to index rehab inpatient admission	-	-	-	-	-
Other inpatient service	80	90	81	98	0.039
Community	9	10	*	-	-
Died during the study period	10	11	6	7	0.366
Age at death (mean, SD)	62.7	11.6	67.7	12.5	0.428

*Supressed due to small numbers.

†The ICD-10 mental health diagnosis with a recorded date closest to the index rehabilitation admission start date (median distance from index start date: 101 days, IQR: 26–211).

‡Whether this ICD-10 diagnosis has ever been recorded during the study period (01 January 2009 to 30 April 2020) for this individual, in addition to the 'Primary mental health ICD-10 diagnosis'.

§Any co-morbidity does not include 'Any other physical health diagnosis (C00-D89, H00-H95 & K00-Q99)' or ICD-10 codes: R00-Z99.

**More than one co-morbidity.

Table 14 shows the inpatient service use before and after the index rehabilitation admission, as well as the length of the index admission and the calendar year in which the index admission started, for both the individuals who were not re-admitted to an inpatient service within 12 months of their discharge from their index admission and for those who were re-admitted within 12 months. The proportion of days spent as an inpatient before the index rehabilitation admission was less for the group who were not re-admitted (mean 34%, SD 30%) than those who were re-admitted (mean 46%, SD 31%), but the evidence for a difference was weak ($t=2.6$, $df=170$, $p=0.011$). The proportion of time spent as an inpatient after the index admission was also less for the group who were not re-admitted (mean 3%, SD 8%) than those who were re-admitted (mean 38%, SD 27%; $t=11.7$, $df=170$, $p<0.001$). Amongst those who were not re-admitted, 64 (72%) individuals had no further recorded inpatient service use after their index inpatient rehabilitation admission.

Table 14: Index rehabilitation admission length and pre- and post-index inpatient service use of patients not re-admitted and re-admitted within one year of their index admission discharge (N=172)

	Not re-admitted within one year (n=89)		Re-admitted within one year (n=83)	
	Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)
Pre-index admission inpatient days	481 (440)	356 (224 to 570)	560 (351)	502 (349 to 705)
Pre-index admission number of admissions	3.4 (2.8)	3 (1 to 5)	4.1 (3.2)	3 (2 to 6)
***Pre-index admission record availability period, in days**	1680 (795)	1581 (1048 to 2260)	1543 (830)	1407 (800 to 2188)
Proportion of days spent as an inpatient during the pre-index admission period	34% (30%)	25% (13% to 41%)	46% (31%)	35% (23% to 70%)
Index rehabilitation admission length (days)	385 (236)	337 (216 to 492)	321 (205)	286 (153 to 394)
Index rehabilitation admission start date calendar year (n, (%))	-	- -	-	- -
2010 2011 2012	5 (6)	13 (15) 11 (12)	17 (20)	9 (11) 13 (16)
2013 2014 2015	15 (17)	13 (15) 11 (12)	8 (10)	12 (14) 4 (5)
2016 2017 2018	6 (7)	11 (12) 4 (4)	12 (14)	6 (7) 2 (2)
2019 - -	0 (0)	- -	0 (0)	- -
Post-index admission inpatient days	62 (149)	0 (0 to 20)	785 (663)	574 (261 to 1199)
Post-index admission number of admissions	0.7 (1.5)	0 (0 to 1)	3.1 (2.5)	3 (1 to 4)
†Post-index admission record availability period, in days	1719 (844)	1746 (890 to 2438)	2059 (847)	1199 (1414 to 2774)
Proportion of days spent as an inpatient during the post-index admission period	3% (8%)	0% (0% to 1%)	38% (27%)	31% (16% to 55%)

*The start date used to calculate the pre-index admission period is the date their first progress note is recorded or on the start date of their first recorded admission, whichever comes first within the study period (1 January 2009 to 30 April 2020).

†The end date used to calculate the post-index admission period is the date records are available up until (30 April 2020) or their date of death if one is recorded.

6.4 Discussion

This study found that admission to a high dependency inpatient rehabilitation unit was associated with a substantial reduction in subsequent inpatient service use. Inpatient service use was reduced by around half in the period after the rehabilitation admission compared to the period before. Over a third of patients had no inpatient service use after their

rehabilitation admission. Adjusting for potential confounding variables had minimal impact on this estimate. This finding is also consistent with what was previously found by Bunyan et al. (150), that inpatient rehabilitation reduces subsequent inpatient service use. However, the current study strengthens this finding through the inclusion of a larger cohort, longer exposure periods, and by controlling for potential confounding variables. The finding is of relevance to patients as it suggests that inpatient rehabilitation is a clinically effective intervention, facilitating greater stability and less time in hospital, which, although not examined in this study, is likely to enable a better quality of life (70). This finding also strongly supports the potential cost-effectiveness of inpatient rehabilitation services. Inpatient service use is the costliest component of mental health care therefore an intervention which reduces inpatient service ought to bring economic benefits to the system. However, this crude inference ignores that the intervention itself is a type of inpatient service and therefore costly in of itself, especially given the long average length of admission. In depth health economic analyses which compares the cost of the inpatient rehabilitation admission with the saved costs through reduced service use, not just inpatient service use, should form part of future studies on inpatient rehabilitation.

High dependency inpatient rehabilitation services are a common starting point for individuals accessing the mental health rehabilitation pathway (65). The findings from this study support the importance of their role in this pathway, providing a fundamental step towards recovery for many individuals. Most patients are referred because they have had repeated acute admissions or are stepping down from a forensic inpatient service. The purpose of the rehabilitation admission is to support people to gain and regain skills to live in more independent settings. They do this by providing a comprehensive approach to mental health rehabilitation that involves a full multidisciplinary team (psychiatrists, psychologists, occupational therapists, nursing staff, and support workers) to assess and address people's needs. Specifically, this involves optimisation of people's medication, addressing physical health co-morbidities, providing a range of activities, and individual and group-based support to encourage the development of everyday living skills (such as self-care, shopping, cooking) and social engagement, supporting people to connect with their communities through community-based activities (leisure, education, work-related), support to engage with their family as well as supporting the family to help them understand the person's mental health

problems, and addressing practical social needs (such as housing and welfare benefits). The fact that the majority were discharged to the community and had a substantial reduction in their subsequent inpatient service use, suggests that inpatient rehabilitation services are successful in meeting their purpose for most individuals.

Nevertheless, a substantial minority were not discharged but transferred to another inpatient service. The only difference between those who were and were not discharged found in this study was their age at the start of the index rehabilitation admission; patients discharged to the community were older. Age and length of contact with mental health services has previously been found to be positively correlated amongst users of inpatient rehabilitation services (70). It is therefore plausible that older patients had achieved a higher level of stability in their mental health problems through longer contact with services and treatment. Alternatively, it could be that older patients were more likely to be discharged to more highly supported accommodation in the community which mitigated the chance of further relapse. Unfortunately, neither of these hypotheses can be explored within the data available for this study but testing these hypotheses would be an interesting avenue for further research.

The lack of any other differences between the patients discharged to the community and those transferred to another inpatient service may in part be due to the small numbers in some of the comparisons that meant there was inadequate power to detect differences. One of the assumptions of the χ^2 is that the minimum cell size should not be below five (213) and this assumption was not met in several comparisons in this study. The comparison of the mean age of the two groups used a t-test, and although the groups were imbalanced, the group sizes were not especially small.

There were more differences found between individuals re-admitted within 12 months following their index rehabilitation admission compared to those not re-admitted within 12 months. Re-admission does not always represent a poor outcome and may be a necessary stage in an individual's recovery, but it is likely to be associated with a worsening of mental health and is usually considered a negative outcome. In this comparison, female patients were found to be more likely to be re-admitted than male patients. Women experience multiple inequalities associated with their gender which impact negatively on their mental health

(214), including social inequalities (e.g. unequal pay), gender expectations (e.g. caring for others), and increased likelihood of experiencing trauma such as physical and sexual violence (215). Sexual abuse is associated with a range of lifetime psychiatric diagnoses, though not schizophrenia (216). It is unclear how prevalent these experiences were among women in this study or among women using mental health rehabilitation services in general. Further research that considers the role of gender in mental health rehabilitation is needed to corroborate whether women do indeed have poorer outcomes after a period of inpatient rehabilitation than men and to investigate the factors associated with this if so.

Patients who were re-admitted were also more likely to be from a Black or minority ethnic group. A meta-analysis by Halvorsrud and colleagues investigating pathways to care for people with psychosis in England found that Black African and Black Caribbean patients were three times more likely to be detained under the MHA compared to White patients, and were also less likely to have General Practitioner involvement in their care (217). A further meta-analysis by Barnett and colleagues using international data and not limited to people with psychosis, found Black African and Black Caribbean patients were twice as likely to have a compulsory mental health admission (218). They also found Black African patients were twice as likely to be re-admitted to hospital. Barnett et al. add that the most common explanations for these findings reported in their included studies were "increased prevalence of psychosis, increased perceived risk of violence, increased police contact, absence of or mistrust of General Practitioners, and ethnic disadvantages" (p.305 (218)) in Black minority ethnic groups compared to White groups. This inequality affects the pathway to mental healthcare and therefore the pathway to mental health rehabilitation. People from Black minority ethnic groups are more likely to access mental healthcare later and via emergency services rather than via their general practitioner (217), and therefore have a more severe mental health problem at first presentation and a more traumatic experience of care. This, in combination with other social and environmental factors such as racism, poverty, and social exclusion, contributes to poorer mental health outcomes (219), such as re-admission following a mental health inpatient rehabilitation admission.

Finally, patients who were re-admitted were also more likely to have a co-morbidity. Co-morbidities are common amongst this patient group (71, 220), and add complexity to their

treatment and successful recovery. Improving outcomes for people with mental health problems and other comorbid conditions is widely recognised as an urgent issue and there are national and international plans to address this by providing greater integration and collaboration between healthcare systems (221, 222). There needs to be careful consideration of how these changes are applied to local mental health rehabilitation pathways and systems. It is therefore encouraging that in England, the NICE guidelines for the rehabilitation of adults with complex psychosis already emphasise the importance of integrated care and close liaison with primary care and process for physical health monitoring (86).

Although this study indicates there is a substantial reduction in inpatient service use after an inpatient rehabilitation admission, there is considerable variation between individuals and around half are re-admitted within 12 months of discharge. As well as the differences in characteristics discussed above, further work is needed to identify whether other variables (not examined in this study) might predict the risk of relapse and re-admission (e.g. psychiatric symptoms, social functioning, substance misuse). This would assist in the development of individualised relapse prevention plans and potentially reductions in re-admission.

6.4.1 Limitations

There are four broad limitations to this study which should be considered when interpreting the findings. These limitations are described in turn, possible solutions are suggested for each, and areas for future research are explored.

6.4.1.1 The limitations of CRIS and secondary research

This study used data primarily collected for the purpose of delivering healthcare. The limitations which commonly apply to secondary research (223) therefore also apply here and were previously explained in Chapter 3 Section 3.2. Inpatient service use was selected as the primary outcome for this study as it is clinically relevant but also one which is expected to be reliably recorded by clinicians, and therefore available in the CRIS database. An inpatient admission is a significant moment in a person's healthcare history which may include being detained under the Mental Health Act 1984. The expectation that inpatient service use would be reliably recorded was tested by validating a sample of the structured records relating to

admissions using free text records. The records were sufficiently accurate, but this approach only involved reviewing free text records recorded on and around the admission dates recorded in the structured fields. It was not feasible in this study to manually review all free text records for mention of inpatient admissions. Therefore, this approach could only validate admissions recorded in the structured fields, it could not identify any admissions that were missing from the structured records.

In another validation, the free text records were reviewed for individuals who did not have a recorded admission in the structured records immediately before their index inpatient rehabilitation admission. In other words, the free text records were reviewed for patients who appeared to be admitted to their index admission from the community rather than transferred from another inpatient service. This did reveal a high number of missing admissions and errors in the dates of admissions in the structured records. Most of the missing admissions were because the patient had been admitted to a non-CIFT inpatient service before their index admission. This occurs when the NHS Trust does not have a suitable bed within their Trust and must refer the individual to an out of area provider. For example, CIFT do not provide any forensic inpatient services so Camden and Islington residents requiring a forensic admission must be treated outside the Trust. Considering the mental health rehabilitation pathway, a forensic admission is much more likely to occur before rather than after the inpatient rehabilitation admission (70). Therefore, this validation will have identified most of the forensic admissions for this cohort, but the high rate of missingness in the structured data fields is still concerning and should be considered in future research.

There is a mechanism for CIFT clinicians to record non-CIFT inpatient admissions, but it is understandable that these admissions are less likely than CIFT admissions to be recorded in the structured fields. However, it seems very unlikely that there would be no mention in the progress notes of a patient's admission, even if outside of the Trust, because the Trust are still responsible for finding the appropriate hospital placement for their patient and should remain involved in the person's care. These validation exercises suggest that the mining of free text records in EHR datasets could be used to improve the accuracy of inpatient admission data. Natural language processing (NLP), a field which crosses linguistics, computer science and artificial intelligence, has already been applied to CRIS databases to extract

information not available or not well completed in the structured fields, such as occupation (118) and medication prescriptions (224). The NIHR Maudsley Biomedical Research Centre has published a library of all the available NLP applications (225). To date, an NLP application for inpatient admissions has not been developed. NLP could also be used to investigate other outcomes. Inpatient service use is an objective outcome and a reliable indicator of successful progress along the mental health rehabilitation pathway. However, there are other factors which contribute to quality of life and can measure successful progress, such as meaningful activity, relationships, and a general sense of purpose. If NLP could reliably capture these indicators of progress, it would potentially enhance opportunities to investigate the effectiveness of inpatient rehabilitation and the broader rehabilitation pathway.

Multisite data linkage is also an effective way of improving the utility of EHR databases for research (226), providing another method to validate data as well as providing new additional data. The SLaM CRIS database has been linked to the Hospital Episode Statistics (HES) database (227, 228). The HES database contains information about all NHS mental and physical health hospital admissions and presentations at Accident and Emergency departments. The HES database also includes NHS-funded admissions in non-NHS services. For example, when a suitable local NHS inpatient bed is unavailable the NHS may refer the patient to an independent sector service. Linking the HES database to the CIFT CRIS database would facilitate identification of non-CIFT admissions for CIFT patients, and also provide a way to validate CIFT admissions.

Missing data is often an issue for secondary research. Although there were no missing data for the reported sociodemographic and clinical characteristics in the current study, there were missing data for HoNOS scores. The HoNOS, a clinician rated clinical and social functioning assessment scale, is routinely used within the NHS following clinical assessments. It is usual practice for a clinical assessment to be carried out at the point of admission and discharge. Despite this, around half of the cohort did not have a recorded HoNOS assessment within three months of the start or end date of the index rehabilitation admission. There were much better completion rates for the first and last recorded HoNOS assessments, but this was to be expected as there was far less restriction of when these assessments could be recorded.

Historically, there was little incentive for clinical staff to collect and record routine outcome assessments and so it was often disregarded by staff (229). This changed in 2012 when the Department of Health and Social Care introduced payment by results in the NHS, a new system for funding healthcare services based on routine assessment data (230). Although this has never been implemented in mental health services, there was a great deal of support and encouragement that staff complete HoNOS ratings at least annually for all patients. However, there has been criticism of the HoNOS as to whether it is a reliable outcome measure for use in mental health services (231) and so its utility in research may be limited. Furthermore, there may be specific context biases which make it inappropriate to compare HoNOS assessments completed in different settings and contexts. Luo and colleagues (232) analysed HoNOS assessments for patients which had been completed at inpatient discharge and then soon afterwards at community intake. Although there was only a median of four days between the two assessments, the overall HoNOS score increased by a mean of 4.11 points (SD 6.97), indicating a considerable worsening of health problems over a short period. The change in the score was found not to be affected by the experience or professional background of the assessor and appeared not to be due to a sudden change in the patient's health. Instead, the change in scores appeared to be due to the differing context between the two assessments. Whilst HoNOS scores are useful to analyse, they should be interpreted with caution.

6.4.1.2 Selection of confounders

The primary analysis included an unadjusted and two adjusted regression models. The selection of potential confounders for the adjusted model may have under- or over-adjusted the effect estimate. Only three of the 12 HoNOS items were adjusted for, they were: 6. hallucinations and delusions, 9. relationship problems, and 10. daily living skills. The rational for this was to select the HoNOS items which are most relevant to individuals with complex psychosis and the areas which rehabilitation services aim to improve. This rational was partially supported by these items scoring higher (i.e. more severe) than other items on the scale. However, there are other relevant items on the HoNOS for this patient group. The most relevant perhaps is item 4. cognitive impairment as it is a recognised difficulty for this group and may affect the effectiveness of rehabilitation. Therefore, there is also rational for

including this, and potentially other HoNOS items, as confounders. The impact of including and excluding HoNOS items as confounders though is limited given the degree of missing data for these variables and the other issues regarding the HoNOS measure as described in the previous section (6.4.1.1)

Conversely, treating the length of the rehabilitation admission as a potential confounder may have contributed to over-adjustment. As explained previously (Section 6.2.5), this variable was selected as a measure of the 'dose' of rehabilitation received, and therefore may confound the relationship between the exposure (inpatient rehabilitation admission) and outcome (post-rehabilitation inpatient service use). However, because this variable does measure the amount of treatment received, it may also explain some of the causal effect the treatment has on the outcome and is therefore an unsuitable confounder. It is unlikely though that excluding the length of the rehabilitation admission as a confounder in the adjusted models would have any considerable effect on the effect estimate given the relevant small different in effect estimates between the unadjusted model and the adjusted model without the HoNOS items.

6.4.1.3 The generalisability of findings

The lack of generalisability of these findings should also be considered as this study used data from a single inner-city London NHS Trust. However, the findings are consistent with the results from similar studies using different data sources (146, 147, 150, 171) and demonstrate the use of de-identified EHR databases in the evaluation of inpatient rehabilitation services. Nevertheless, replicating this study in other CRIS sites in England would add to the credibility and generalisability of the findings. There are several potential sites where such a replication study could be conducted. In addition to CIFT and SLaM, there are 12 other NHS Trusts where CRIS has been deployed (233), with catchment areas that are less urban than CIFT and located outside of London.

6.4.1.4 The lack of a comparison group

Like other studies investigating inpatient rehabilitation and inpatient service use (234), this study is observational in its design and does not include a control comparison group but

instead uses a pre-post comparison. The capacity to infer causality from such a study design is limited because they are affected by 'maturation' and 'regression to the mean' (235). Applied to the current study, this means that the reduced inpatient service use observed after admission to a mental health inpatient rehabilitation unit compared to before the admission could be due to individuals requiring less inpatient service use over time regardless of the intervention (maturation), and this effect being stronger for individuals who previously had a higher level of inpatient service use (regression to the mean). It seems unlikely that the magnitude of the difference in inpatient service use before and after a rehabilitation admission seen in this study can be entirely explained by these factors, and that it is reasonable to assume the intervention has had some effect in reducing inpatient service use. However, a study with a comparison group would help disentangle these factors and allow for greater confidence in the causal relationship between an inpatient rehabilitation admission and reduced inpatient service use.

The gold standard design for a study testing an intervention is a randomised controlled trial (RCT), but RCTs are not appropriate for many interventions and inappropriate for the current scenario. There are clear clinical indications for a referral to an inpatient rehabilitation service: a complex longer term mental health problem (usually a diagnosis of schizophrenia or schizoaffective disorder) which is treatment resistant (i.e. the person's symptoms have not responded to first-line medications) and recurrent mental health hospital admissions due to the severity of their mental health needs (86). It would be unethical to randomise an individual with such a presentation to interventions where there is no equipoise between the interventions on the expected outcomes. Studies using alternative methods of comparison to identify a valid control group, such as propensity score matching (236), may provide a viable alternative approach.

6.5 Summary

The study reported in this Chapter adds to the existing evidence that inpatient service use is reduced after an inpatient rehabilitation admission and demonstrates the utility of using de-identified electronic health records, such as CRIS, to evaluate inpatient rehabilitation services. Studies using large databases like CRIS usually have large cohort sizes, but this study shows that smaller cohorts can also be examined using CRIS. This study also demonstrates that with

smaller cohorts it is feasible to conduct validation checks which can improve the accuracy and reliability of the data. Replicating the study at other CRIS sites would improve the generalisability of the current findings, and further developments in NLP and database linkages would improve both the availability and reliability of data.

The current evidence on mental health inpatient rehabilitation units and their effect on inpatient service use, including the current study, is exclusively drawn from research with a single group study design. This limits the degree to which causality can be inferred. Traditional approaches to address this, such as RCTs, are not appropriate in this field of research for the reasons previously described (Section 6.4.1.4), but other approaches which aim to mimic RCTs using observational data, such as propensity score matching methods, may provide a viable alternative.

7 Chapter 7: Using propensity score matching to identify a valid comparison group for a mental health inpatient rehabilitation group

7.1 Introduction

Inference of causality is limited in study designs with a single group (235). A study design with at least two groups allows for the comparison between groups and infer that any difference identified is related to the group to which the individual belongs. This holds true as long as anything which confounds the relationship between group membership and the outcome has been accounted for. In other words, if there is something which affects both group membership and outcome, otherwise known as a confounding variable, then it may be that it is this variable, or variables, that is causing the effect on the outcome rather than group membership (or it could be a combination of both).

Confounding often occurs in observational studies where groups are compared. This is because there are usually systematic reasons why someone belongs to one group and not another. For example, someone is more likely to receive treatment if their clinical presentation indicates they would benefit from treatment, or if the individual seeks out treatment. Such examples result in selection bias and make any comparison between the groups inappropriate, or at least limited, because the individuals differ between groups on factors other than their group membership (and it may be that these other factors explain any difference in the outcome between the groups rather than the group membership itself). There are statistical techniques which can control for confounding but only for variables which are known or suspected to be confounding.

Randomised controlled trials (RCTs) are considered the gold standard in study design for inferring causality because they address the issues of confounding and selection bias (237). By randomly allocating individuals to groups, confounding variables should be equally distributed between the groups. Importantly, this includes variables which are unknown to be confounding as well as any known or suspected confounding variables. Therefore, any difference found on the outcome can be attributed to the group membership as the groups should overall be the same or very similar on all the other variables. This equal distribution by randomisation is more effective the larger the groups are. This is because by chance,

randomisation may create groups which are not equally distributed but the likelihood of this is reduced with larger groups. Researchers can check the effectiveness of randomisation on equal distribution by measuring variables at baseline after group allocation and before individuals in the intervention group receive the study intervention. However, this only works for the measured variables and not for any unmeasured or unknown confounding variables.

Although they are widely considered the gold standard, RCTs are not always appropriate. For example, it would be unethical to randomly allocate individuals to receive an intervention known to be harmful (e.g. cigarette smoking). Another disadvantage to RCTs is that because they are typically very carefully controlled trials, they may not generalise to real world settings and therefore lack ecological validity. Naturalistic observational studies do, in theory, address both these issues. Individuals are not allocated to groups so there are no ethical issues around the study causing any additional harm (or providing a treatment which is suspected to be less effective than another). Also, naturalistic observational studies do not involve any manipulations or additions to the experiences or interventions of the study participants and thus ecological validity is ensured.

As found in my systematic review reported in Chapter 5, there are a lack of RCTs investigating the effectiveness of mental health rehabilitation services (234). This is unsurprising because as these services are considered the appropriate intervention for people with severe and complex mental health problems, it would therefore be unethical to withhold access through randomisation to a control group. The observational studies which do exist indicate there is a reduction in inpatient service use after being admitted to an inpatient mental health rehabilitation unit (Blow, 2000 #104; Nordentoft, 2012 #106; Bunyan, 2016 #48; Killaspy, 2016 #50; Awara, 2017 #105). This finding was supported by my CIFT CRIS study reported in Chapter 6 which compared inpatient service use before and after admission to an inpatient rehabilitation unit. However, neither this study nor the studies included in my systematic review included valid comparison groups. The degree to which causality can be inferred from these results is therefore limited i.e. that the reduction in inpatient service use was due to the admission to the rehabilitation unit. It may have been the case that these individuals would have required less inpatient service use over time regardless of whether they were admitted to an inpatient rehabilitation unit or not (235). There is however an approach to

study design that can mimic the advantages of an RCT and potentially produce valid comparison groups using observational data: propensity score matching.

Propensity score matching was first introduced in 1983 by Rosenbaum and Rubin (238), and has since has been used extensively to infer causality from observational data (239-242). The propensity score estimates the probability that an individual in a population is 'allocated' to the treatment group using measures that have been observed before the individual receives the treatment of interest. The variables used to calculate the propensity score are called covariates.

Once the groups are matched, the 'missing outcome' for each individual can be estimated. The missing outcome for individuals who received the treatment is an estimate of their outcome value assuming they did not receive the treatment, and vice-versa for individuals who did not receive treatment. The missing outcome is often termed 'the potential outcome' or 'counterfactual', and this approach to analysis is known as the potential outcome approach or the Roy-Rubin model (243, 244). Therefore, each individual has two potential outcomes: the outcome if they did receive treatment and the outcome if they did not receive treatment. The problem when it comes to evaluating the treatment is that only one of the potential outcomes is observed. Propensity score matching attempts to resolve this problem by estimating the individual's unobserved potential outcome using the observed potential outcome of that individual's 'match(es)' (an individual can have more than one match, as described below in Section 7.2.2).

The estimated unobserved values are then used to estimate either the average treatment effect (ATE) or the average treatment effect on the treated (ATET). The ATE model estimates the effect by calculating the difference in the outcome between the treatment and control groups, using the observed and estimated unobserved outcomes of both treatment and control cases. The ATET model estimates the effect by calculating the difference between the observed and estimated unobserved outcomes of treatment cases only.

A fundamental assumption of the propensity score is that group assignment is "strongly ignorable" given the covariates (238). There are two conditions to this assumption. Treatment

assignment is independent of the potential outcomes given the covariates, and there is a non-zero chance for each case to be assigned to either group (236). I have already described what is meant by 'potential outcomes', I will now briefly describe what is meant by 'non-zero chance of assignment to either group'.

The estimated propensity score is usually calculated as a number between one and zero, with scores closer to one representing a greater likelihood of receiving the treatment. If, for any case, their true propensity score is zero or a negative number for either group (i.e. an individual has no chance or a negative chance of receiving a treatment), then this is a violation of the strongly ignorable group assignment assumption and propensity score matching would be inappropriate. For example, a person over 18-years-old has zero chance of participating in a youth programme designed exclusively for people under 18.

In this Chapter, I report a study in which the viability of using propensity score matching to match a group of individuals with an inpatient rehabilitation admission (the treatment group) with a group who have not had an inpatient rehabilitation admission (the control group), was explored. Propensity score matching involves several decisions and studies using this method are often poorly reported, even in highly regarded journals (241). Therefore, before I report the Methods, Results, and Discussion of this study, I describe how propensity score matching ought to be implemented.

Propensity scores can be used to match individuals in studies with more than two groups, but this does add complexity, making the outputs difficult to interpret, and is rarely done. I will therefore continue with the assumption that propensity score matching is being used to match two groups, as is the case in the study I report in this Chapter, and these groups will be referred to as the treatment group and the control group.

7.2 Propensity score matching: Implementation

There are three main stages to the implementation of propensity score matching, they are: (1) estimating the propensity score; (2) matching individuals from opposite groups on the propensity score; and (3) reviewing the adequacy of the specified propensity score matching model in balancing covariates between the matched groups and where appropriate, refining

the model to improve the balance. Of note, propensity scores can be used for more than just matching. They can also be used to adjust a regression model, stratify a sample, or to apply weighting to a sample (236). As I am using propensity scores for matching, this is what I focus on here.

7.2.1 Estimating the propensity score

The first step in estimating the propensity score is to select the variables which are to be used in its estimation i.e. the covariates. The aim with the propensity score is to construct a single variable which best estimates the probability an individual will be allocated to the treatment group using the available covariates. Therefore, the selection of covariates should be based on the theoretical, empirical, and experiential knowledge of the researcher(s) in what contributes to the group allocation. Also, the covariates should have been collected at baseline or remain unchanged throughout the study period (e.g. date of birth) and they should not be affected by the treatment (236).

There is some contention in the literature as to what degree comprehensiveness over parsimony should be taken when selecting covariates (245), but generally, if the variable has any predictive value of group allocation whatsoever, then it should be included as a covariate (246). However, a covariate must not perfectly predict group allocation (e.g. a binary variable which is zero for all individuals who received the treatment and is one for all individuals who did not receive the treatment), because if it does then individuals cannot be matched with individuals from the opposite group on this covariate.

Also, missingness should be considered as the methods used to calculate the propensity score apply listwise deletion, meaning that a propensity score will not be generated for an individual with missing data for any of the covariates (246). The selection of covariates is clearly critical to the viability of the propensity score matching analysis. Therefore, the data source and the availability of information which predicts group allocation is fundamental to this method.

Once the covariates have been selected, the next step is to decide which model to use to estimate the propensity score. When the grouping variable is binary (e.g. individuals are admitted to an inpatient rehabilitation service or they are not), the propensity score can be

estimated using a logit or probit model, where the selected covariates are treated as the independent variables and the grouping variable is treated as the dependent variable. The logit and probit model yield similar results (245) but the logit model tends to be the most commonly used model and is the default method for calculating propensity scores in popular statistical programmes (e.g. the 'teffects psmatch' command in Stata (247)). The decision on which model to use becomes more important where the grouping variable has three or more levels (245), but as explained previously (Section 7.1), I focus here on propensity score matching where there are only two groups.

7.2.2 Matching on the propensity score

Once the propensity score is estimated, it can be used to match cases from opposite groups. There are a number of options to consider for the matching algorithm, the first is whether to match individuals from the opposite group using 'nearest neighbour' matching (otherwise known as 'greedy' matching) or 'optimal' matching. Nearest neighbour matching matches each individual in turn with the individual in the opposite group who has the closest propensity score. Optimal matching considers the whole sample when matching and is based on minimising the summed difference in propensity scores between all matches (248).

Matching can be done with or without replacement. With replacement allows each individual to be matched with an individual from the opposite group more than once, whereas without replacement only allows each individual to be matched once. Deciding on with or without replacement is a trade-off between bias and variance (249). With replacement provides better matches (reduced bias) because one individual with a propensity score closest to the propensity score of several in the opposite group can be matched more than once, and those several individuals from the opposite group are not matched to individuals with a more distant propensity score. Furthermore, if the groups are uneven, it will not be possible to match all the cases without replacement as the cases from the smaller group will all be matched before all the cases from the larger group can be matched, and once matched they cannot be matched again. This results in what Rosenbaum and Rubin described as "bias due to incomplete matching" (p. 103 (250)). The re-use of information in matching with replacement is accounted for using weighting when estimating standard errors. Therefore, it is not as if new individuals are added to the sample when information is re-used and the

independence assumption (that data from one individual is independent and not affected by data from another individual), which is critical to most statistical tests, is not violated. However, because with replacement uses less distinct individuals and smaller samples, the amount of variance is increased.

It should also be considered that the order in which cases are matched does not matter with nearest neighbour matching with replacement but it does matter with nearest neighbour matching without replacement. For example, consider the scenario where there are five treatment cases with propensity scores 0.9, 0.8, 0.7, 0.7 and 0.5, and five control cases with propensity scores 0.8, 0.6, 0.5, 0.4, 0.3 (as a reminder, a propensity score can be anything between 0 and 1, where scores closer to 1 indicate greater probability of being assigned to the treatment group). Using nearest neighbour matching without replacement, if the treatment case with propensity score 0.9 is matched first it will match to the control case with a propensity score of 0.8, but if the treatment case with a propensity score of 0.8 was matched first then this case instead would match to the control case with a propensity score of 0.8. However, if we instead used nearest neighbour matching with replacement the order of matching would not matter and the treatment cases with propensity scores of 0.9 and 0.8 would both match to the control case with a propensity score of 0.8 regardless of the order in which they were matched.

Another option for the matching algorithm which also serves as a trade-off between bias and variance is deciding on the number of individuals to match each individual to. Using more than one individual from the opposite group provides a more accurate estimate of their counterfactual outcome, and because it uses more information it reduces the amount of variance. However, the next match is always going to be further away on the propensity score than the last match. Therefore, increasing the number of matches for each individual increases the average distance in the propensity score between matches and increases bias.

The increase in bias can be limited by setting a maximum distance between matches. This is often referred to as the caliper width. It is usually measured in terms of the standard deviation of the propensity score for the full sample, using the logit scale. Although Austin posited a caliper width of between 0.20 and 0.55 should sufficiently remove selection bias, they

concluded there was not a universal caliper width which should be used (236). The width of the caliper is again a trade-off between bias and variance: bias can be reduced by only having matches which are very similar but this decreases the number of matches and therefore increases variance (a narrow caliper width), or the researcher can allow for some selection bias by allowing for more distant matches and a larger sample (a wide caliper width) (236).

7.2.3 Reviewing the adequacy of the propensity score matching model

After individuals have been matched on the propensity score to individuals in the opposite group, the model should be reviewed and modified if appropriate. The review and subsequent modifications should not be guided by the coefficient which estimates the effect of treatment on the outcome, as modification of the matching model should not be part of an attempt to obtain the desired result. Instead, the model should be reviewed by comparing the distribution and overlap of the propensity score between groups before and after matching; comparing the differences between groups on each covariate before and after matching; and if matching has been carried out with replacement, then the number of times each individual has been matched should also be considered.

The degree to which the propensity score overlaps between groups indicates the degree of similarity between groups and how matchable they are, so this should be reviewed before and after matching. Greater overlap will result in better matches i.e. less difference between matches on the propensity score. Also, a wider distribution in the propensity score in both groups will mean there are fewer difficult to match cases and less over reliance on matching the same case multiple times when matching with replacement.

The distribution and overlap of the propensity score provide a useful indication to how matchable the groups are and whether the assumption that group assignment is “strongly ignorable” given the covariates (238) is met. However, further information on the adequacy of the model can be gleaned by comparing the differences of each covariate used to calculate the propensity score. Again, this should be reviewed before and after matching. A reduced difference on the covariate after matching shows that matching has made the two groups more similar on this covariate.

Usually in statistics, differences between groups are examined by significance tests, but for this purpose, they are not appropriate for two reasons. First, significance tests are confounded by sample size and matched groups are invariably smaller than the original unmatched groups; lack of a significant difference after matching where there was a difference before matching could be due to the reduced sample size rather than a reduced difference. Second, significance tests make an inference as to the probability the observed difference found in the sample would also be found in the population the sample is from. However, the balance of covariates is specific to the sample and therefore reference to the population level is not appropriate (236, 251). Instead, differences in covariates before and after matching should be reviewed by observing the standardised differences between groups, which compares means between groups in terms of the pooled standard deviation (236). There is not a consistent threshold by which a standardised difference of a covariate is acceptable but Austin (236) recommends a difference of no more than 0.1 for each covariate. Standardised differences before and after matching on propensity scores are often reported graphically using Love plots (251, 252), so called after the researcher who first appeared to report standardised differences this way (253, 254). Significance tests are still useful to indicate where there may be differences between groups, and so can be used to indicate differences in the original dataset but should not be used when reviewing the balancing of covariates after matching.

Finally, if with replacement has been used, then the number of repeat matches should also be reviewed. Although the re-use of individual data is accounted for by weighting, this review provides another check on how matchable the two groups are. A high number of repeat matches for a few cases indicates a lack of overlap between the two groups on the propensity score before matching and an over reliance on these few cases during the matching process. An over reliance on a few cases is likely to result in a large amount of variance in the effect estimate.

Rosenbaum and Rubin (255), and subsequently elaborated on by Austin (236), explained that the propensity score matching method should be an iterative process. If the groups are imbalanced after a round of matching, the model should be modified by adding covariates if additional covariates are available, adding interaction terms between covariates, and/or

adding non-linear terms to continuous covariates. When there are apparently no further modifications which can improve the propensity score matching model, and the final model is arrived at, the coefficient estimating the effect of treatment on outcome can be interpreted.

7.3 Aims and objectives

The aim of this study is to explore the viability of using propensity score matching methods to match a group of individuals who have had an inpatient rehabilitation admission with a group of individuals who have not had an inpatient rehabilitation admission, using the CIFT CRIS database. If propensity score matching is a viable method, then the matched groups can be used to estimate the effect of an inpatient rehabilitation admission on subsequent inpatient service use. The objectives of this study are to:

I. Use the cohort previously reported on in Chapter 6 as the treatment group, i.e. a group of individuals with an inpatient rehabilitation admission of at least three months
II. Use the CIFT CRIS database to identify a control group
III. Use the available data on treatment cases and control cases to estimate the propensity score for each case
IV. Match treatment cases with controls on the propensity score, creating matched treatment and control groups
V. Review the propensity score matching model and modify it where appropriate
VI. If the propensity score matching model has adequately matched the treatment and control group, use the matched groups to estimate the effect of an inpatient rehabilitation admission on inpatient service use

7.4 Methods

7.4.1 Design and cohort

This study estimates the effect of an inpatient rehabilitation admission on subsequent inpatient service use by matching patients who have had an inpatient rehabilitation admission (treatment group) with patients who have not had an inpatient rehabilitation admission (control group) using propensity score matching. The data source was the CIFT CRIS database which contains de-identified electronic health records pertaining to individuals using

statutory NHS mental health services in the London boroughs of Camden and Islington. Development of CRIS and its deployment at CIFT was described in Chapter 3. The sociodemographic and mental health morbidity of both Camden and Islington was described in Chapter 2 Section 2.9. The local mental health rehabilitation pathway, including the inpatient rehabilitation units available in Camden and Islington, was described in Chapter 2 Section 2.10.

The process of identifying the inpatient rehabilitation group, from herein referred to as the treatment group comprised of treatment cases, was described in Chapter 6. In brief, a treatment case is any individual with an inpatient rehabilitation admission of at least 84 days and with at least 365 days of records available before and after their rehabilitation admission. The same data extracted for treatment cases were extracted for the control group, including sociodemographic variables (age, gender, ethnicity, and marital status), ICD-10 diagnoses, Health of the Nation Outcome Scale (HoNOS (207)) assessments, and inpatient service use. The control group was comprised of any individual:

I. With records on the CIFT CRIS database
II. Not included in the treatment group
III. Aged between 18-and-65-years-of-age at the start of their records (anyone with a missing date of birth was excluded)
IV. Had at least four inpatient admissions recorded (see below for an explanation as to why this was required for controls)
V. Had a recorded diagnosis of schizophrenia (ICD-10 code F20 to F24 or F26 to F29), schizoaffective disorder (F25), or bipolar affective disorder (F31). This diagnosis criterion was added because for 94% of the treatment group, the primary diagnosis at the start of the inpatient rehabilitation admission was schizophrenia, schizoaffective disorder, or bipolar affective disorder (see Section 6.3.1)

The baseline for treatment cases was the start date of their index inpatient rehabilitation admission. The mean number of inpatient admissions for treatment cases before they received treatment (i.e. an inpatient rehabilitation admission of at least 84 days) was 3.8 (see Section 6.3.4). It was therefore decided that for the control group, the baseline was the start

date of their fifth recorded inpatient admission. Treatment cases had at least 365 days of records available before and after their baseline admission. Therefore, it was specified that control cases must also have at least 365 days of records available before and after their baseline admission.

7.4.2 Selection of covariates

The following variables were selected as covariates to estimate the propensity score:

- Gender (binary)
- Age at baseline (continuous, rounded to the nearest year)
- Ethnicity (binary: 0 = White, 1 = non-White)
- Marital status (binary: 0 = married or previously married, 1 = never married)
- A series of binary variables indicating whether the ICD-10 mental health diagnosis recorded closest to baseline was:
    - Schizophrenia disorder (ICD-10 code: F20 to F24 or F26 to F29)
    - Schizoaffective disorder (F25)
    - Manic episode (F30) or bipolar affective disorder (F31)

  ('Other mental health disorder' was omitted to avoid multi-collinearity when creating a series of binary variables from a categorical variable, colloquially referred to as the 'dummy variable trap')
- The calendar year of the baseline date (continuous)
- Three items from the first recorded HoNOS assessment (continuous, each item could score: 0, 1, 2, 3, or 4, with 0 indicating there is no problem in this area affecting health or functioning and 4 indicating a very severe problem):
    - Item 6. Hallucinations & delusions
    - Item 9. Relationship problems
    - Item 10. Daily living skills
- The average number of inpatient days per-year pre-baseline (continuous)

7.4.3 Statistical methods

Data management and analysis were carried out using Stata 16.0 (211). The Stata command 'teffects psmatch' was used to fit the propensity score matching model using a logistic

regression model. The matched groups were used to estimate the average treatment effect on the treated (ATET) i.e. the effect of an inpatient rehabilitation admission on subsequent inpatient service use. The outcome was calculated as the number of inpatient days per year recorded after their baseline admission. The nearest neighbour match option was added with the minimum number of matches per case set to three and a maximum distance between potential neighbours specified as 0.2 of the pooled standard deviation of the logit of the propensity score (i.e., the caliper width). Matching was carried out with replacement.

Before interpreting the ATET estimate, the specification of the propensity score matching model was reviewed and modified if indicated. To review the matching model, the descriptive results of covariates before and after matching were reviewed using frequencies and percentages for categorical variables and means and standard deviations for continuous variables. Differences in covariates between the treatment and control group before matching were analysed using chi-squared tests and student's t-tests for categorical and continuous covariates, respectively. The distribution of the propensity score and the degree this overlapped between groups before and after matching was reviewed using box plots. The balance of covariates before and after matching was reviewed using standardised differences (236). A standardised difference of more than 0.1 after matching was regarded as a meaningful difference i.e. the groups were not sufficiently matched on this covariate. To facilitate the review of standardised differences, they were reported graphically using a Love plot.

Finally, as matching was carried out with replacement, the total number of times each case was matched was reported using descriptive statistics. All this information was used to inform whether the model could be improved by one or more of the following modifications: adding an interaction term between covariates; and/or adding quadratic terms to continuous covariates. All the available covariates were used in the first model so adding further covariates to the model was not an option.

7.4.4 Ethics

This study was granted the necessary ethical approvals. Further details are provided in Chapter 3 Section 3.11.

7.5 Results

7.5.1 Sociodemographic and clinical characteristics of the treatment and control group before matching

Table 15

Table 15 shows the sociodemographic and clinical characteristics of the treatment and control groups before matching. There were 172 individuals in the treatment group and 817 in the control group. There were several differences between the two groups. Patients in the treatment group were slightly older (mean 44.2, SD 13.8 vs mean 41.8, SD 12.7; p=0.024), more likely to be White (n=98, 57% vs n=301, 38%; p<0.001), and more likely to have a diagnosis of schizophrenia disorder (n=127, 74% vs n=395, 55%; p<0.001). Around three-fifths of both the treatment (n=101, 59%) and control group (n=497, 61%) were male, and a similar proportion had a co-morbid condition (treatment group: n=97, 56%; control group: n=95, 57%). The vast majority in both groups had never been married, but more so in the treatment group (n=155, 91% vs n=665, 82%; p=0.004).

Table 15: Sociodemographic and clinical characteristics of the treatment and control before matching (N=989)

	Treatment group (n=172)		Control group (n=817)		p-value
	n	%	n	%	
Age at baseline (mean, SD)	44.2	13.8	41.8	12.7	0.024
Male	101	59	497	61	0.607
Ethnicity	-	-	-	-	-
White (British, Irish, Other)	98	57	301	38	<0.001
Non-White (Asian, Black, Mixed, Other)	74	43	489	62	-
Marital status	-	-	-	-	-
Married or previously married	16	9	150	18	0.004
Never married	155	91	665	82	-
Primary mental health ICD-10 diagnosis*	-	-	-	-	-
Schizophrenia disorder (F20-F24 & F26-F29)	127	74	457	56	<0.001
Schizoaffective disorder (F25)	25	15	84	10	0.105
Manic episode (F30) or bipolar affective disorder (F31)	11	6	163	20	<0.001
Other mental health disorder	9	5	113	14	0.002
Co-morbid mental health diagnosis†	-	-	-	-	-
Substance misuse disorders (F10-F19)	42	26	233	29	0.275
Depression and anxiety disorders (F32-F48)	10	6	74	9	0.165
Disorders of adult personality and behaviour (F60-F69)	15	9	71	9	0.990
Co-morbid physical health diagnosis†	-	-	-	-	-
Endocrine, nutritional and metabolic diseases (E00-E90)	41	24	173	21	0.441
Diseases of the nervous system (G00-G99)	8	5	39	5	0.945
Diseases of the circulatory system (I00-I99)	21	12	98	12	0.937
Diseases of the respiratory system (J00-J99)	10	6	83	10	0.076
Any other diagnosis (C00-D89, H00-H95 & K00-Q99)	24	14	145	18	0.230
Any co-morbidity‡	97	56	509	63	0.148
Multiple co-morbidity§	53	31	247	30	0.880

*The ICD-10 mental health diagnosis with a recorded date closest to the baseline date (median distance from baseline date before matching: 1 day, interquartile range (IQR): 0 to 43; and after matching: 2 days, IQR: 0 to 45).

†Whether this ICD-10 diagnosis had ever been recorded during the study period (1st January 2009 to 30th April 2020) for this individual, in addition to the 'Primary mental health ICD-10 diagnosis'.

‡Any co-morbidity does not include 'Any other physical health diagnosis (C00-D89, H00-H95 & K00-Q99)' or ICD-10 codes: R00-Z99.

§More than one co-morbidity.

7.5.2 HoNOS item scores for the treatment and control group before matching

Table 16 shows the HoNOS item scores for the treatment and control groups before matching. Three of these HoNOS items were selected as covariates. The proportion of individuals who scored three (severe problem) or four (very severe problem) on the first covariate, item 6. hallucinations and delusions, were similar between groups (treatment group: n=53, 37%; control group: n=281, 38%). The proportions were also similar between groups for the second covariate, item 9. relationship problems, (treatment group: n=52, 31%; control group: n=214, 38%). There were differences however for the third HoNOS item selected as a covariate, item 10. daily living skills (treatment group: n=48, 30%; control group: n=130, 18%).

Table 16: HoNOS item scores for the treatment and control group before matching (N=989)

Item	Treatment group (n=172) or control group (n=817)	Score (n (%*)) 0	1	2	3	4	Missing
1. Aggression and overactivity	Treatment	79 (47)	25 (15)	41 (25)	14 (8)	8 (5)	5 (3)
	Control	303 (41)	140 (19)	132 (18)	124 (17)	48 (6)	70 (9)
2. Self-harm	Treatment	141 (85)	13 (8)	6 (4)	5 (3)	0 (0)	7 (4)
	Control	617 (83)	44 (6)	42 (6)	30 (4)	10 (1)	74 (9)
3. Problem drinking and drugs	Treatment	104 (62)	18 (11)	21 (13)	19 (11)	6 (4)	4 (2)
	Control	446 (60)	63 (8)	83 (11)	113 (15)	4 (1)	73 (9)
4. Cognitive impairment	Treatment	87 (52)	42 (25)	22 (13)	10 (6)	5 (3)	6 (3)
	Control	457 (61)	111 (15)	100 (13)	70 (9)	9 (1)	70 (9)
5. Physical impairment	Treatment	106 (64)	21 (13)	23 (14)	13 (8)	3 (2)	6 (3)
	Control	531 (71)	84 (11)	78 (10)	46 (6)	5 (1)	73 (9)
6. Hallucinations and delusions	Treatment	47 (28)	18 (11)	40 (24)	44 (26)	19 (11)	4 (2)
	Control	252 (34)	72 (10)	142 (19)	195 (26)	86 (12)	70 (9)
7. Depressed mood	Treatment	94 (56)	43 (26)	19 (11)	8 (5)	4 (2)	4 (2)
	Control	313 (42)	178 (24)	155 (21)	83 (11)	19 (3)	69 (8)
8. Other mental health problem	Treatment	76 (47)	16 (10)	33 (20)	28 (17)	10 (6)	9 (5)
	Control	210 (31)	84 (12)	161 (24)	186 (27)	43 (6)	133 (16)
9. Relationship problems	Treatment	48 (29)	26 (15)	42 (25)	34 (20)	18 (11)	4 (2)
	Control	245 (33)	116 (15)	175 (23)	166 (22)	48 (6)	67 (8)
10. Daily living skills	Treatment	36 (21)	24 (14)	60 (36)	44 (26)	4 (2)	4 (2)
	Control	315 (42)	128 (17)	160 (21)	120 (16)	23 (3)	71 (9)
11. Living conditions	Treatment	85 (51)	22 (13)	31 (18)	18 (11)	12 (7)	4 (2)
	Control	414 (56)	102 (14)	97 (13)	88 (12)	42 (6)	74 (9)
12. Occupation/ activities	Treatment	77 (46)	34 (20)	26 (15)	24 (14)	7 (4)	4 (2)
	Control	325 (44)	114 (15)	142 (19)	124 (17)	37 (5)	75 (9)
Total standardised score† (mean, SD)	Treatment	27.5	14.6	-	-	-	4 (2)
	Control	27.7	15.2	-	-	-	67 (8)

*Score percentages are calculated using the total number of patients with complete data for the corresponding item. Missing percentages are calculated using the total number of patients in the cohort.

†Total score is out of 100 and standardised so that assessments with 1, 2, or 3 missing items are comparable. HoNOS assessments with more than 3 items missing are treated as missing for total standardised score.

Table 17 shows the length of the baseline inpatient admission in days, the number of days per year before and after the baseline admission, and the calendar year when the baseline admission started, before matching. Although the pre-baseline period of records was similar for both the treatment and control group (treatment group: mean 4.4 years, SD 2.2; control group: mean 4.2 years, SD 2.4), the number of inpatient days pre-baseline was much higher in the treatment group (treatment group: mean 519, SD 400; control group: mean 136, SD 168). This is unsurprising given that individuals who have had an inpatient rehabilitation admission have complex mental health problems and are therefore more likely than individuals who have not had a rehabilitation admission to have more and longer admissions. Likewise, although the post-baseline admission period was similar between groups (treatment group: mean 5.2 years, SD 2.4; control group: mean 5.4 years, SD 2.7), the inpatient days post-baseline was much higher in the treatment group (treatment group: mean 411, SD 595; control group: mean 184, SD 297). However, post-baseline, 64 (37%) patients in the treatment group had zero inpatient days compared to 198 (24%) in the control group.

Table 17: Baseline admission length and pre- and post-baseline admission inpatient service use before matching (N=989)

	Treatment group (n=172)		Control group (n=817)	
	Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)
Pre-baseline admission inpatient days	519 (400)	420 (262 to 653)	136 (168)	92 (54 to 164)
Pre-baseline admission number of admissions	3.8 (3.0)	3 (1.5 to 5)	4 (0)	4 (4 to 4)
***Pre-baseline admission period, in years**	4.4 (2.2)	4.1 (2.6 to 6.2)	4.2 (2.4)	3.7 (2.1 to 6.0)
Pre-baseline admission inpatient days per year	145 (112)	105 (65 to 189)	44 (53)	27 (14 to 53)
Baseline admission start date calendar year (n (%))	-	-	-	-
2010 2011 2012	22 (13)	22 (13) 24 (14)	92 (11)	104 (13) 83 (10)
2013 2014 2015	23 (13)	25 (15) 15 (9)	78 (10)	90 (11) 88 (12)
2016 2017 2018	18 (10)	17 (10) 6 (3)	65 (8)	100 (12) 101 (12)
2019 - -	0 (0)	- -	16 (2)	- -
Baseline admission length, in days	354 (223)	318 (191 to 455)	45 (89)	28 (13 to 54)
Post-baseline admission inpatient days	411 (595)	153 (0 to 583)	184 (297)	75 (5 to 243)
Post-baseline admission number of admissions	1.9 (2.4)	1 (0 to 3)	3.9 (4.9)	2 (1 to 6)
****Post-baseline admission period, in years**	5.2 (2.4)	5.4 (3.1 to 7.0)	5.4 (2.7)	5.3 (2.8 to 7.8)
Post-baseline admission inpatient days per year	73 (96)	29 (0 to 114)	37 (59)	15 (1 to 47)

SD = standard deviation, IQR = interquartile range.

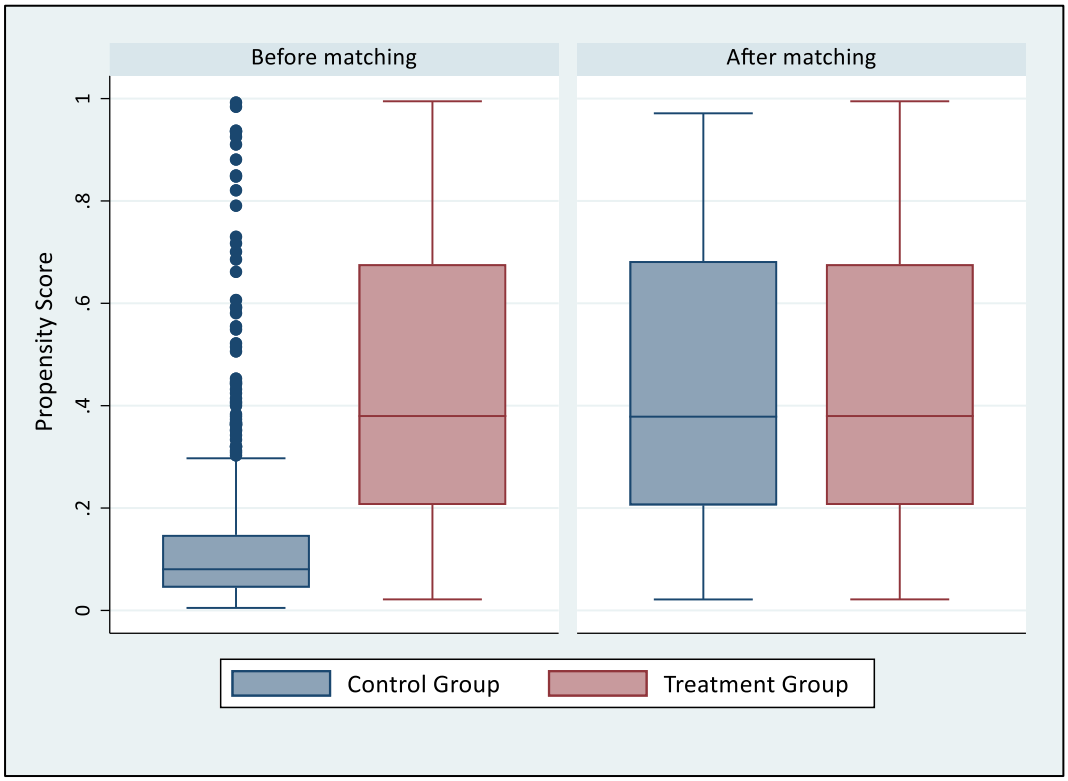
*The start date used to calculate the pre-baseline admission period for each case is the date their first progress note is recorded or on the start date of their first recorded admission, whichever comes first within the study period (1 January 2009 to 30 April 2020).

**The end date used to calculate the post-baseline admission period is the date records are available up until (30 April 2020) or their date of death if one is recorded.

7.5.3 Distribution and overlap of the propensity score between groups, before and after matching

Figure 5 illustrates the distribution of the propensity score for the treatment and control group before and after matching. Prior to matching there was minimal overlap in the distribution of the propensity score between groups, with no overlap between the interquartile range of each group. The distribution of the propensity score for the control group narrowly centred around 0.1, whereas the distribution for the treatment group broadly centred around 0.4 to 0.5. After matching, there was almost perfect overlap. The lower tails first quartiles, and medians appear to be equal or very close to it, and the third quartiles, and upper tails are not equal but very similar.

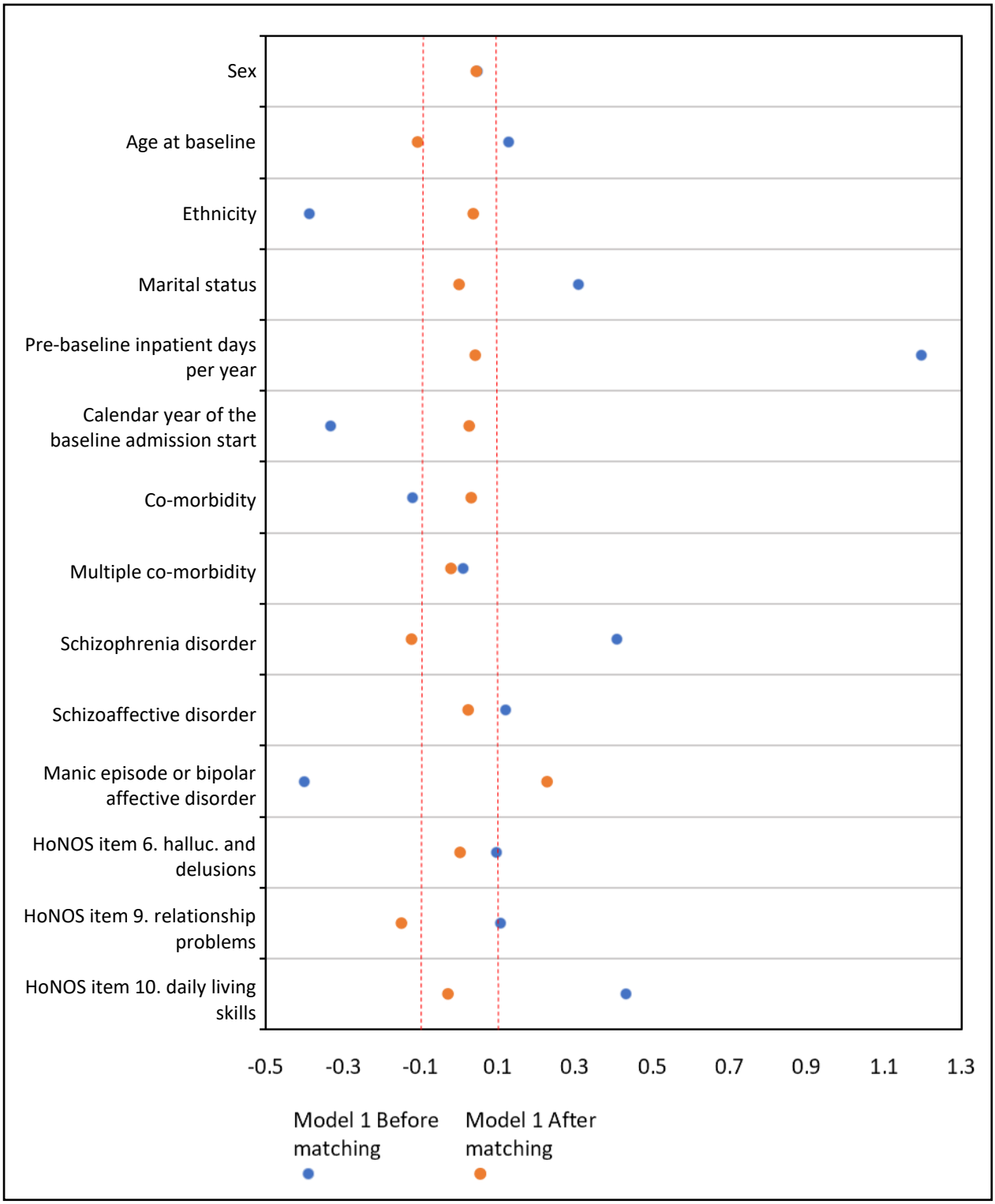
Figure 5: Model 1: Distribution of the propensity score between groups before and after matching



7.5.4 Balance of covariates

Figure 6 is a Love plot showing the standardised differences before and after matching on the propensity score, for the first model as specified previously in Section 7.4. For both before and after matching, the standardised differences are calculated only for patients included in the model (i.e. where matched to an individual in the opposite group). The standardised differences after matching account for matching with replacement. From the treatment group, five patients were pruned as there was not an appropriate match in the control group, leaving a total of 167. From the control group, 101 patients were pruned leaving a total of 716. Standardised differences falling outside the two vertical red dotted lines indicate a meaningful difference between groups on that covariate (i.e. a standardised difference of more than 0.1). Matching appears to have successfully balanced the covariates to a degree but there were still five covariates, out of a total of 14, where there remained a meaningful difference between groups. The five covariates were: age at baseline, ethnicity, schizophrenia as the primary diagnosis at baseline, manic episode or bipolar affective disorder as the primary diagnosis at baseline, and HoNOS item 10, daily living skills. The most substantial difference between groups before matching was the pre-baseline admission inpatient days per year covariate, which matching appeared to be especially effective at balancing.

Figure 6: Model 1: Standardised differences of covariates before and after matching on the propensity score



7.5.5 Matching with replacement: The number of times each treatment and control patient were matched to a patient in the opposite group

Out of the treated group where 167 patients were included in the propensity score matching model, 23 did not match to a control (but at least one control matched to them as otherwise they would not have been included in the model). 34 treated patients were matched to a control patient once, 33 were matched twice, 19 were matched thrice, and five were matched to four controls. The remaining 53 treated patients included in the model matched to controls on five or more occasions. Four treated patients matched to controls 154 or more times (one patient matched 154 times, one patient matched 225 times, one patient matched 347 times, and one patient matched 351 times). The next highest number of matches for a single treated case was 52.

Out of the 716 controls included in the PSM model, 536 cases did not match to a treated case. Therefore, only 180 of the 716 control patients were used to estimate the counterfactual outcome for the matched treated patients. Of these 180 control patients, 91 matched to a treatment patient once, 30 matched twice, 11 matched thrice, and the remaining 48 treated cases included in the model matched to controls on four or more occasions. Three control patients matched to treated patients 20 or more times (two patients matched 20 times, and one patient matches 24 times). The next highest number of matches for a single treated case was 11. Table 18 provides further descriptive statistics on the number of matches for each patient.

Table 18: The number of times each treatment and control patient were matched to a patient in the opposite group

	Mean	SD	Min-imum	First quartile	Median	Third quartile	Max-imum
Treatment group (n=167)	12.9	43.4	0	1	2	12	351
Control group (n=716)	0.7	2.0	0	0	0	1	24
Total (N=883)	3	19.5	0	0	0	1	351

7.5.6 Model refinement

The propensity score matching model was refined by adding quadratic terms to two continuous covariates: age at baseline admission start date and the number of inpatient days per year before index admission. This model is referred to as 'model two'. The affect this had on the distribution of the propensity score in the treatment and control group before and after matching is illustrated in Figure 7.

Adding the quadratic terms (model two) slightly widened the distribution of the propensity score in the control group before matching, whilst reducing the median of the propensity score and narrowing its distribution in the treatment group. However, after matching, the distribution of the propensity score for both groups narrowed compared to the corresponding distributions in model one.

The effect of adding the quadratic terms on the balance of the covariates before and after matching is illustrated in Figure 8. After matching, the covariate for age appears now to be better balanced but the balancing of the covariate pre-inpatient rehabilitation inpatient days has slightly worsened. The effect on the balancing of the other covariates was minimal.

A further refinement was made whereby the three HoNOS items were dichotomised so that an item score of zero, one, or two was coded as zero, and an item score of three or four was coded as one. These binary HoNOS variables were entered into the model as categorical covariates. This model is referred to as 'model three'. As adding quadratic equations to the age and pre-inpatient rehabilitation inpatient days covariates improved the balance for age but worsened it for pre-rehabilitation inpatient days, the quadratic equation for age was kept but removed for pre-rehabilitation inpatient days in model three.

The distribution of the propensity score before and after matching in model three, and how it compares to models one and two, is also illustrated in Figure 7. Before and after matching, the distribution of the propensity score in model three is similar to model one but with slightly higher third quartiles. However, as can be seen in Figure 8, there was a mixed effect on the balancing of the three HoNOS items. The balance of item 9. Relationship problem improved but the balance for item 6. hallucination and delusions, and item 10. daily living skills, slightly

worsened. Models two and three pruned the same patients as were pruned in model one. Therefore, models two and three both also included 167 patients in the treatment group and 716 in the control group.

Figure 7: Distribution of the propensity score between groups before and after matching, for models one, two, and three

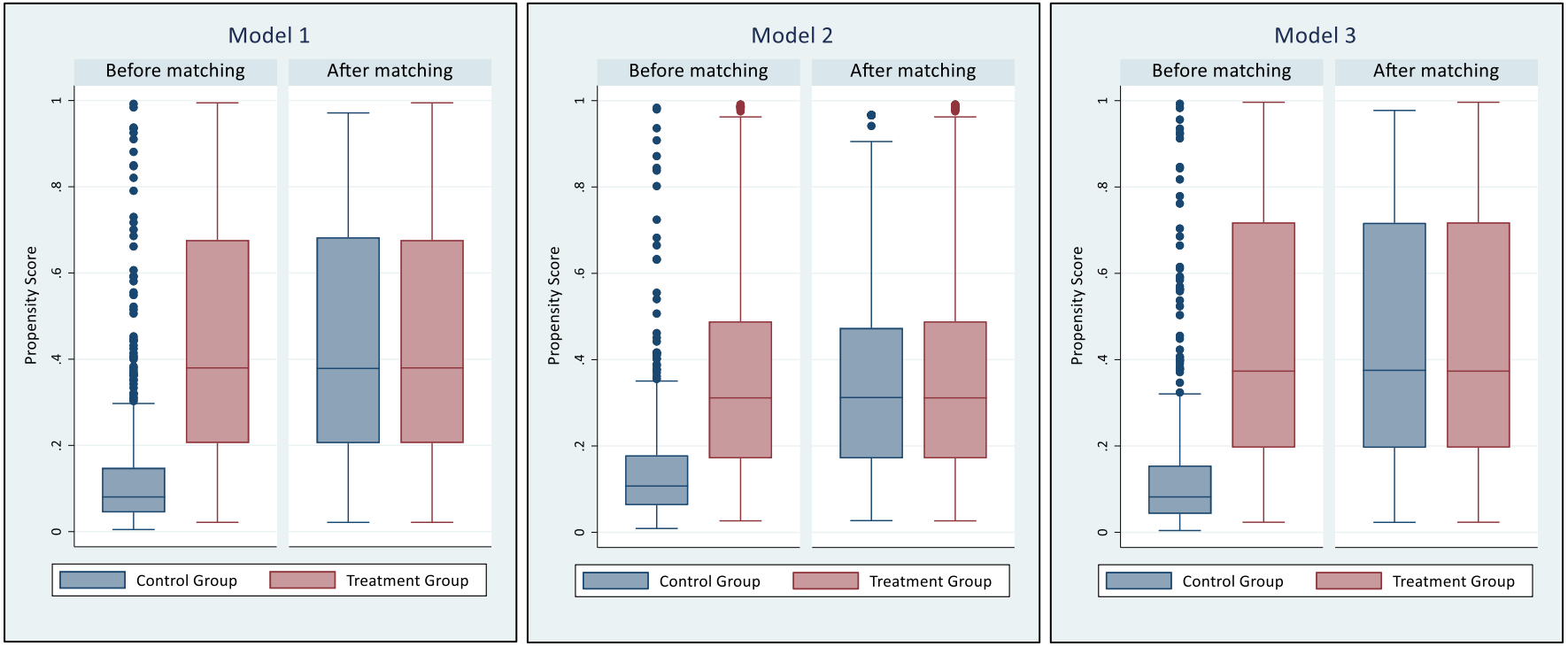
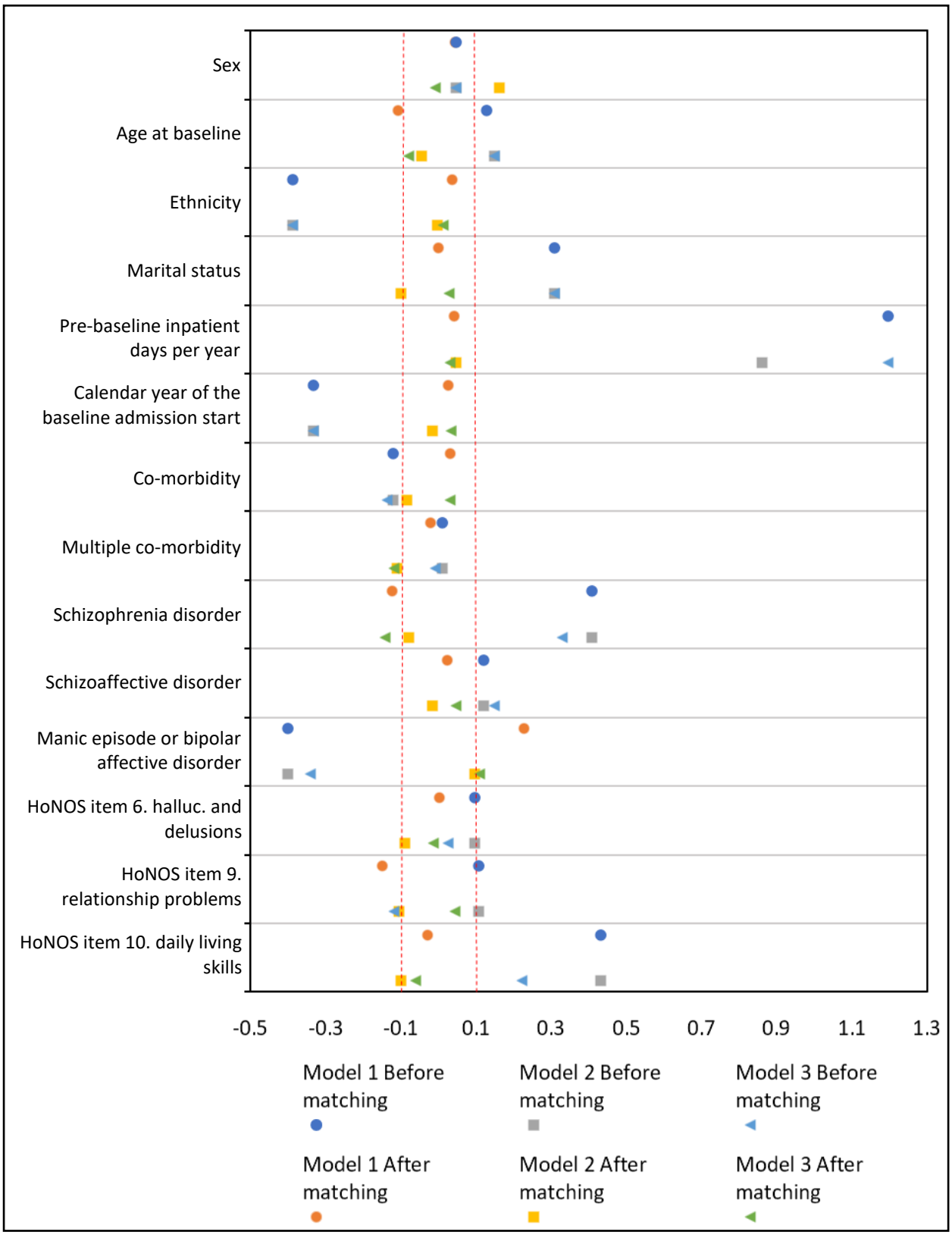


Figure 8: Standardised differences of covariates before and after matching on the propensity score, for models one, two, and three



When considering the balance of the covariates and the distribution and overlap of the propensity score, there were no clear improvements following the modifications made to how the propensity score matching model was specified. As there were no further obvious modifications to make, model one was selected as the final model, and was the model used to report the estimated ATET.

7.5.7 The estimated effect of treatment on the outcome

The final propensity score matching model estimated that if cases had not received treatment they would have subsequently had 14.2 inpatient days less per year, but the 95% confidence intervals were wide and included zero (-11.1 to 39.6), indicating a high degree of variance and no evidence that an inpatient rehabilitation admission affected inpatient service use. However, this result should only be interpreted within the context of the propensity score matching model from which it was derived.

7.6 Discussion

This study suggests propensity score matching is not a valid method to identify a comparison group for an inpatient rehabilitation group using the current study sample. Therefore, the result that there was no evidence an inpatient rehabilitation admission effected inpatient service use after matching on the propensity score should be disregarded or at least interpreted with a high level of caution. There was only a small amount of overlap in the propensity score between the treatment and control group before matching. This meant that for most cases there was not a match in the opposite group with a similar propensity score. Although the balance of the covariates between the groups was substantially improved by matching on the propensity score, this was due to matching with replacement and an over-reliance on matching on several treatment cases. Most of the control group were not used as a match for any of the treatment cases, and several in the treatment group were used to match with hundreds of cases in the control group. This over-reliance on relatively few cases meant the sample was smaller than desired. This in turn meant there was a large amount of variance in the estimate of the treatment effect as can be observed in the wide confidence intervals.

The lack of a substantial overlap on the propensity score between the treatment and control group before matching suggests that the two groups were not matchable. This may be because the estimated propensity score in this study approximates the true propensity score, and individuals with NHS records who have had an inpatient rehabilitation admission at a group level have a much greater propensity to be admitted to an inpatient rehabilitation unit (i.e. the treatment group) compared to individuals with NHS records who are not admitted to an inpatient rehabilitation unit (i.e. the control group). It is to be expected in most circumstances where group allocation has not been controlled, that the treatment group are on average more likely to receive treatment than the control group. Propensity score matching can function adequately in these conditions but there still needs to be a substantial degree of overlap in the distribution of the propensity score between the two groups for matching to work.

If the estimated propensity score does approximate the true propensity score in this study, then the treatment and control group are too different to adequately match, and this difference should be explainable through the covariates. The covariate with the largest standardised mean difference was the average number of inpatient days per-year pre-baseline. This is despite the baseline for controls being defined as the start date of their fifth recorded inpatient admission. This is equivalent to the mean number of admissions pre-baseline for treatment cases i.e. the start date of their index inpatient rehabilitation admission. Therefore, although the pre-baseline admissions for the treatment group were not of greater frequency, they must have been of longer duration on average compared to the control group. This finding needs to be substantiated but could potentially be used to inform clinical practice. Prior inpatient service use is already used to assess the appropriateness of referrals for inpatient rehabilitation, but this finding suggests that the length of previous admissions as well as their frequency should be considered.

There are potentially further clinical implications if the estimated propensity score does approximate the true propensity for being admitted to an inpatient rehabilitation service. As the two groups are substantially different, it suggests that there may not be many individuals in the control group who would benefit from an inpatient rehabilitation admission. This in turn would suggest that patients in the study locality are well served in regard to the provision

of inpatient rehabilitation beds. The provision of high dependency rehabilitation beds in Camden and Islington equates to around eight per 100,000 population aged between 20 and 69 years-old (calculated based on the total population in Camden and Islington aged between 20 and 69 years-old is 381,424 according to mid-2020 estimates (100), and that there were 30 high dependency rehabilitation beds in the area at that time). However, as recommended in the NICE guidelines on rehabilitation for adults with complex psychosis (86), and described previously in Chapter 2 Section 2.8.5, the planning and provision of local mental health rehabilitation services should be informed by a thorough assessment of local needs. The appropriate number of rehabilitation beds for Camden and Islington may not be the same as in other areas of the country and is likely to be higher than many areas given the high levels of psychiatric morbidity in the two boroughs (101). There are however other explanations where the propensity score in the present study does approximate the likelihood of individuals accessing NHS mental health services being admitted to an inpatient rehabilitation service, but the lack of matches does not mean that the local population have adequate provision of inpatient rehabilitation. It may by that there are individuals in Camden and Islington who would benefit from inpatient rehabilitation but are not included in this study because they were not accessing NHS mental health services and so could not be matched to individuals who did receive inpatient rehabilitation. These individuals for example could be street homeless or in prison instead of being in contact with NHS mental health services. It therefore may be more accurate to suggest the lack of matches may indicate that there is an adequate level of inpatient rehabilitation provision in Camden and Islington for people who are already accessing mental health services.

Alternatively, the treatment and control group may not be as dissimilar in their propensity to receive treatment as the lack of overlap in the distribution of the propensity score generated in this study suggests. If this is true, the clinical implications described above would not hold. It would also mean that the propensity score has not been adequately specified, which would mean that there are variables which predict group allocation that have not been considered in the model (i.e. they have not been selected as a covariate). This is perhaps the most important limitation in the estimation of propensity scores. In practice, it is unlikely that everything which contributes or predicts group allocation is known and/or observed.

Previous research has demonstrated that inpatient rehabilitation patients have extensive inpatient use prior to their rehabilitation admission (70, 146, 147, 150, 171). This finding was supported by the pre- and post-inpatient rehabilitation admission study reported in Chapter 6. Also, the vast majority of patients have treatment resistant psychosis (86), difficulties with managing everyday activities (e.g. self-care, cleaning, shopping, cooking, budgeting, medication management) (86), most have comorbid conditions (71), and some have problematic use of alcohol and illicit substances (79). To varying degrees, these factors are accounted for as covariates in this study. Extensive inpatient service use and a diagnosis of schizophrenia or schizoaffective disorder can be used as a proxy for treatment resistant psychosis but there are likely to be more direct and informative measures for this. For example, a history of being prescribed many different antipsychotic medications would suggest difficulties in finding the optimal treatment. Prescription of clozapine could also indicate treatment resistant psychosis as it is an antipsychotic usually reserved for treatment resistant cases (256).

Difficulties with managing everyday activities is accounted for in the current study by selecting HoNOS item 10, daily living skills, as a covariate. Aside from the issues regarding the HoNOS discussed in Chapter 6 (Section 6.4.1), there are other limitations to using this variable for this function. This is a single item on a 12-item scale designed to measure overall health in a mental health population and may not have the sensitivity to detect small differences in something as complex as skills in managing everyday activities. Such a measure has recently been developed (257), but it has not been widely used or recorded with the sample in the current study.

Furthermore, because of the amount of missingness on this HoNOS variable for the treatment group at the start date of their index rehabilitation admission (Section 6.3.6), there was minimal constraint placed around when this measure was recorded. Ideally, the assessment would have been recorded soon before baseline for all patients in this sample, but it was instead defined as the patient's first recorded HoNOS assessment. Therefore, its utility as a predictor of receiving treatment or not is questionable. Also, for some patients this measure will have been recorded after their baseline which violates the assumption that selecting covariates for calculating the propensity score should be recorded at or before baseline (239).

The potential and methods for extracting additional variables from electronic health record (EHR) databases, such as the CIFT CRIS database used in this study, were discussed in Chapter 6 Section 6.4.1.1).

In addition to the variables we know predict or are associated with admission to an inpatient rehabilitation service, there are also variables that we are unaware of which predict admission. These unknown variables will inevitably be omitted from calculating the propensity of being admitted. To some extent, this may always be the case. It seems unlikely that we will ever be able to understand everything which explains why someone will require admission to an inpatient rehabilitation service. It seems even less likely we will be able to measure everything which predicts admission. Therefore, propensity score methods may always be to a degree limited in this research area. Beyond studies using propensity score methods and the viability of the approach in this area of research, a better understanding of the aetiology of longer term complex psychosis may improve prevention, identification of persons who may benefit from rehabilitation services, and the treatment and support provided by rehabilitation services.

Another methodological limitation applying to all propensity score matching study was demonstrated by King and Nielsen (258). They showed that matching on the propensity score is suboptimal compared to other matching methods, and often increases imbalance between groups. The propensity score matching attempts to mimic traditional RCTs, whereas other matching methods attempt to mimic block randomisation trials, which is a more effective method than traditional RCTs in balancing covariates between groups. This is because in traditional RCTs, each individual is randomised to a group, and their measured and unmeasured characteristics are on average equally distributed. However, in block randomisation trials, individuals are first placed in pairs who are exactly the same on the observed characteristics, and this pair is then randomised so that one is allocated to the control group and the other is allocated to the treatment group. This way, the distribution of the observed characteristics used to create the pairs are exactly equal between groups, they are not just equal on average, as is the case with traditional RCTs.

Therefore, propensity score matching sets out to achieve suboptimal conditions for estimating effects compared to other matching methods. However, replicating the traditional RCT in an observational dataset is still useful in inferring causality, but King and Nielsen demonstrated another flaw in propensity score matching (258). They showed that as propensity score matching starts to approximate the RCT dataset, imbalance increases. King and Nielsen called this the "propensity score matching paradox" (p.2 (258)) as it is the opposite of what the technique is intended to do. They explained this is because of how cases and matches are pruned in propensity score matching. With any matching technique, cases which do not match are pruned. Leaving aside the issues of pruning datasets and the bias that this creates, this does reduce imbalance. However, when the cases remaining in the dataset start to look very similar and there are potentially many viable matches for each case which have equal or close to equal distances on the propensity score, propensity score matching starts to prune cases (and matches if a caliper is applied) at random, and pruning at random increases imbalance (258). This is unlikely to have been an issue in the present study given that there were not many unique cases with good multiple matches, but it is important to consider in studies using propensity score matching.

King and Nielsen suggest Mahalanobis distance matching and coarsened exact matching as alternatives to propensity score matching (258). However, for any matching technique to be effective the dataset requires a reasonable overlap in the covariates, as discussed previously in this section. These alternative approaches to matching therefore are unlikely to produce matched groups with less bias than what was achieved with propensity score matching in the present study.

7.7 Summary

Propensity score matching is a very popular approach for inferring causality from observational datasets. There are multiple ways of conducting a propensity score matching analysis which require careful consideration and detailed reporting of how it was undertaken. The treatment group (patients with an inpatient rehabilitation admission) and control group (a subset of patients with EHRs) in the current dataset were too different for matching on the propensity score to be a valid approach. It is unclear if the difference between the two groups on the observed covariates were due to a true difference between the two groups on their

propensity to have a inpatient rehabilitation admission, or if there are important unknown and/or unobserved variables which predict group allocation that were not used in the calculation of the propensity score. There are other approaches to matching but for any matching technique to be effective requires a degree of similarity between the groups on the observed covariates, and at least with the current sample and current dataset, the difference between the two groups appear not to lend itself to any matching technique.

8 Chapter 8: Discussion and overall conclusion

8.1 Introduction

In this chapter, I summarise the main findings from my studies and how these fit within the current literature. I also summarise the main limitations which should be considered when interpreting the main findings and discuss potential areas for future research and the implications of my findings. Finally, this Chapter and thesis ends with an overall conclusion.

8.2 Main findings

8.2.1 The limitations of using CRIS to research mental health supported accommodation

The Clinical Records Interactive Search (CRIS) is a tool with vast potential for evaluating mental healthcare in the NHS (259). There are however limitations in using it to evaluate mental health supported accommodation services, as demonstrated by my study I reported in Chapter 4. This is primarily because the use of supported accommodation is not systematically recorded on NHS electronic health record (EHR) systems. Supported accommodation services in England are not usually provided by the NHS; they are typically provided by charities and housing associations which have their own EHR systems that are not connected to the NHS systems which CRIS has been deployed on. Although NHS staff often report whether service users are living in or using mental health supported accommodation - supported accommodation is a core component in the mental health rehabilitation pathway (see Chapter 2 Section 2.8.3) and an important aspect in an individual's healthcare - they are not required to routinely report the use of these services in the same way that they report the use of NHS services. Using CRIS to identify a sample of people using supported accommodation is therefore likely to be affected by sampling bias. In addition, the lack of systematic recording of the use of supported accommodation also means that it is unlikely that accurate start and end dates of supported accommodation service use could be obtained from NHS EHRs.

Another limitation in using CRIS to research mental health supported accommodation is that reference to many of these services in free text records is masked. This is because the name of supported accommodation services often includes part of the service address. This address is effectively the individual's home address, and home address is classified as a patient

identifier and masked by CRIS (see Chapter 3 Section 3.5 for further detail on the de-identification process). For this reason, many individuals with reference to supported accommodation in their free text records will not be identifiable through searches of free text records.

This raises the question of whether it is ethical to use CRIS to identify individuals who have used supported accommodation by searching free text records where the search is based on the name of individual services. In my study, the search of free text records was developed as a series of 'single service searches', where the aim was not to identify individuals who had used a specific service but those who had used any supported accommodation service (see Chapter 4 Section 4.2.2 for a description of how the free text search was developed). The final free text 'all service search' contained a group of individuals where around two-thirds (accounting for the estimated positive predictive value) had at one point over a period of 10 years, lived in one of 31 mental health supported accommodation services. This is not information that can be used to identify an individual in the same way a home address could be used. In other words, although single service searches do reveal an individual's address, the approach I adopted in this study was to use the single service searches to develop the all service search, and individuals could not be identified from the all service search.

Another issue to consider in relation to this is that, arguably, a specific supported accommodation service address is not as identifiable as the address of a person living in an independent tenancy. This is because at any one time there are several unrelated people living in a supported accommodation service, but usually only a single person or group of related persons living in an independent tenancy. Furthermore, this issue of identifying individual patients from their supported accommodation service addresses should be considered within the approach taken to develop CRIS. As explained in Chapter 3 Section 3.7, the developers of CRIS accept that CRIS users can probably use CRIS EHRs to identify a person if this was the intention of the user (1). The developers mitigate against this risk by putting in place security protocols including only allowing access to approved researchers with approved projects. In addition, the researcher has an individual responsibility to not use CRIS with the intention of identifying individuals and to protect against incidentally identifying

individuals. For example, in my CRIS studies where cell sizes were less than five in tables including patient characteristics, these numbers were supressed to protect identities.

8.2.2 Systematic review: Reduced inpatient service use following a mental health inpatient rehabilitation admission

My systematic review (reported in Chapter 5) identified a number of studies that found reduced inpatient service use following an admission to a mental health inpatient rehabilitation unit compared to the period before the admission (146, 147, 150, 171). However, the degree to which inpatient service use reduced varied considerably between studies and there were substantial limitations to each of these studies, including small sample size, the length of the before and after period, the lack of controlling for potential confounding, and the fact that all these studies were observational in design. The lack of a comparison group limits the extent to which causality can be inferred. This is because it is not possible to disentangle the effect of the intervention, regression to the mean, and time (235). In other words, it may be that over time individuals tend to use inpatient services less, regardless of an inpatient rehabilitation admission. A study with a control group, i.e. a group of individuals who did not have an inpatient rehabilitation admission, would remove any regression to the mean and effect of time because a comparison can be made between individuals who did and did not receive the treatment. The difficulty in conducting such a study is that the two groups must be similar on other variables otherwise the difference between the two groups on the outcome may be due to differences other than whether they received the treatment or not. However, it seems unlikely that the large reductions in inpatient service use found in the observational studies (146, 147, 150) can be fully explained by regression to the mean and patients' mental health simply improving over time without any intervention. This population have complex and enduring mental health problems and usually come into contact with rehabilitation services after more than 10 years of mental health treatment (65). Nevertheless, these issues should be considered when interpreting findings from studies with a pre-post design without a comparison group.

8.2.3 Systematic review: Reduced inpatient service use following a move to a mental health supported accommodation service

My systematic review (Chapter 5) also identified a number of studies which reported reduced inpatient service use following a move to mental health supported accommodation service (148, 158, 168-170). Like the inpatient rehabilitation studies, these studies tended to be pre-post observational studies without a comparison group and so the same limitations described previously (Section 8.2.2) also apply to this finding. However, this finding does make clinical sense. If someone is provided appropriate support in the community (for example, support with managing medication and practical support with activities of daily living (e.g. preparing meals and managing one's own finances)), one would expect that their chances of relapse and re-admission would be reduced.

In Chapter 2 I described the deinstitutionalisation of mental healthcare: the process of shifting mental healthcare from being based in hospitals to predominantly being based in the community. In the main, deinstitutionalisation was regarded as a success, as people who were stuck in hospitals for decades had been discharged to the community without any deterioration in their mental health and were benefiting from living in their new environment (47, 48, 260). There were however criticisms of deinstitutionalisation. Some felt that the large hospitals were being replaced by other institutions, including supported accommodation services (50, 170). Some services may resemble institutions to some degree (51), and it is acknowledged that there is a need to improve the quality of mental health services worldwide (52). However, small residential services that are part of the local community based mental health care system, where individuals have choice about such things as how to furnish their rooms, when they can leave the service, and how to occupy their time, are not the same as the large, remote, long-stay mental hospitals ubiquitous in the mid-20th century.

Nordentoft et al. (170), in a study which was critical of the wide scale closure of hospitals and rise of supported accommodation services in Denmark, did acknowledge that residents in supported accommodation did in supported accommodation "have a higher level of civil rights" (p.1252 (170) than when they were patients in mental hospitals. However, they raised concerns that in supported accommodation they were being under treated because of a lack of qualified staff. Mental hospitals are staffed by qualified healthcare professionals such as

nurses, psychiatrists, and psychologists, whereas supported accommodation staff are not usually professionally qualified. However, Nordentoft et al. also note that almost all residents have contact with professionally qualified staff from community mental health services. It should also be considered that replacing staff in supported accommodation services with professionally qualified staff risks duplicating the kinds of clinical practices that can foster institutionalisation. A house with nurses and psychiatrists on site, especially when they are the same nurses and psychiatrists who previously staffed mental hospitals, may not operate very differently from a ward. It would also be prohibitively expensive. The recent NICE guideline on rehabilitation services for people with complex psychosis recommends that clinical input to people living in mental health supported accommodation should be provided by community mental health rehabilitation teams who can work across multiple local supported accommodation services (86).

8.2.4 Systematic review: Limited move-on from mental health supported accommodation services

A systematic review on training programmes for mental health supported accommodation staff found limited evidence on their effectiveness in terms of improving the recovery-based practice of the service and outcomes for residents (261). In my systematic review (Chapter 5), I found that move-on from highly supported accommodation services to lower levels of supported accommodation (or to an independent tenancy) were limited across several countries (5, 153-155, 164, 165, 175). To what extent this is due to inadequate staff training, a lack of adequate accommodation for individuals to move to, or services providing the optimal level of independence for some individuals, is unclear, but higher rates of 'forward' moves have been found to be associated with services that provide a greater focus on recovery-based practice (5).

The development of training programmes tailored to staff of supported accommodation services which equip them to better provide recovery focussed care, and the deployment of such a programme, may increase the rate of forward move-on. However, the impact of this will be limited if the reason for a lack of move-on is primarily due to a lack of appropriate housing or support accommodation to move to, or if individuals have already found their optimal level of independence. If a resident is living in a setting which at the current point in

their recovery is their optimal level of independence, they should not be unduly encouraged to move to another service. The other side to this is that supported accommodation services can resemble the long-stay institutions of the 20th century if there are not clear plans in place to help support residents toward discharge to more independent settings. This can be addressed by having services that are recovery focussed and tailored to the individual rather than services with universal rules or targets; the service should not aim for everyone to move-on within two years. There are challenges to this in some systems. Supported accommodation services in England are usually commissioned on a relatively short term basis and their performance measured in terms of their move-on rate. Services may not exist long enough to provide very long term accommodation and support, or they may no longer exist if they do not provide a track record of their residents moving on to other settings.

8.2.5 Using CRIS to evaluate mental health inpatient rehabilitation units

The study I undertook and reported in Chapter 6 demonstrates that it is viable to evaluate inpatient mental health rehabilitation services using CRIS. In this study I identified a cohort of individuals who had an admission to an inpatient rehabilitation service and compared their inpatient service use before and after this admission. This study included validation of structured records regarding inpatient service use by reviewing free text records to see if admission start and end dates recorded in structured fields were consistent with what was reported in free text records. Although the structured records were deemed sufficiently accurate to be used in the study, the validation process did reveal that there may be value in developing a natural language processing (NLP) application for inpatient admissions, and/or linking the CIFT CRIS database with the Hospital Episodes Statistics (HES) database (the South London and Maudsley NHS Foundation Trust CRIS database has already been linked to the HES database) (227, 228). This would likely improve the accuracy of inpatient admission data, especially non mental health admissions and admissions to wards provided by other healthcare providers. The potential to use CRIS to evaluate other aspects of inpatient rehabilitation units and other components in the mental health rehabilitation pathway were not explored in this study but are discussed later in this Chapter in Section 8.4.

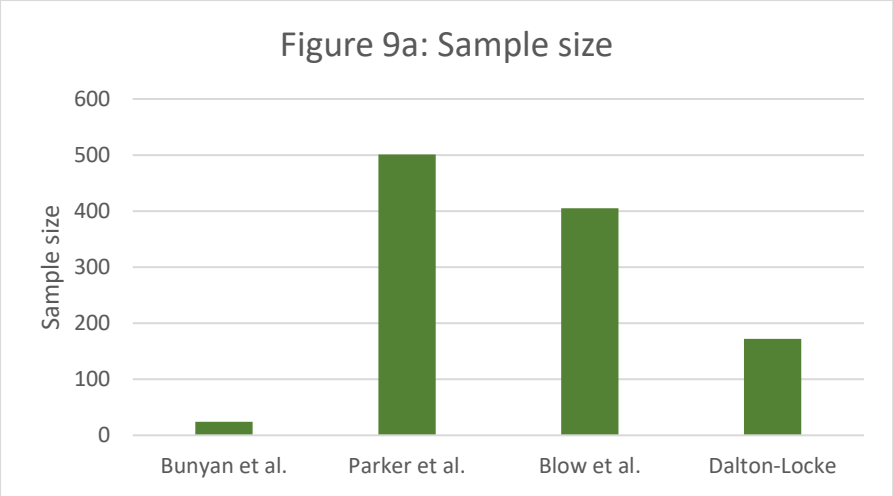
8.2.6 Reduced inpatient service use after an inpatient rehabilitation admission

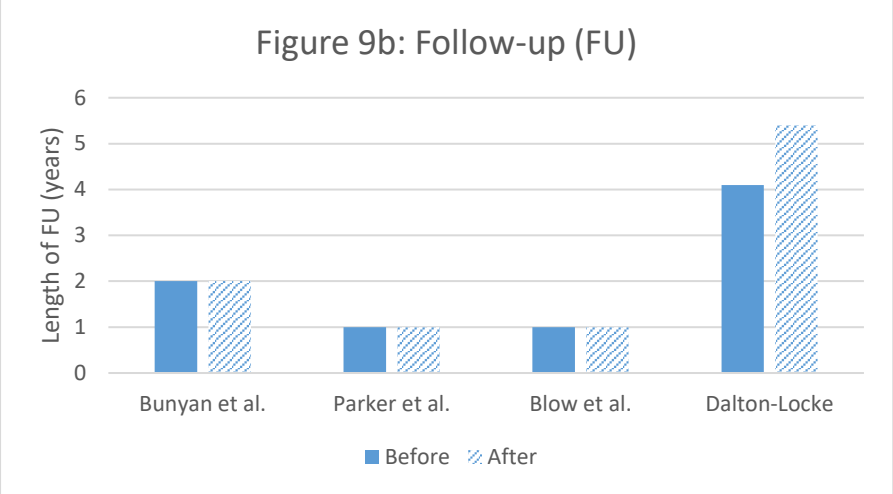
In my CIFT CRIS study which compared inpatient service use before and after an inpatient rehabilitation admission (Chapter 6), I found inpatient service use reduced by around 48% (an incident rate ratio of 0.520, with a 95% confidence interval of 0.367 to 0.737). This was after controlling for potential confounding variables. This finding is consistent with the four studies I identified in my systematic review (Chapter 5) which made a similar comparison (146, 147, 150, 171). Each of these studies also reported a reduction in inpatient service use after the rehabilitation admission, but the magnitude of the reduction varies, as does the size of the cohorts and the length of the before and after periods.

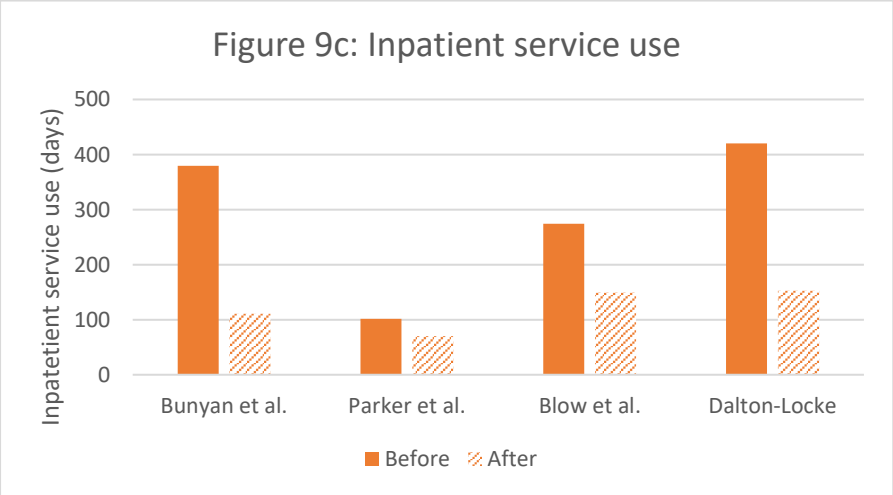
Bunyan et al. (150) compared inpatient days two years before with two years after an inpatient rehabilitation admission for 24 individuals from three units in South London. They reported the mean inpatient days reduced from 379.45 (standard error (SE) 56.26) before to 110.59 (SE 52.45) after. Parker et al. (171) compared inpatient days one-year before admission with one-year after discharge for 501 patients from five inpatient rehabilitation units in Australia. The mean inpatient days reduced from 101.54 (standard deviation (SD) 113.01) before the admission to 70.39 (SD 118.33) afterwards. Blow et al. (147) evaluated an inpatient rehabilitation programme in the United States during the 1990s. For 405 individuals, inpatient days reduced from a mean of 274.0 (SD 101.7) in the one-year before the programme to 149.1 (SD 157.6) in the one-year before the three-year follow-up. The last study reporting this outcome only looked at the period six months before and after an admission to a Canadian inpatient rehabilitation unit for 53 individuals (146). They reported the number of individuals with no inpatient admissions before the rehabilitation admission was five (9.4%) compared to 43 (81.1%) after.

Figures 9 compares the key characteristics of the four studies which report the number of inpatient days before and after an inpatient mental health rehabilitation admission, the three studies identified in Chapter 5 (147, 150, 171), and my study which I reported in Chapter 6. My study had a cohort of 172 individuals from two inpatient rehabilitation services. Not as many as in the studies by Parker et al. (N=501) (171) or Blow et al. (N=405) (147), but considerably more than in the studies by Bunyan et al. (N=22) (150) and Awara et al. (N=53) (146). The before (median = 4.1 years, interquartile range (IQR) = 2.6 to 6.2) and after period (median = 5.4 years, IQR = 3.1 to 7.0) in my study were longer than these studies which at most looked at a two-year period before and after (150). The length of follow-up is important in mental health rehabilitation research given the long-term view of rehabilitation services. My study is an improvement on previous studies in this field when considering in combination the cohort size, the before and after period, and that it was the first study in this field to control for potential confounding variables. Therefore, the findings form my study that inpatient service use is reduced following an inpatient rehabilitation admission, adds considerable strength to the overall conclusion from these studies that inpatient rehabilitation services reduce inpatient service use.

Figures 9a-c: Sample size, length of follow up, and standardised inpatient service use per year, of studies reporting inpatient days before and after an inpatient mental health rehabilitation admission (Bunyan et al. (150), Parker et al. (171), Blow et al. (147), and Dalton-Locke (Chapter 6)







8.2.7 Identifying a valid comparison group for a mental health inpatient rehabilitation cohort using propensity score matching

In Chapter 7, I reported a study where I used propensity score matching methods to identify a valid comparison group for the group of individuals with an inpatient mental health rehabilitation admission I had previously identified using the CIFT CRIS database (Chapter 6). Propensity score matching aims to mimic the equivalence of comparison groups in RCTs by using observational data to identify individuals with similar characteristics other than the exposure variable of interest (in this case, admission to an inpatient mental health rehabilitation unit). I identified from the CRIS database individuals with at least four inpatient admissions and a diagnosis of schizophrenia, schizoaffective disorder, or bipolar affective disorder. I extracted the same descriptive data for these individuals as I had extracted for the inpatient rehabilitation group and used these data to estimate the probability of each individual, including those with and without a rehabilitation admission, to be admitted to an inpatient rehabilitation service (i.e. the propensity score). This estimate was used to match individuals from each group. Therefore, individuals on the CIFT CRIS database who did and did not have an inpatient rehabilitation admission were matched for their propensity to be admitted to an inpatient rehabilitation unit based on the extracted data. However, there was a lack of similarity and overlap between the two groups on the propensity score (and the variables used to estimate the propensity score, i.e. the covariates) and, ultimately, this approach proved to be an ineffective method to identify a valid comparison group.

8.3 Limitations

8.3.1 The limitations of my systematic review

I consider my systematic review (Chapter 5) to have two main limitations. The first is that the outcome was very specific and it did not include other outcomes that are important in mental health rehabilitation. My review focused on studies which reported inpatient service use and move-on to other settings (e.g. a patient being discharged from an inpatient mental health rehabilitation unit to supported accommodation or from a higher level of supported accommodation to a lower level of supported accommodation), but other outcomes such as quality of life, recovery goals, and activities of daily living, are also important when reviewing the effectiveness of mental health rehabilitation services and the mental health rehabilitation pathway as a whole. There were however sound reasons for omitting these other outcomes.

There was a need during the design phase of the systematic review to specify and narrow the search itself to provide focus but also to make it feasible within the time and resource available. Inpatient service use and move-on were selected as outcomes as this data is available in NHS/CRIS records, and although they are not the only important outcomes when it comes to rehabilitation, they are still important outcomes in rehabilitation from a clinical, recovery, and economic perspective.

Although the review outcomes were narrow, the search of relevant databases for eligible articles yielded a large number of studies. This may have been due to another important limitation: the broad use of the term 'rehabilitation' in mental health, and the fact that this term was particularly important to my search and eligibility criteria. The term 'rehabilitation' is often used to describe mental health services which do not specialise in providing support for adults with complex psychosis. It was therefore not always clear when screening studies whether the 'rehabilitation' service or intervention referred to met the criteria for a rehabilitation service that I had set. The main reason for excluding articles at the full text screening stage was because it was unclear if the service or intervention did provide rehabilitation as described in Chapter 2 and in the NICE guideline (86). Relevant studies which did investigate rehabilitation services (at least rehabilitation as defined in this thesis), but which did not provide the detail to make this clear, may therefore have been excluded.

8.3.2 Limited measurement of 'effectiveness' in evaluating mental health rehabilitation services

Only measuring effectiveness in terms of inpatient service use is also a limitation to my before and after inpatient rehabilitation CRIS study reported in Chapter 6. I previously explained in this thesis the justification for selecting inpatient service use as the main outcome in my studies (see Section 6.4.1.1 and Section 8.3.1). In brief, it is an important clinical outcome (it usually represents the point when it is no longer appropriate or feasible to support the person in the community) and it represents the most expensive component of the mental healthcare system. It is therefore reasonable to assume it is reliably recorded in mental healthcare record systems, and therefore available as a reliable variable in CRIS databases.

However, like the limitation described for my systematic review (Section 8.3.1), there are other important outcomes which should be considered when assessing the effectiveness of mental health rehabilitation services. As described in Chapter 2 Section 2.8, mental health rehabilitation services aim to support people with complex psychosis to live in settings which provide their optimal level of independence. This is achieved through management of their symptoms associated with their psychosis and support with gaining and regaining skill in everyday functioning. Although reducing inpatient service use may be a credible proxy for these outcomes, it is clearly not the same. Investigating the impact of mental health rehabilitation on outcomes such as social and everyday function, quality of life, and autonomy, may help inform how inpatient rehabilitation reduces inpatient service use and help improve the effectiveness of these services.

The challenge is whether these variables can be extracted from CRIS databases or if these outcomes can only reliably be investigated via primary research (see Section 3.2 for a discussion on the pros and cons of primary and secondary research). The HoNOS (207), used in my studies reported in Chapters 6 and 7, is the most routinely used standardised outcome measure in the NHS. It does however have its limitations (231, 232) and on the CIFT CRIS database, recorded assessments were missing at important time points in my study (at inpatient admission and discharge, see Section 6.4.1.1). Also, the HoNOS is not intended as a specific measure for outcomes important to mental health rehabilitation such as quality of life, social functioning, or skills which facilitate and enable independence, but rather as a general measure for overall health in populations with mental health problems. Primary research would typically use measures designed to specifically measure specific outcomes (like the Manchester Short Assessment of Quality of Life (262) and the Life Skills Profile (263)), but as they are currently not used routinely in healthcare services, they cannot be used in secondary research using healthcare records.

8.3.3 Important components in the mental health rehabilitation pathway that were not evaluated

In Chapter 2 Section 2.8, I described the rehabilitation pathway and the types of service of which it is comprised. Although there may be many other forms of local support available to people with severe and complex mental health problems, including access to non-mental

health specific community activities, the core components in the rehabilitation pathway are inpatient rehabilitation services (both hospital and community based), supported accommodation, and community rehabilitation teams.

I did explore the feasibility of using CRIS to research supported accommodation (Chapter 4) and found that the use of these services was not systematically recorded on NHS/CRIS databases. This is most likely because these services are not provided by the NHS. However, as demonstrated by my study reported in Chapter 6, the use of hospital based inpatient rehabilitation services is systematically recorded on the CIFT database as they are provided by the NHS. Community based inpatient rehabilitation services and community rehabilitation teams are also usually provided by the NHS, and they are provided by CIFT in Camden and Islington. Therefore, in theory, the use of these services should be systematically recorded on the CIFT database and CRIS could also be used to evaluate the effectiveness of these service in the same fashion that hospital based inpatient rehabilitation services were evaluated in Chapter 6. The potential of this is discussed at greater lengths later in this Chapter (Section 8.4.2).

8.3.4 The limitations of a pre-post comparison and lack of a control group

Previously in this Chapter (Section **Error! Reference source not found.**), I described my efforts to use propensity score matching (reported in Chapter 7) to identify a valid comparison group for the group of individuals with an inpatient rehabilitation admission I identified using CIFT CRIS (reported in Chapter 6). Propensity score matching proved to be an ineffective method in this instance, and although popular, it has been argued that it is not the most efficient approach to matching as it tries to mimic a traditional randomised controlled trial (RCT), whereas other matching methods attempt to mimic block RCTs which produce more balanced groups than the traditional RCT design (258). The rational for attempting to identify a valid control group was because the study conducted previously (Chapter 6), only compared the outcome (inpatient service use) before and after an inpatient rehabilitation admission, and pre-post comparisons like this are limited in terms of what can be inferred from the results. This was discussed in further detail in Chapter 6 Section 6.4.1.4, but to briefly recap here, the degree to which causality can be inferred from a pre-post study design is limited because the effect of time or 'maturation' cannot be separated from the intervention (235). That I was

unable to identify a valid comparison/control group in my subsequent study means this limitation remains unaddressed. It should however be noted that there is value in pre-post comparisons, and the results reported in Chapter 6 do suggest an inpatient rehabilitation admission reduces inpatient service use, but comparison with a similar group of individuals who did not have an inpatient rehabilitation admission would have made the argument for causality stronger.

8.3.5 The generalisability of CIFT CRIS studies

As a rule, the generalisability of research is limited to the population or the subject that the research is based on, or is at least limited to similar populations or subjects. For example, a study analysing the rainfall in Iceland over the last ten years may inform the expected annual rate of rainfall over the next ten years in Iceland, but it is going to be of far less use in predicting the annual rainfall in Columbia. In the same vein, findings from CIFT CRIS studies can be applied to NHS mental healthcare in Camden and Islington but the extent to which they can be applied to other regions within England and beyond is variable.

The findings are most relevant to areas or contexts with similar characteristics. For the studies reported in this thesis, when considering other areas in England, the most relevant characteristics are the local demographics, the local mental health morbidity, and the local provision of mental health care. As discussed in Chapter 2 Section 2.9, Camden and Islington are not representative of England on demographics or mental health morbidity. Nor are they representative of England in the provision of mental health rehabilitation services, where there is an established rehabilitation pathway with a range of local rehabilitation services. Both boroughs have a community rehabilitation team, a range of local inpatient rehabilitation services including hospital and community based inpatient services, and various types of supported accommodation offering different levels of support (see Chapter 2 Section 2.10 for more detail). Most areas in England have inpatient rehabilitation services (65, 81) and supported accommodation (4) but the level of provision varies greatly, and half of the NHS Trusts in England do not provide a local community rehabilitation team (64, 95).

The degree to which the findings from the CIFT CRIS studies in this thesis can be applied to inpatient rehabilitation services in other parts of England is therefore variable. There is even

greater variation when applying the findings to other countries as additional characteristics need to be considered. However, the findings are still of relevance to other high-income countries with similar healthcare systems, and similar societal and cultural approaches to mental health care.

8.3.6 Lack of patient and public involvement

The only patient and public involvement (PPI) in this thesis were the reviews of the CRIS project proposals by the CIFT CRIS oversight committee, which includes services users and clinicians. As briefly discussed in Chapter 3 Section 3.7, PPI is widely recognised as an important aspect in healthcare research (126, 127), and has been shown to improve the quality and relevance of research (129). It is therefore a limitation of the studies included in this studentship that it did not include more PPI than it did.

A large component of this studentship was assessing the feasibility of using CIFT CRIS to evaluate mental health rehabilitation services. Consulting and collaborating with people who have lived experience of using mental health rehabilitation services and their close friends and relatives, would have provided insight into what is important when it comes to mental health rehabilitation, including what outcomes should have been used in the study. PPI at the early stages of the studentship would have likely affected its aims and objectives and therefore fundamentally altered the contents of this thesis. PPI at a later stage would have helped inform the interpretation of the results.

8.3.7 Lack of qualitative research

A valuable contribution to this thesis would have been a qualitative study which explored the experiences and perspectives of people who have used mental health rehabilitation services. Such a study would give rich detail on what does and does not work well in mental health rehabilitation, providing insight into how services can be improved. It could also provide insight into what is important to people who use these services and what they hope the service will help them achieve.

As far as I am aware, the only qualitative study exploring the experiences and perspectives of people admitted to inpatient rehabilitation services was conducted by Bredski et al. in 2015

(264). They interviewed 31 patients from four inpatient services in Edinburgh, Scotland, about what they felt facilitated recovery. The themes which emerged related to hope, agency, relationships, and opportunity. These themes could perhaps be used to inform measures of effectiveness, but further research is required to determine whether similar themes emerge for patients from other inpatient rehabilitation services.

Qualitative research has been conducted on other components in the rehabilitation pathway, including supported accommodation (98). However, there is a general lack of qualitative research in mental health rehabilitation, including research which considers the whole rehabilitation pathway as described in the recent NICE guideline (86) and in Chapter 2 Section 2.8 of this thesis. Understanding the views of the various stakeholders, including patients, carers of patients, staff, and commissioners, in areas with an established local rehabilitation pathway, could provide valuable information in how to improve these pathways both in areas where they have already been established and in areas planning to implement such a pathway.

8.4 Future research

In the following Section I will discuss how CRIS may potentially be used to research the effectiveness of mental health rehabilitation in ways other than inpatient service use, how it may be used to investigate the other components in the rehabilitation pathway, and how it could be used to evaluate the effectiveness of the overall rehabilitation pathway.

8.4.1 Using CRIS to research the effectiveness of mental health rehabilitation services beyond inpatient service use

In Section 8.3.2, I discussed the limitation to my studies in only measuring the effectiveness of mental health rehabilitation services in terms of inpatient service use. Part of the rational for this was that inpatient service use should be reliably and systematically recorded on NHS/CRIS databases. In this Section I am going to discuss how other outcomes which should be considered when evaluating the effectiveness of rehabilitation services may potentially be extracted from CRIS.

Natural language processing (NLP) was discussed in Chapter 6 (Section 6.4.1) as a method commonly used in extracting data from free text records and in CRIS research. A wide range of NLP applications have been developed and validated on the CRIS South London and Maudsley NHS Foundation Trust (SLaM) database and are available to CRIS researchers. They include specific mental health symptoms such as disturbed sleep, hopelessness, guilt, and social withdrawal, and contextual factors such as loneliness and violence (225). These applications perform to varying degrees, measured in terms of precision (out of the total number of returns, the proportion that are true positives) and sensitivity (sometimes described as 'recall', of the true positives that do exist in the database, the proportion that are returned by the application). Developing an NLP application with acceptable precision and sensitivity that can be used to measure constructs as complex as wellbeing, social functioning, or skills for independent living - all important outcomes in mental health rehabilitation - may be beyond the current capabilities of NLP (and/or beyond the information that is contained in free text healthcare records). However, if NLP can be used to extract specific symptoms and contextual factors, it is reasonable to assume it has potential to extract behaviours, specific skills, or events that constitute these complex constructs. For example, positive interactions with others, cooking meals, managing one's own medication, hobbies/interests, and signs of progress towards common recovery goals such as meaningful relationships, education, and work.

8.4.2 Using CRIS to research the other components in the local mental health rehabilitation pathway

As discussed in Section 8.3.3, CRIS was used in my thesis to evaluate the effectiveness of inpatient mental health rehabilitation services (Chapter 6), and I explored the feasibility of evaluating supported accommodation using CRIS (Chapter 4). However, there are other important components in the rehabilitation pathway which could potentially also be evaluated using CRIS.

For example, CRIS could be used to study community rehabilitation teams and community inpatient rehabilitation units in a similar way to how inpatient rehabilitation services were studied in Chapter 6, by comparing inpatient service use of individuals before and after they used the service. Furthermore, by extracting data on an individual's use of the different types

of rehabilitation services, may provide useful information on the overall rehabilitation pathway. As found in my systematic review (Chapter 5), few studies consider more than one type of rehabilitation service. A study which investigates transitions between services in the rehabilitation pathway may provide valuable insights into how the pathway can be best structured by identifying 'bottlenecks' (or delayed discharges). Such an insight may inform where resource in the pathway would be best allocated. Furthermore, despite my finding that the use of supported accommodation was not systematically recorded on the CIFT database, it may be possible to identify individuals who progress to supported accommodation from inpatient rehabilitation services by reviewing the free text of discharge summaries (which should be completed for each individual upon discharge and include a care plan moving forward and details of the type of accommodation they have moved to). Therefore, it may be possible to explore the whole rehabilitation pathway using CRIS.

8.4.3 Replication using other CRIS databases

"Replication is repeating a study's procedure and observing whether the prior finding recurs" (p.1 (265)), often repeating the procedure on another dataset or population and with slight changes to the analysis. Replication is a fundamental cornerstone of science. If a study is repeated and the results are consistent this adds strength to the finding. However, if the results are inconsistent this weakens the finding, and one may interpret that the original (or new) finding was based on spurious results. The apparent failure to replicate findings in science, particularly in social science and psychology, and including articles published in highly respected peer reviewed journals (266), has received a huge amount of attention both by academics and in the media over the last decade (267, 268), leading to headlines declaring that science is in 'crisis' (269).

A comprehensive discussion on the importance of replication in science, and coverage of the evidence and debate over whether science is in a replication crisis or evolving to a position of greater methodological rigor and transparency, is beyond the scope of this thesis. Rather, this section will focus specifically on how replication of the studies reported in this thesis, especially the study reported in Chapter 6 which found reduced inpatient service use following an inpatient rehabilitation admission using the CIFT CRIS database, may add strength and credibility to this finding.

Replicating the study reported in Chapter 6 using other CRIS databases or other EHR sources would add to the generalisability of the findings. As discussed in Section 8.3.5, that the study only used data from the CIFT CRIS database limits the degree to which the findings can be applied to other settings; Camden and Islington will have some similarities with other inner-city regions across the world, but they are not representative of England, or any other country. Therefore, repeating the procedure as described in Chapter 6 Section 6.2, using other populations would improve the generalisability of the study findings. CRIS at South London and Maudsley NHS Foundation Trust (SLaM) is well established and has produced a wealth of research (259), it is therefore perhaps the most obvious site for a replication study. Although, the catchment area served by SLaM does not differ vastly from CIFT, SLaM is one of the largest mental healthcare providers in Europe. The SLaM CRIS database contains records for more than 340,000 individuals going back to 2007 (3, 118). Furthermore, rather than an exact replication of the procedure reported in Chapter 6 Section 6.2, there may be opportunity to expand the outcomes used to measure effectiveness (as discussed in Section 8.4.1) and include more types of rehabilitation service (as discussed in Section 8.4.2).

Expanding the research question may enhance the generalisability of any finding beyond what is achievable in an exact replication on another population or dataset. Burchett et al. recently proposed that there is more to the generalisability of research than the setting in which the research took place, that understanding "why or how an intervention was effective" (p.1 (270)), is also informative of when an intervention may be effective. A study using the SLaM CRIS database may provide greater scope for expanding the research question to include the 'why or how' relative to other CRIS databases given the stage of its development. Of course, such a replication study may produce results that are contrary to those reported in Chapter 6. It may be argued that this would contribute to the 'replication crisis', or instead, critically appraising the differences between CIFT and SLaM and the two studies may enhance our understanding of when and why mental health rehabilitation is effective.

8.4.4 Continuing development of CRIS

Very broadly, there are three areas in which CRIS can be developed to address a more expansive range of research questions and address research questions more efficiently. All three areas have been discussed to some extent already in this thesis. The first area is the

continuing development and validation of Natural Language Processing (NLP) applications, on the SLaM CRIS database and other less established CRIS databases. As discussed previously in this Chapter (Section 8.4.1) and in Chapter 6 (Section 6.4.1.1), NLP could potentially be used to investigate the effectiveness of mental health rehabilitation services beyond inpatient service use and enable the investigation of other outcomes stored in free text records.

The second area is database linkage. As also discussed in Chapter 6 (Section 6.4.1.1), linking CRIS databases provides opportunity to validate CRIS data and additional data for CRIS researchers to analyse (226). For example, linking the SLaM CRIS database with the Hospital Episode Statistics (HES) database provides a means to validate the inpatient admissions in the SLaM CRIS database, and adds data on general medical admissions as well as any admission funded by the NHS in the independent sector, Accident and Emergency presentations, and mortality (227, 228).

There are different ways to linking databases depending on the identifiable information that is available in both databases. Healthcare databases in the UK usually contain the individual's NHS number and as this number is unique to each individual, it is an efficient way of linking databases before they are de-identified. It is however possible to also link a healthcare database with a non-healthcare database which does not contain the NHS number, as long as they both contain the same identifiable variable or set of variables which together can be used to identify an individual. For example, name, date of birth, and postcode alone may not be unique to a person, but it is very unlikely that two individuals will have the same name, date of birth, and postcode. Therefore, these three variables were used to link the SLaM database with the Department for Education's National Pupil Database, and enabled an analysis which found an ICD-10 mental health diagnosis was associated with school absence (271). The SLaM database has also been linked to the Department for Work and Pensions database, and with UK census data (227).

If the databases used by the providers of mental health supported accommodation could be linked to NHS Trust databases and made available for research using the CRIS tool, the effectiveness of supported accommodation could be investigated (at least in terms of inpatient service use and potentially other outcomes as discussed in Section 8.4.1). The

rational for the study reported in Chapter 4 was that there are substantial barriers to researching supported accommodation. Such a linkage would help address this, but this approach also has substantial barriers. The linkage would not be any more technically challenging than linking the SLaM and HES databases as one would expect the supported accommodation database to contain NHS numbers, but there are usually multiple providers of local supported accommodation, each with their own EHR system and database. Therefore, to establish a database which included the use of all local supported accommodation services would likely require linkages between multiple databases. There are also other barriers to consider, including the availability of electronic data (some organisations still use a paper based system for their records), regulations on data sharing, and the willingness of the organisation to share their data.

Finally, a further possibility would be to combine NHS mental health Trust databases with one another, for example, the SLaM and CIFT databases. This would generate a database with a larger, more diverse set of individuals, and would go some way to addressing the limitation discussed previously in this Chapter: the generalisability of CRIS studies (Section 8.3.5). The more Trust databases that are combined, and the greater the differences between the combined Trusts in terms of the catchment areas they serve, the more generalisable the findings will be.

The third area in the continuing development of CRIS, is not necessarily about the improvement of health records research or the capabilities of CRIS, but it is necessary if the use of de-identified mental healthcare records in research is to continue and develop. The patient and public perspective and awareness on the use of mental healthcare records in research is largely unknown. The limited research which does exist was discussed in Chapter 3 Section 3.8. It suggests that people are generally supportive of research using de-identified healthcare records, if the research is being conducted by a trusted organisation and with the purpose of improving healthcare (123, 124). However, the limited research also suggested that most people are unaware over their own rights when it comes to the use of their health data in research (123). Further research is needed to understand public perception of research using mental health care records as the current research mainly looks at the perception in the use of physical health care records. There also needs to be research on the

awareness of mental health patients and staff over individual's right regarding the use of their health records in research, and if indicated, staff training on how to communicate patient's rights and campaigns which increase public awareness over their rights, ought to be commissioned.

8.5 Implications

8.5.1 Methodological implications

As has been discussed throughout this thesis, there is vast potential for the use of routinely collected healthcare records in mental health research. For decades, healthcare records have been used in primary and secondary research (see Chapter 3 Section 3.2 for a discussion on primary and secondary research). However, the development of systems like CRIS which de-identify healthcare records making them available for secondary research without the explicit consent of the individuals the records are about, is much more recent. This thesis, as well as demonstrating the value and potential of CRIS, has also demonstrated some of the practical methodological challenges in using it, and in turn, has highlighted ways in which CRIS can be improved and made more efficient.

My study reported in Chapter 4 showed that there are substantial limitations to using CIFT CRIS in research evaluating the effectiveness of mental health supported accommodation. As explained previously in this Chapter (Section 8.2.1), there were systematic reasons for why some individuals who have used supported accommodation could not be identified with the search approach used. There was a high rate of missing data in the structured fields which recorded the individual's type of accommodation, and the name of some supported accommodation services will not appear in the free text records because the text matched the individual's home address and is therefore treated as a patient identifier and masked by CRIS. Also, because supported accommodation in England is primarily provided by housing associations and charities, and not the NHS, the use of these services (including admission and discharge) is not systematically recorded in NHS records. Some of the ways that this could be addressed were discussed in Section 8.4. One way would be to link the NHS and supported accommodation datasets. This may or may not be practical given the number of local providers of supported accommodation and their permissions relating to data sharing.

However, previous data linkage projects involving SLaM CRIS have shown that this latter issue can be overcome.

The CRIS studies reported in my thesis, and other CRIS research, can also indicate where healthcare records are missing and/or where they are inaccurate. As research and evaluation of healthcare services become more dependent on healthcare records, the accuracy and reliability of these records become increasingly important. It ought therefore to be an imperative of research and healthcare organisations to work together to find solutions that improve the quality of healthcare records. This could be achieved by making EHR systems 'smarter'. Structured fields could be made mandatory to complete, for example, when a clinician is recording an individual's demographics (e.g. sex, date of birth, etc.), they are forced (or prompted) to also record the individual's accommodation status; limitations/rules could be added to certain fields to prevent data being recorded in error (e.g. an inpatient discharge date occurring before the admission start date); and auto-reminders could be built-in to help support clinicians to add information that is missing or update old records. In conjunction with making EHR systems smarter, healthcare organisations could introduce or update their policy and organisational oversight to have a greater emphasis on supporting clinicians to ensure their records are up to date, accurate, and comprehensive. Improving the quality of healthcare records will not just improve the reliability of research which rely on these records but will also improve the quality of healthcare through clinicians having access to more detailed and accurate information about their patients.

8.5.2 Clinical implications

The main clinical implication from my thesis is the finding that an inpatient rehabilitation admission appears to reduce inpatient service use. This finding was critically analysed previously in this Chapter (see Section 8.2.6, Section 8.3.4, and Section 8.3.5) and I will not repeat that discussion here, but it is important to consider the generalisability of the finding and the degree to which causality can be inferred given the limitations of the study design. The finding supports the recommendations made in the NICE guideline on rehabilitation for adults with complex psychosis (86), in that it provides further evidence to support the role of inpatient rehabilitation services as a fundamental component in the local rehabilitation pathway. I also found in my thesis that female patients, Black patients, and patients with a

comorbid health condition were more likely to be re-admitted following an inpatient rehabilitation admission. However, these findings need to be substantiated through further research.

8.6 Overall conclusion

Inpatient mental health rehabilitation services appear to help reduce inpatient service use. My study reported in Chapter 6 which uses the CIFT CRIS database to compare inpatient service use before and after an inpatient rehabilitation admission found that inpatient service use was reduced by half after the rehabilitation admission. This effect was reduced only slightly when adjusting for potentially confounding variables. This finding is consistent with previous research in the field as identified in my systematic review reported in Chapter 5 and strengthens the evidence-base for mental health inpatient rehabilitation services.

My systematic review identified four studies which reported reduced inpatient service use following an admission to an inpatient rehabilitation service (146, 147, 150, 171). Out of these four studies, the most similar to mine in terms of study design was conducted by Bunyan et al. (150). My study had a larger cohort and used a longer before and after period compared to Bunyan et al. My study also controlled for potential confounding variables whereas Bunyan et al.'s study did not. My study therefore provides a valuable contribution to our knowledge on the effectiveness of inpatient mental health rehabilitation services.

There were limitations to my study which ought to be considered when interpreting its findings. My study only included individuals from two inpatient rehabilitation services, both located in North London. These individuals and services may not be representative of individuals and services in other locations where healthcare systems, the local mental health morbidity, and other aspects of the local environment, are substantially different to North London. For example, a rural area with a much lower population density. Also, the before-after study design, without a comparison group, makes it unclear to what degree causality can be inferred. It is not possible to determine the extent to which the inpatient rehabilitation admission caused the reduction in inpatient service use. I did attempt to address this issue of causality by using propensity score matching methods, reported in Chapter 7, but this approach proved to not be viable in this instance.

My thesis has also demonstrated some of the potential of using CRIS and de-identified health records to research mental health rehabilitation services, as well as its limitations and potential areas for improvement. As mentioned above, I was able to use CIFT CRIS to compare inpatient service use before and after an inpatient rehabilitation admission. It remains to be seen exactly how else CRIS might be used to investigate the effectiveness of the mental health rehabilitation pathway and its components. There are substantial limitations currently in using CRIS to research mental health supported accommodation, but there are potential solutions, and further developments in NLP applications and databases linkages will only enhance the utility of CRIS databases in mental health rehabilitation research and beyond.

Although this is an exciting prospect for mental health researchers, as with any secondary research, the quality of the research will be determined by the quality of the data. Healthcare records primarily serve a clinical function, but as they are relied upon more and more for research and evaluation which ultimately aim to improve healthcare, greater attention and emphasis should be placed on how to support clinicians accurately and comprehensively record healthcare related information. There will however always be research questions that cannot be appropriately addressed using secondary research methods and so there will always be a need for primary research, including within the field of mental health rehabilitation research.

References

1. Stewart R, Soremekun M, Perera G, Broadbent M, Callard F, Denis M, et al. The South London and Maudsley NHS Foundation Trust Biomedical Research Centre (SLAM BRC) case register: development and descriptive data. Bmc Psychiatry. 2009;9:51. doi:10.1186/1471-244X-9-51

2. Fernandes AC, Cloete D, Broadbent MT, Hayes RD, Chang CK, Jackson RG, et al. Development and evaluation of a de-identification procedure for a case register sourced from mental health electronic records. BMC Med Inf Decis Mak. 2013;13:71. doi:10.1186/1472-6947-13-71

3. Perera G, Broadbent M, Callard F, Chang CK, Downs J, Dutta R, et al. Cohort profile of the South London and Maudsley NHS Foundation Trust Biomedical Research Centre (SLaM BRC) Case Register: current status and recent enhancement of an Electronic Mental Health Record-derived data resource. BMJ Open. 2016;6(3). doi:10.1136/bmjopen-2015-008721

4. Killaspy H, Priebe S, Bremner S, McCrone P, Dowling S, Harrison I, et al. Quality of life, autonomy, satisfaction, and costs associated with mental health supported accommodation services in England: a national survey. Lancet Psychiatry. 2016;3(12):1129-37. doi:10.1016/S2215-0366(16)30327-3

5. Killaspy H, Priebe S, McPherson P, Zenasni Z, Greenberg L, McCrone P, et al. Predictors of moving on from mental health supported accommodation in England: national cohort study. Br J Psychiatry. 2020;216(6):331-7. doi:10.1192/bjp.2019.101

6. Killaspy H, Priebe S, McPherson P, Zenasni Z, McCrone P, Dowling S, et al. Feasibility Randomised Trial Comparing Two Forms of Mental Health Supported Accommodation (Supported Housing and Floating Outreach); a Component of the QuEST (Quality and Effectiveness of Supported Tenancies) Study. Front Psychiatry. 2019;10:258. doi:10.3389/fpsyt.2019.00258

7. Killaspy H, White S, Dowling S, Krotofil J, McPherson P, Sandhu S, et al. Adaptation of the Quality Indicator for Rehabilitative Care (QuIRC) for use in mental health supported accommodation services (QuIRC-SA). Bmc Psychiatry. 2016;16:101. doi:10.1186/s12888-016-0799-4

8. Sandhu S, Priebe S, Leavey G, Harrison I, Krotofil J, McPherson P, et al. Intentions and experiences of effective practice in mental health specific supported accommodation services: a qualitative interview study. BMC Health Serv Res. 2017;17(1):1-13. doi:10.1186/s12913-017-2411-0

9. Werbeloff N, Osborn DPJ, Patel R, Taylor M, Stewart R, Broadbent M, et al. The Camden & Islington Research Database: Using electronic mental health records for research. PLoS ONE. 2018;13(1). doi:10.1371/journal.pone.0190703

10. Dalton-Locke C, Thygesen JH, Werbeloff N, Osborn D, Killaspy H. Using de-identified electronic health records to research mental health supported housing services: A feasibility study. PLoS ONE. 2020;15(8). doi:10.1371/journal.pone.0237664

11. Andrews J, Briggs A, Porter R, Tucker P, Waddington K. The History of Bethlem. 1 ed. New York, USA: Routledge; 1997. 766 p.

12. Earle P. Bloodletting in mental disorders. Am J Psychiatry. 1854;10(4):287-405. doi:10.1176/ajp.10.4.287

13. Peterson F. HYDROTHERAPY IN THE TREATMENT OF NERVOUS AND MENTAL DISEASES. The American Journal of the Medical Sciences (1827-1924). 1893;105(2):132. doi:10.1001/jama.1915.02570460026009

14. Hodgkinson RG. Provision for pauper lunatics 1834–1871. Medical History. 1966;10(2):138-54. doi:10.1017/S0025727300010930

15. Colaizzi J. Seclusion & restraint: A historical perspective. Journal of psychosocial nursing and mental health services. 2005;43(2):31-7. doi:10.3928/02793695-20050201-07

16. Boardman J. Mental health services and policy in the UK. In: Boardman J, Killaspy H, Mezey G, editors. Social Inclusion and Mental Health. 2 ed: Cambridge University Press; in press.

17. Murphy E. The Metropolitan Pauper Farms 1722–1834. The London Journal. 2002;27(1):1-18. doi:10.1179/ldn.2002.27.1.1

18. Bartlett P. The poor law of lunacy: A&C Black; 1999.

19. Driver F. Power and pauperism: the workhouse system, 1834-1884: Cambridge University Press; 2004.

20. Miller E. 'Pauper Lunatics and their Treatment', by Joshua Harrison Stallard (1870). History of Psychiatry. 2013;24(3):356-68. doi:10.1177/0957154X13483051

21. Bynum W. Rationales for Therapy in British Psychiatry, 1780–1835. In: Scull A, editor. Madhouses, Mad-Doctors, and Madmen: The Social History of Psychiatry in the Victorian Era. Philadelphia, USA: University of Pennsylvania Press; 1981. p. 35-57.

22. Walton J. The Treatment of Pauper Lunatics in Victorian England: The Case of Lancaster Asylum, 1816-1870. In: Scull A, editor. Madhouses, Mad-Doctors, and Madmen: The Social History of Psychiatry in the Victorian Era. Philadelphia, USA: University of Pennsylvania Press; 1981. p. 166-98.

23. Lancet Commission. The Lancet Reports on Workhouse Infirmaries 1865-7. 1867.

24. Charland LC. Benevolent theory: moral treatment at the York Retreat. History of Psychiatry. 2007;18(1):61-80. doi:10.1177/0957154X07070320

25. Scull AT. Moral treatment reconsidered: some sociological comments on an episode in the history of British psychiatry. Psychological Medicine. 1979;9(3):421-8. doi:10.1017/S0033291700031962

26. Digby A. Changes in the asylum: The case of York, 1777-1815. Economic History Review. 1983:218-39. doi:10.2307/2595921

27. Parry-Jones W. The Trade in Lunacy. London: Routledge and Kegan Paul; 1972.

28. Cherry S. Mental Health Care in Modern England: The Norfolk Lunatic Asylum/St. Andrew's Hospital C. 1810-1998: Boydell Press; 2003.

29. Hilton C. Royal College of Psychiatrists. 2020. [cited 2021, 20 Oct]. Available from: https://www.rcpsych.ac.uk/news-and-features/blogs/detail/history-archives-and-library-blog/2020/09/09/90-years-ago-the-mental-treatment-act-1930-by-dr-claire-hilton.

30. Goffman E. Asylums: Essays on the social situations of mental patients and other inmates. UK: Anchor Books; 1961.

31. The National Archives. 1940's Origins of the Welfare State [cited 2021, 20 Oct]. Available from: https://www.nationalarchives.gov.uk/cabinetpapers/alevelstudies/1940-origins-welfare-state.htm.

32. Faria MA, Jr. Violence, mental illness, and the brain - A brief history of psychosurgery: Part 1 - From trephination to lobotomy. Surg Neurol Int. 2013;4:49. doi:10.4103/2152-7806.110146

33. Robison RA, Taghva A, Liu CY, Apuzzo ML. Surgery of the mind, mood, and conscious state: an idea in evolution. World Neurosurg. 2012;77(5-6):662-86. doi:10.1016/j.wneu.2012.03.005

34. Pieters T, Majerus B. The introduction of chlorpromazine in Belgium and the Netherlands (1951–1968); tango between old and new treatment features. Studies in History and Philosophy of Science Part C: Studies in History and Philosophy of Biological and Biomedical Sciences. 2011;42(4):443-52. doi:10.1016/j.shpsc.2011.05.003

35. Ramachandraiah CT, Subramaniam N, Tancer M. The story of antipsychotics: Past and present. Indian J Psychiatry. 2009;51(4):324-6. doi:10.4103/0019-5545.58304

36. Shepherd M, Goodman N, Watt DC. The application of hospital statistics in the evaluation of pharmacotherapy in a psychiatric population. Comprehensive Psychiatry. 1961;2(1):11-9. doi:10.1016/S0010-440X(61)80002-3

37. Ministry of Health. Mental Health Act 1959. In: Health Mo, editor. London, UK: Her Majesty's Stationery Office; 1959.

38. Powell E. Enoch Powell's Water Tower Speech: Study More; 1961 [cited 2021, 21 Oct]. Available from: http://studymore.org.uk/xpowell.htm.

39. Turner J, Hayward R, Angel K, Fulford B, Hall J, Millard C, et al. The History of Mental Health Services in Modern England: Practitioner Memories and the Direction of Future Research. Medical History. 2015;59(4):599-624. doi:10.1017/mdh.2015.48

40. Department of Health and Social Security. Hospital Services for the Mentally Ill. London1971.

41. Department of Health. Better services for the mentally ill. HMSO; 1975.

42. Department of Health. The Care Programme Approach for People with a Mental Illness Referred to the Specialist Psychiatric Services. London, UK: Her Majesty's Stationery Office; 1990.

43. Cooling NJ. Lessons to be learnt from the Christopher Clunis story: a mental health perspective. Clinical Risk. 2002;8(2):52-5. doi:10.1258/1356262021928869

44. Coid J. Failure in community care: psychiatry's dilemma. British Medical Journal Publishing Group; 1994. doi:10.1136/bmj.308.6932.805a

45. Burns T, Priebe S. Mental health care failure in England: myth and reality. Br J Psychiatry. 1999;174(3):191-2. doi:10.1192/bjp.174.3.191

46. BBC. Care in the community to be scrapped 1998 [cited 2021, 15 Oct]. Available from: http://news.bbc.co.uk/1/hi/uk/48168.stm.

47. Leff J, Trieman N. Long-stay patients discharged from psychiatric hospitals. Social and clinical outcomes after five years in the community. The TAPS Project 46. Br J Psychiatry. 2000;176:217-23. doi:10.1192/bjp.176.3.217

48. Leff J, Trieman N, Gooch C. Team for the Assessment of Psychiatric Services (TAPS) Project 33: prospective follow-up study of long-stay patients discharged from two psychiatric hospitals. Am J Psychiatry. 1996;153(10):1318-24. doi:10.1176/ajp.153.10.1318

49. Trieman N, Leff J. Long-term outcome of long-stay psychiatric in-patients considered unsuitable to live in the community. TAPS Project 44. Br J Psychiatry. 2002;181:428-32. doi:10.1192/bjp.181.5.428

50. Priebe S, Badesconyi A, Fioritti A, Hansson L, Kilian R, Torres-Gonzales F, et al. Reinstitutionalisation in mental health care: comparison of data on service provision from six European countries. BMJ. 2005;330(7483):123-6. doi:10.1136/bmj.38296.611215.AE

51. Santone G, de Girolamo G, Falloon I, Fioritti A, Micciolo R, Picardi A, et al. The process of care in residential facilities. Soc Psych Psych Epid. 2005;40(7):540-50. doi:10.1007/s00127-005-0922-1

52. Funk M, Bold ND. WHO's QualityRights initiative: Transforming services and promoting rights in mental health. Health and Human Rights. 2020;22(1):69-75.

53. Penrose LS. Mental disease and crime: outline of a comparative study of European statistics. British Journal of Medical Psychology. 1939;18(1):1-15. doi:10.1111/j.2044-8341.1939.tb00704.x

54. Mundt AP, Chow WS, Arduino M, Barrionuevo H, Fritsch R, Girala N, et al. Psychiatric hospital beds and prison populations in South America since 1990: does the Penrose hypothesis apply? JAMA Psychiatry. 2015;72(2):112-8. doi:10.1001/jamapsychiatry.2014.2433

55. Hartvig P, Kjelsberg E. Penrose's law revisited: the relationship between mental institution beds, prison population and crime rate. Nord J Psychiatry. 2009;63(1):51-6. doi:10.1080/08039480802298697

56. O'Neill C, Kelly B, Kennedy H. A 25-year dynamic ecological analysis of psychiatric hospital admissions and prison committals: Penrose's hypothesis updated. Irish Journal of Psychological Medicine. 2021;38(3):182-5. doi:10.1017/ipm.2018.40

57. Wild G, Alder R, Weich S, McKinnon I, Keown P. The Penrose hypothesis in the second half of the 20th century: investigating the relationship between psychiatric bed numbers and the prison population in England between 1960 and 2018–2019. Br J Psychiatry. 2021:1-7. doi:10.1192/bjp.2021.138

58. Fazel S, Hayes AJ, Bartellas K, Clerici M, Trestman R. Mental health of prisoners: prevalence, adverse outcomes, and interventions. Lancet Psychiatry. 2016;3(9):871-81. doi:10.1016/S2215-0366(16)30142-0

59. Winkler P, Barrett B, McCrone P, Csémy L, Janouskova M, Höschl C. Deinstitutionalised patients, homelessness and imprisonment: systematic review. Br J Psychiatry. 2016;208(5):421-8. doi:10.1192/bjp.bp.114.161943

60. Piantadosi S, Byar DP, Green SB. The Ecological Fallacy. American Journal of Epidemiology. 1988;127(5):893-904. doi:10.1093/oxfordjournals.aje.a114892

61. Houston RA. Asylums: the historical perspective before, during, and after. Lancet Psychiatry. 2020;7(4):354-62. doi:10.1016/S2215-0366(19)30395-5

62. Thornicroft G, Tansella M. Components of a modern mental health service: A pragmatic balance of community and hospital care: Overview of systematic evidence. Br J Psychiatry. 2004;185(4). doi:10.1192/bjp.185.4.283

63. Tansella M, Thornicroft G. A conceptual framework for mental health services: the matrix model. Psychological Medicine. 1998;28(3):503-8. doi:10.1017/s0033291796005880

64. Killaspy H, Harden C, Holloway F, King M. What do mental health rehabilitation services do and what are they for? A national survey in England. J Ment Health. 2005;14(2). doi:10.1080/09638230500060144

65. Killaspy H, Marston L, Omar RZ, Green N, Harrison I, Lean M, et al. Service quality and clinical outcomes: an example from mental health rehabilitation services in England. Br J Psychiatry. 2013;202(1):28-34. doi:10.1192/bjp.bp.112.114421

66. World Health Organization. International Classification of Diseases 11th Revision (ICD-11). Geneva, Switzerland: World Health Organization; 2019.

67. Kirkbride JB, Hameed Y, Ankireddypalli G, Ioannidis K, Crane CM, Nasir M, et al. The Epidemiology of First-Episode Psychosis in Early Intervention in Psychosis Services: Findings From the Social Epidemiology of Psychoses in East Anglia [SEPEA] Study. Am J Psychiatry. 2017;174(2):143-53. doi:10.1176/appi.ajp.2016.16010103

68. Simon GE, Coleman KJ, Yarborough BJ, Operskalski B, Stewart C, Hunkeler E, et al. Incidence and presentation of first-episode psychosis in a population-based sample. Psychiatr Serv. 2017;68(5):456. doi:10.1176/appi.ps.201600257

69. Morgan C, Lappin J, Heslin M, Donoghue K, Lomas B, Reininghaus U, et al. Reappraising the long-term course and outcome of psychotic disorders: The AESOP-10 study. Psychological Medicine. 2014;44(13). doi:10.1017/S0033291714000282 25066181

70. Killaspy H, Marston L, Green N, Harrison I, Lean M, Holloway F, et al. Clinical outcomes and costs for people with complex psychosis; a naturalistic prospective cohort study of mental health rehabilitation service users in England. Bmc Psychiatry. 2016;16:95. doi:10.1186/s12888-016-0797-6

71. Public Health England. Severe mental illness (SMI) and physical health inequalities: briefing. 2018 27SEP2018.

72. Hasnain M, Fredrickson SK, Vieweg WV, Pandurangi AK. Metabolic syndrome associated with schizophrenia and atypical antipsychotics. Curr Diab Rep. 2010;10(3):209-16. doi:10.1007/s11892-010-0112-8

73. Pramyothin P, Khaodhiar L. Metabolic syndrome with the atypical antipsychotics. Curr opin endocrinol diabetes obes. 2010;17(5):460-6. doi:10.1097/MED.0b013e32833de61c

74. Aucoin M, LaChance L, Cooley K, Kidd S. Diet and Psychosis: A Scoping Review. Neuropsychobiology. 2020;79(1):20-42. doi:10.1159/000493399

75. de Leon J, Diaz FJ. A meta-analysis of worldwide studies demonstrates an association between schizophrenia and tobacco smoking behaviors. Schizophr Res. 2005;76(2-3):135-57. doi:10.1016/j.schres.2005.02.010

76. Reilly S, Olier I, Planner C, Doran T, Reeves D, Ashcroft DM, et al. Inequalities in physical comorbidity: a longitudinal comparative cohort study of people with severe mental illness in the UK. BMJ Open. 2015;5(12). doi:10.1136/bmjopen-2015-009010

77. Arican I, Bass N, Neelam K, Wolfe K, McQuillin A, Giaroli G. Prevalence of attention deficit hyperactivity disorder symptoms in patients with schizophrenia. Acta Psychiatrica Scandinavica. 2019;139(1):89-96. doi:10.1111/acps.12948

78. Kincaid DL, Doris M, Shannon C, Mulholland C. What is the prevalence of autism spectrum disorder and ASD traits in psychosis? A systematic review. Psychiatry Res. 2017;250:99-105. doi:10.1016/j.psychres.2017.01.017

79. Hunt GE, Large MM, Cleary M, Lai HMX, Saunders JB. Prevalence of comorbid substance use in schizophrenia spectrum disorders in community and clinical settings, 1990-2017: Systematic review and meta-analysis. Drug Alcohol Depend. 2018;191:234-58. doi:10.1016/j.drugalcdep.2018.07.011

80. Mental Health Strategies. The 2009/10 National Survey of Investment in Mental Health Services. London: Department of Health; 2010.

81. Care Quality Commission. Mental health rehabilitation inpatient services: Results from the 2019 information request. Newcastle, UK; 2020.

82. Care Quality Commission. Mental health rehabilitation inpatient services: Ward types, bed numbers and use by clinical commissioning groups and NHS trusts. Newcastle, UK; 2018.

83. Royal College of Psychiatry's Rehabilitation Faculty. Mental Health Inpatient Rehabilitation Services Typology Table London, UK: Royal College of Psychiatry; 2019 [cited 2021, 19 Aug]. Available from: https://www.rcpsych.ac.uk/docs/default-source/members/faculties/rehabilitation-and-social-psychiatry/mental-health-inpatient-rehabilitation-services-typology-table-20-3-19.pdf?sfvrsn=8fc19480_2.

84. Care Quality Commission. The state of care in mental health services 2014 to 2017. Newcastle upon Tyne, UK; 2018.

85. Mountain D, Killaspy H, Holloway F. Mental health rehabilitation services in the UK in 2007. Psychiatric Bulletin. 2009;33(6):215-8. doi:10.1192/pb.bp.107.018697

86. NICE. Rehabilitation for adults with complex psychosis: NICE guideline [NG181]. 2020.

87. United Nations. Universal Declaration of Human Rights (UDHR). Paris, France; 1948.

88. Committee on Economic SaCRC. International Covenant on Economic, Social and Cultural Rights. United Nations (UN); 1976.

89. Ministry of Housing Communities & Local Government. Rough Sleeping Statistics Autumn 2018, England (Revised). 2019.

90. Wright PA, Kloos B. Housing environment and mental health outcomes: A levels of analysis perspective. J Environ Psychol. 2007;27(1):79-89. doi:10.1016/j.jenvp.2006.12.001

91. McPherson P, Krotofil J, Killaspy H. What works? Toward a new classification system for mental health supported accommodation services: the simple taxonomy for supported accommodation (STAX-SA). International Journal of Environmental Research and Public Health. 2018;15(2):190. doi:10.3390/ijerph15020190

92. Department for Communities and Local Government, Department for Work and Pensions. Funding Supported Housing: Policy Statement and Consultation. London, UK: Department for Communities and Local Government; 2017.

93. Newman-Taylor K, Stone N, Valentine P, Hooks Z, Sault K. The Recovery College: A unique service approach and qualitative evaluation. Psychiatr Rehabil J. 2016;39(2):187-90. doi:10.1037/prj0000179

94. Becker DR, Drake RE. Individual Placement and Support: a community mental health center approach to vocational rehabilitation. Community Mental Health Journal. 1994;30(2):193-206. doi:10.1007/BF02188630

95. Kalidindi S. Mental health rehabilitation in England. The gettiting it right first time (GIRFT) initiative. 2021.

96. Holloway F. The Forgotten Need for Rehabilitation in Contemporary Mental Health Services. Royal College of Psychiatrists, London: A position statement from the Executive Committee of the Faculty of Rehabilitation and Social Psychiatry. The Royal College of Psychiatrists; 2005.

97. Slade M, Wallace G. Recovery and mental health. In: Slade M, Oades L, Jarden A, editors. Wellbeing, Recovery and Mental Health. UK: Cambridge University Press; 2017. p. 24-34.

98. Krotofil J, McPherson P, Killaspy H. Service user experiences of specialist mental health supported accommodation: a systematic review of qualitative studies and narrative synthesis. Health & Social Care in the Community. 2018;26(6):787-800. doi:10.1111/hsc.12570

99. Office for National Statistics. Population profiles for local authorities in England. 2021.

100. Office for National Statistics. Estimates of the population for the UK, England and Wales, Scotland and Northern Ireland. 2021.

101. Public Health England. Fingertips: Public Health Profiles. 2021.

102. Killaspy H, Priebe S, King M, Eldridge S, McCrone P, Shepherd G, et al. Supported accommodation for people with mental health problems: the QuEST research programme with feasibility RCT. Programme Grants for Applied Research. 2019. doi:10.3310/pgfar07070

103. Evans RS. Electronic Health Records: Then, Now, and in the Future. Yearb med inform. 2016;Suppl 1:48-61. doi:10.15265/IYS-2016-s006

104. Warner JH. The uses of patient records by historians: patterns, possibilities and perplexities. Health and History. 1999;1(2/3):101-11. doi:10.2307/40111336

105. Hecht J. The future of electronic health records. Nature. 2019;573:114-S6. doi:10.1038/d41586-019-02876-y

106. Roberts A. Language, Structure, and Reuse in the Electronic Health Record. AMA J Ethics. 2017;19(3):281-8. doi:10.1001/journalofethics.2017.19.3.stas1-1703

107. Public Health England, Care Quality Commission, NHS Improvement. Five Year Forward View. 2014.

108. US Congress. American Recovery and Reinvestment Act of 2009. 2009.

109. Langhoff-Roos J, Krebs L, Klungsøyr K, Bjarnadottir RI, Källén K, Tapper AM, et al. The Nordic medical birth registers–a potential goldmine for clinical research. Acta obstetricia et gynecologica Scandinavica. 2014;93(2):132-7. doi:10.1111/aogs.12302

110. Bonamy A-KE, Parikh NI, Cnattingius S, Ludvigsson JF, Ingelsson E. Birth characteristics and subsequent risks of maternal cardiovascular disease: effects of gestational age and fetal growth. Circulation. 2011;124(25):2839-46. doi:10.1161/CIRCULATIONAHA.111.034884

111. Håberg SE, Trogstad L, Gunnes N, Wilcox AJ, Gjessing HK, Samuelsen SO, et al. Risk of fetal death after pandemic influenza virus infection or vaccination. New England Journal of Medicine. 2013;368(4):333-40. doi:10.1056/NEJMoa1207210

112. Bakken IJ, Revdal E, Nesvåg R, Brenner E, Knudsen GP, Surén P, et al. Substance use disorders and psychotic disorders in epilepsy: a population-based registry study. Epilepsy Research. 2014;108(8):1435-43. doi:10.1016/j.eplepsyres.2014.06.021

113. Terhune J, Dykxhoorn J, Mackay E, Hollander A-C, Kirkbride J, Dalman C. Migrant status and risk of compulsory admission at first diagnosis of psychotic disorder: a population-based cohort study in Sweden. Psychological Medicine. 2020:1-10. doi:10.1017/S0033291720002068

114. Ludvigsson JF, Haberg SE, Knudsen GP, Lafolie P, Zoega H, Sarkkola C, et al. Ethical aspects of registry-based research in the Nordic countries. Clin Epidemiol. 2015;7:491-508. doi:10.2147/CLEP.S90589

115. CPRD. The Clinical Practice Research Datalink 2021 [cited 2021, 10 Sep]. Available from: https://www.cprd.com/.

116. CPRD. The Clinical Practice Research Datalink: Bibliography 2021 [cited 2021, 10 Sep]. Available from: https://cprd.com/bibliography.

117. Tyrer F, Zaccardi F, Khunti K, Morriss R. Incidence of Depression and First-Line Antidepressant Therapy in People with Obesity and Depression in Primary Care. Obesity (Silver Spring). 2020;28(5):977-84. doi:10.1002/oby.22772

118. Chilman N, Song X, Roberts A, Tolani E, Stewart R, Chui Z, et al. Text mining occupations from the mental health electronic health record: a natural language processing approach using records from the Clinical Record Interactive Search (CRIS) platform in south London, UK. BMJ Open. 2021;11(3). doi:10.1136/bmjopen-2020-042274

119. EU. General Data Protection Regulation. 2016.

120. UK Public General Acts. Data Protection Act 2018. 2018.

121. NIHR Maudsley Biomedical Research Centre. Clinical Record Interactive Search (CRIS) 2021 [Available from: https://www.maudsleybrc.nihr.ac.uk/facilities/clinical-record-interactive-search-cris/.

122. NHS Digital. National data opt-out: NHS Digital; 2018 [cited 09 Sep, 2021]. Available from: https://digital.nhs.uk/services/national-data-opt-out.

123. Atkin C, Crosby B, Dunn K, Price G, Marston E, Crawford C, et al. Perceptions of anonymised data use and awareness of the NHS data opt-out amongst patients, carers and healthcare staff. Res Involv Engagem. 2021;7(1):40. doi:10.1186/s40900-021-00281-2

124. Adanijo A, McWilliams C, Wykes T, Jilka S. Investigating mental health service user opinions on clinical data sharing: qualitative focus group study. JMIR Mental Health. 2021;8(9). doi:10.2196/30596

125. Jewell A, Pritchard M, Barrett K, Green P, Markham S, McKenzie S, et al. The Maudsley Biomedical Research Centre (BRC) data linkage service user and carer advisory group: creating and sustaining a successful patient and public involvement group to guide research in a complex area. Res Involv Engagem. 2019;5:20. doi:10.1186/s40900-019-0152-4

126. UK Public Involvement Standards Development Partnership. UK standards for public involvement: Better public involvement for better health and social care research. 2019.

127. Consumers Health Forum of Australia. Statement on consumer and community involvement in health and medical research Australia: National Health and Medical Research Council (NHMRC); 2016 [cited 2021, 10th Sep]. Available from: https://www.nhmrc.gov.au/about-us/publications/statement-consumer-and-community-involvement-health-and-medical-research.

128. HRA. What is public involvement in research? : Health Research Authority (HRA); 2021 [cited 2021, 09 Sep]. Available from: https://www.hra.nhs.uk/planning-and-improving-research/best-practice/public-involvement/.

129. Brett J, Staniszewska S, Mockford C, Herron-Marx S, Hughes J, Tysall C, et al. Mapping the impact of patient and public involvement on health and social care research: a systematic review. Health Expectations. 2014;17(5):637-50. doi:10.1111/j.1369-7625.2012.00795.x

130. Jewell A, Broadbent M, Hayes RD, Gilbert R, Stewart R, Downs J. Impact of matching error on linked mortality outcome in a data linkage of secondary mental health data with Hospital Episode Statistics (HES) and mortality records in South East London: a cross-sectional study. BMJ Open. 2020;10(7). doi:10.1136/bmjopen-2019-035884

131. Patel R, Shetty H, Jackson R, Broadbent M, Stewart R, Boydell J, et al. Delays before diagnosis and initiation of treatment in patients presenting to mental health services with bipolar disorder. PLoS ONE. 2015;10(5). doi:10.1371/journal.pone.0126530

132. South London and Maudsley NHS Foundation Trust. SLaM CRIS project application form [cited 2021, 07 Nov]. Available from: https://projects.slam.nhs.uk/research/cris/cris-project-application.

133. Camden and Islington NHS Foundation Trust. C&I CRIS project application form [cited 2021, 07 Nov]. Available from: https://www.candi.nhs.uk/health-professionals/research/ci-research-database.

134. Dalton-Locke C, Attard R, Killaspy H, White S. Predictors of quality of care in mental health supported accommodation services in England: a multiple regression modelling study. Bmc Psychiatry. 2018;18(1):1-11. doi:10.1186/s12888-018-1912-7

135. McPherson P, Krotofil J, Killaspy H. Mental health supported accommodation services: a systematic review of mental health and psychosocial outcomes. Bmc Psychiatry. 2018;18(1):1-15. doi:10.1186/s12888-018-1725-8

136. Moher D, Liberati A, Tetzlaff J, Altman DG, Group P. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. PLoS Medicine. 2009;6(7). doi:10.1371/journal.pmed.1000097

137. Dieterich M, Irving CB, Bergman H, Khokhar MA, Park B, Marshall M. Intensive case management for severe mental illness. Cochrane Database of Systematic Reviews. 2017(1). doi:10.1002/14651858.CD007906.pub3

138. The EndNote Team. EndNote. EndNote X9 ed. Philadelphia, PA: Clarivate; 2013.

139. Kmet LM, Cook LS, Lee RC. Standard quality assessment criteria for evaluating primary research papers from a variety of fields. 2004. doi:10.7939/R37M04F16

140. Nyaga VN, Arbyn M, Aerts M. Metaprop: a Stata command to perform meta-analysis of binomial data. Archives of Public Health. 2014;72(1):1-10. doi:10.1186/2049-3258-72-39

141. StataCorp. Stata Statistical Software: Release 14. College Station, Texas: StataCorp LLC; 2015.

142. Higgins JP, Thompson SG. Quantifying heterogeneity in a meta-analysis. Stat Med. 2002;21(11):1539-58. doi:10.1002/sim.1186

143. Higgins JP, Thompson SG, Deeks JJ, Altman DG. Measuring inconsistency in meta-analyses. BMJ. 2003;327(7414):557-60. doi:10.1136/bmj.327.7414.557

144. Popay J, Roberts H, Sowden A, Petticrew M, Arai L, Rodgers M, et al. Guidance on the conduct of narrative synthesis in systematic reviews. A product from the ESRC methods programme. 2006.

145. Anderson RL, Lyons JS, West C. The prediction of mental health service use in residential care. Community Mental Health Journal. 2001;37(4):313-22. doi:10.1023/A:1017548507608

146. Awara M, Simon P, Lewis N, Edem D, Morrison J. Psychiatric Rehabilitation: Quality of Care and Clinical Effectiveness. Journal of Psychosocial Rehabilitation and Mental Health. 2017;4:61-71. doi:https://doi.org/10.1007/s40737-017-0082-0

147. Blow F, Ullman E, Barry K, Bingham C, Copeland L, McCormick R, et al. Effectiveness of specialized treatment programs for veterans with serious and persistent mental illness: a three-year follow-up. Am J Orthopsychiatry. 2000;70(3):389-400. doi:10.1037/h0087648

148. Bota RG, Munro JS, Sagduyu K. Benefits of boarding home placement in patients with schizophrenia. Southern Medical Journal. 2007;100(2):145-9. doi:10.1097/01.smj.0000254188.27513.34

149. Bradshaw W. Integrating cognitive-behavioral psychotherapy for persons with schizophrenia into a psychiatric rehabilitation program: results of a three year trial. Community Mental Health Journal. 2000;36(5):491-500. doi:10.1023/A:1001911730268

150. Bunyan M, Ganeshalingam Y, Morgan E, Thompson-Boy D, Wigton R, Holloway F, et al. In-patient rehabilitation: clinical outcomes and cost implications. BJPsych Bull. 2016;40(1):24-8. doi:10.1192/pb.bp.114.049858

151. Chan KPK, Kathryn K, Igoumenou A, Killaspy H. Predictors of successful move-on to more independent accommodation amongst users of the community mental health rehabilitation team: a prospective cohort study in inner London. Soc Psych Psych Epid. 2020;56(1):75-84. doi:10.1007/s00127-020-01910-z

152. Dalum HS, Waldemar AK, Korsbek L, Hjorthøj C, Mikkelsen JH, Thomsen K, et al. Illness management and recovery: Clinical outcomes of a randomized clinical trial in community mental health centers. PLoS ONE. 2018;13(4). doi:10.1371/journal.pone.0194027

153. D'Avanzo B, Battino RN, Gallus S, Barbato A. Factors predicting discharge of patients from community residential facilities: a longitudinal study from Italy. Australian and

New Zealand journal of psychiatry. 2004;38(8):619-28. doi:10.1080/j.1440-1614.2004.01424.x

154. de Girolamo G, Candini V, Buizza C, Ferrari C, Boero ME, Giobbio GM, et al. Is psychiatric residential facility discharge possible and predictable? A multivariate analytical approach applied to a prospective study in Italy. Soc Psych Psych Epid. 2014;49(1). doi:10.1007/s00127-013-0705-z 23712514

155. de Girolamo G, Buizza C, Sisti D, Ferrari C, Bulgari V, Iozzino L, et al. Monitoring and predicting the risk of violence in residential facilities. No difference between patients with history or with no history of violence. Journal of psychiatric research. 2016;80:5-13. doi:10.1016/j.jpsychires.2016.05.010

156. de Mooij LD, Kikkert M, Lommerse NM, Theunissen J, de Koning MB, de Haan L, et al. Homesick: residential and care patterns in patients with severe mental illness. Bmc Psychiatry. 2016;16(1):1-10. doi:10.1186/s12888-016-1137-6

157. Färdig R, Lewander T, Melin L, Folke F, Fredriksson A. A randomized controlled trial of the illness management and recovery program for persons with schizophrenia. Psychiatr Serv. 2011;62(6):606-12. doi:10.1176/ps.62.6.pss6206_0606

158. Hanrahan P, Luchins DJ, Savage C, Goldman HH. Housing satisfaction and service use by mentally ill persons in community integrated living arrangements. Psychiatr Serv. 2001;52(9):1206-9. doi:10.1176/appi.ps.52.9.1206

159. Incedere A, Yildiz M. Case management for individuals with severe mental illness: outcomes of a 24-month practice. Turk Psikiyatri Dergisi. 2019;30(4):245. doi:10.5080/u23532

160. Jensen SB, Dalum HS, Korsbek L, Hjorthøj C, Mikkelsen JH, Thomsen K, et al. Illness management and recovery: one-year follow-up of a randomized controlled trial in Danish community mental health centers: long-term effects on clinical and personal recovery. Bmc Psychiatry. 2019;19(1):1-12. doi:10.1186/s12888-019-2048-0

161. Kavanagh A, Nkire N, Lavelle E. Characteristics and progress of patients who receive inpatient rehabilitation services. Irish Journal of Psychological Medicine. 2009;26(2):64-8. doi:10.1017/S0790966700000240

162. Killaspy H, Zis P. Predictors of outcomes for users of mental health rehabilitation services: a 5-year retrospective cohort study in inner London, UK. Social Psychiatry and Psychiatric Epidemiolgy. 2013;48(6):1005-12. doi:10.1007/s00127-012-0576-8

163. King C, Singh K, Shepherd G. An analysis of process and outcomes for new long-stay patients in a 'ward-in-a-house'. J Ment Health. 2000;9(2):179-91. doi:10.1080/09638230050009177

164. Lascorz D, Serrats E, Ruiz B, Ximenos AR, Vegué J, Pérez V. Descriptive study of evolution experienced by users of mental health residence, after 10 years of operation. Actas Esp Psiquiatr. 2018;46(1):12-20.

165. Lee S, Wong Y-LI, Rothbard AB. Factors associated with departure from supported independent living programs for persons with serious mental illness. Psychiatr Serv. 2009;60(3):367-73. doi:10.1176/ps.2009.60.3.367

166. Lichtenberg P, Levinson D, Sharshevsky Y, Feldman D, Lachman M. Clinical case management of revolving door patients–a semi-randomized study. Acta Psychiatrica Scandinavica. 2008;117(6):449-54. doi:10.1111/j.1600-0447.2008.01170.x

167. Macpherson R, Calciu C, Foy C, Humby K, Lozynskyj D, Garton C, et al. A service evaluation of outcomes in two in-patient recovery units. BJPsych Bulletin. 2017;41(6):330-6. doi:10.1192/pb.bp.116.055137

168. Malinovsky I, Lehrer P, Silverstein SM, Shankman SA, O'Brien W, Samuelson T, et al. An empirical evaluation of recovery transformation at a large community psychiatric rehabilitation organization. Psychological Services. 2013;10(4):428. doi:10.1037/a0032747

169. Muir K, Fisher KR, Dadich A, Abello D. Challenging the exclusion of people with mental illness: the Mental Health Housing and Accommodation Support Initiative (HASI). Australian Journal of Social Issues. 2008;43(2):271-90. doi:10.1002/j.1839-4655.2008.tb00102.x

170. Nordentoft M, Pedersen M, Pedersen C, Blinkenberg S, Mortensen P. The new asylums in the community: severely ill psychiatric patients living in psychiatric supported housing facilities. A Danish register-based study of prognostic factors, use of psychiatric services, and mortality. Soc Psych Psych Epid. 2012;47(8):1251-61. doi:http://dx.doi.org/10.1007/s00127-011-0432-2

171. Parker S, Arnautovska U, Siskind D, Dark F, McKeon G, Korman N, et al. Community-care unit model of residential mental health rehabilitation services in Queensland, Australia: predicting outcomes of consumers 1-year post discharge. Epidemiology and Psychiatric Sciences. 2020;29. doi:10.1017/S2045796020000207

172. Sakiyama S, Iida J, Minami Y, Kishimoto T. Factors of good outcome after discharge from support house (engoryou) for schizophrenia. Psychiatry and Clinical Neurosciences. 2002;56(6):609-15. doi:10.1046/j.1440-1819.2002.01063.x

173. Shadmi E, Gelkopf M, Garber-Epstein P, Baloush-Kleinman V, Doudai R, Roe D. Routine patient reported outcomes as predictors of psychiatric rehospitalization. Schizophr Res. 2018;192:119-23. doi:10.1016/j.schres.2017.04.049

174. Tan CHS, Ishak RB, Lim TXG, Marimuthusamy P, Kaurss K, Leong JYJ. Illness management and recovery program for mental health problems: reducing symptoms and increasing social functioning. Journal of Clinical Nursing. 2017;26(21-22):3471-85. doi:10.1111/jocn.13712

175. Wong Y-LI, Poulin SR, Lee S, Davis MR, Hadley TR. Tracking residential outcomes of supported independent living programs for persons with serious mental illness.

Evaluation and Program Planning. 2008;31(4):416-26. doi:10.1016/j.evalprogplan.2008.07.001

176. Aubry T, Tsemberis S, Adair CE, Veldhuizen S, Streiner D, Latimer E, et al. One-year outcomes of a randomized controlled trial of housing first with ACT in five Canadian cities. Psychiatr Serv. 2015;66(5):463-9. doi:10.1176/appi.ps.201400167

177. Aubry T, Goering P, Veldhuizen S, Adair CE, Bourque J, Distasio J, et al. A multiple-city RCT of housing first with assertive community treatment for homeless Canadians with serious mental illness. Psychiatr Serv. 2016;67(3):275-81. doi:10.1176/appi.ps.201400587

178. Gilmer TP, Stefancic A, Ettner SL, Manning WG, Tsemberis S. Effect of full-service partnerships on homelessness, use and costs of mental health services, and quality of life among adults with serious mental illness. Archives of General Psychiatry. 2010;67(6):645-52. doi:10.1001/archgenpsychiatry.2010.56

179. Gilmer TP, Stefancic A, Tsemberis S, Ettner SL. Full-service partnerships among adults with serious mental illness in California: impact on utilization and costs. Psychiatr Serv. 2014;65(9):1120-5. doi:10.1176/appi.ps.201300380

180. Gilmer TP, Stefancic A, Katz ML, Sklar M, Tsemberis S, Palinkas LA. Fidelity to the housing first model and effectiveness of permanent supported housing programs in California. Psychiatr Serv. 2014;65(11):1311-7. doi:10.1176/appi.ps.201300447

181. Gulcur L, Stefancic A, Shinn M, Tsemberis S, Fischer SN. Housing, hospitalization, and cost outcomes for homeless individuals with psychiatric disabilities participating in continuum of care and housing first programmes. Journal of Community & Applied Social Psychology. 2003;13(2):171-86. doi:10.1002/casp.723

182. Lipton FR, Siegel C, Hannigan A, Samuels J, Baker S. Tenure in supportive housing for homeless persons with severe mental illness. Psychiatr Serv. 2000;51(4):479-86. doi:10.1176/appi.ps.51.4.479

183. McHugo GJ, Bebout RR, Harris M, Cleghorn S, Herring G, Xie H, et al. A randomized controlled trial of integrated versus parallel housing services for homeless adults with severe mental illness. Schizophr Bull. 2004;30(4):969-82. doi:10.1093/oxfordjournals.schbul.a007146

184. Stefancic A, Tsemberis S. Housing First for long-term shelter dwellers with psychiatric disabilities in a suburban county: A four-year study of housing access and retention. Journal of Primary Prevention. 2007;28(3-4):265-79. doi:10.1007/s10935-007-0093-9

185. Tsemberis SJ, Moran L, Shinn M, Asmussen SM, Shern DL. Consumer preference programs for individuals who are homeless and have psychiatric disabilities: A drop-in center and a supported housing program. American Journal of Community Psychology. 2003;32(3-4):305-17. doi:10.1023/B:AJCP.0000004750.66957.bf

186. Tsemberis S, Gulcur L, Nakae M. Housing first, consumer choice, and harm reduction for homeless individuals with a dual diagnosis. American Journal of Public Health. 2004;94(4):651-6. doi:10.2105/AJPH.94.4.651

187. van Kranenburg G, van Den Brink R, Mulder W, Diekman W, Pijnenborg G, Mulder C. Clinical effects and treatment outcomes of long-term compulsory in-patient treatment of treatment-resistant patients with severe mental illness and substance-use disorder. Bmc Psychiatry. 2019;19(1):1-9. doi:10.1186/s12888-019-2254-9

188. Baloush-Kleinman V, Schneidman M. System flexibility in the rehabilitation process of mentally disabled persons in a hostel that bridges between the hospital and the community/discussion. Israel Journal of Psychiatry. 2003;40(4):274-82.

189. Barbato A, D'Avanzo B, Rocca G, Amatulli A, Lampugnani D. A study of long-stay patients resettled in the community after closure of a psychiatric hospital in Italy. Psychiatr Serv. 2004;55(1):67-70. doi:10.1176/appi.ps.55.1.67

190. Bartholomew T. A program to discharge individuals with long term psychiatric hospitalizations. Journal of Psychosocial Rehabilitation and Mental Health. 2018;5(2):213-22. doi:10.1007/s40737-018-0126-0

191. Chan H, Inoue S, Shimodera S, Fujita H, Fukuzawa K, Kii M, et al. Residential program for long-term hospitalized persons with mental illness in Japan: Randomized controlled trial. Psychiatry and Clinical Neurosciences. 2007;61(5):515-21. doi:10.1111/j.1440-1819.2007.01701.x

192. Chopra P, Herrman HE. The long-term outcomes and unmet needs of a cohort of former long-stay patients in Melbourne, Australia. Community Mental Health Journal. 2011;47(5):531-41. doi:10.1007/s10597-010-9351-z

193. Duurkoop P, Van Dyck R. From a ‘state mental hospital’to new homes in the city: longitudinal research into the use of intramural facilities by long-stay care-dependent psychiatric clients in Amsterdam. Community Mental Health Journal. 2003;39(1):77-92. doi:10.1023/A:1021230008729

194. Gamble K, Abate S, Seibold M, Wenzel K, Ducharme J. Promoting readiness for discharge for long-term state hospital residents. Psychiatr Rehabil J. 2011;35(2):133. doi:10.2975/35.2.2011.133.136

195. Hallam A, Trieman N. The cost effectiveness of specialised facilities for service users with persistent challenging behaviours. Health & Social Care in the Community. 2001;9(6):429-35. doi:10.1046/j.1365-2524.2001.00322.x

196. Hobbs C, Tennant C, Rosen A, Newton L, Lapsley HM, Tribe K, et al. Deinstitutionalisation for long-term mental illness: a 2-year clinical evaluation. Australian & New Zealand Journal of Psychiatry. 2000;34(3):476-83. doi:10.1080/j.1440-1614.2000.00734.x

197. Hobbs C, Newton L, Tennant C, Rosen A, Tribe K. Deinstitutionalization for long-term mental illness: a 6-year evaluation. Australian & New Zealand Journal of Psychiatry. 2002;36(1):60-6. doi:10.1046/j.1440-1614.2002.00984.x

198. Macpherson R, Williams K, Elliot H, Brewer A-M, McGee T. The outcome of treatment in hostels. Irish Journal of Psychological Medicine. 2004;21(2):53-6. doi:10.1017/S0790966700008296

199. McCrone P, Hallam A, Knapp M, Swaray F, Nazir A, Leff J, et al. Service use and costs of supporting the most socially disabled patients in a hospital reprovision programme. Soc Psych Psych Epid. 2006;41(8):656-61. doi:10.1007/s00127-006-0075-x

200. Meehan T, Stedman T, Robertson S, Drake S, King R. Does supported accommodation improve the clinical and social outcomes for people with severe psychiatric disability? The Project 300 experience. Australian & New Zealand Journal of Psychiatry. 2011;45(7):586-92. doi:10.3109/00048674.2011.559634

201. Noda F, Clark C, Terada H, Hayashi N, Maeda K, Sato M, et al. Community discharge of patients with schizophrenia: a Japanese experience. Psychiatr Rehabil J. 2004;28(2):143. doi:10.2975/28.2004.143.149

202. Ryu Y, Mizuno M, Sakuma K, Munakata S, Takebayashi T, Murakami M, et al. Deinstitutionalization of long-stay patients with schizophrenia: the 2-year social and clinical outcome of a comprehensive intervention program in Japan. Australian & New Zealand Journal of Psychiatry. 2006;40(5):462-70. doi:10.1080/j.1440-1614.2006.01823.x

203. Tanioka T, Chiba S, Onishi Y, Kataoka M, Kawamura A, Tomotake M, et al. Factors associated with discharge of long-term inpatients with schizophrenia in Japan: a retrospective study. Issues in Mental Health Nursing. 2013;34(4):256-64. doi:10.3109/01612840.2012.742602

204. Trauer T, Farhall J, Newton R, Cheung P. From long-stay psychiatric hospital to Community Care Unit: evaluation at 1 year. Soc Psych Psych Epid. 2001;36(8):416-9. doi:10.1007/s001270170032

205. O'Campo P, Stergiopoulos V, Nir P, Levy M, Misir V, Chum A, et al. How did a Housing First intervention improve health and social outcomes among homeless adults with mental illness in Toronto? Two-year outcomes from a randomised trial. BMJ open. 2016;6(9). doi:10.1136/bmjopen-2015-010581

206. Aubry T, Bloch G, Brcic V, Saad A, Magwood O, Abdalla T, et al. Effectiveness of permanent supportive housing and income assistance interventions for homeless individuals in high-income countries: a systematic review. Lancet Public Health. 2020;5(6). doi:10.1016/S2468-2667(20)30055-4

207. Wing JK, Beevor AS, Curtis RH, Park SB, Hadden S, Burns A. Health of the Nation Outcome Scales (HoNOS). Research and development. Br J Psychiatry. 1998;172:11-8. doi:10.1192/bjp.172.1.11

208. Eagar K, Trauer T, Mellsop G. Performance of routine outcome measures in adult mental health care. Aust N Z J Psychiatry. 2005;39(8):713-8. doi:10.1080/j.1440-1614.2005.01655.x

209. Parabiaghi A, Barbato A, D'avanzo B, Erlicher A, Lora A. Assessing Reliable and Clinically Significant Change on Health of the Nation Outcome Scales: Method for Displaying Longitudinal Data. Australian & New Zealand Journal of Psychiatry. 2005;39(8):719-24. doi:10.1080/j.1440-1614.2005.01656.x

210. Wing J, Lelliott P, Beevor A. Progress on HoNOS. Br J Psychiatry. 2000;176(APR.):392-3. doi:http://dx.doi.org/10.1192/bjp.176.4.392

211. StataCorp. Stata Statistical Software: Release 16. College Station, Texas: StataCorp LLC; 2019.

212. Proudfoot JA, Lin T, Wang B, Tu XM. Tests for paired count outcomes. General Psychiatry. 2018;31(e100004). doi:10.1136/gpsych-2018-100004

213. McHugh ML. The chi-square test of independence. Biochemia Medica. 2013;23(2):143-9. doi:10.11613/BM.2013.018

214. McNeish D, Scott S. Women and girls at risk: Evidence across the life course. Lankelly Chase; 2014.

215. Scott S, McManus S. Hidden hurt: Violence, abuse and disadvantage in the lives of women. DMSS Research for Agenda; 2016.

216. Chen LP, Murad MH, Paras ML, Colbenson KM, Sattler AL, Goranson EN, et al., editors. Sexual abuse and lifetime diagnosis of psychiatric disorders: systematic review and meta-analysis. Mayo clinic proceedings; 2010: Elsevier.

217. Halvorsrud K, Nazroo J, Otis M, Brown Hajdukova E, Bhui K. Ethnic inequalities and pathways to care in psychosis in England: a systematic review and meta-analysis. BMC Med. 2018;16(1):223. doi:10.1186/s12916-018-1201-9

218. Barnett P, Mackay E, Matthews H, Gate R, Greenwood H, Ariyo K, et al. Ethnic variations in compulsory detention under the Mental Health Act: a systematic review and meta-analysis of international data. Lancet Psychiatry. 2019;6(4):305-17. doi:10.1016/S2215-0366(19)30027-6

219. Williams DR, Williams-Morris R. Racism and mental health: The African American experience. Ethnicity & Health. 2000;5(3-4):243-68. doi:10.1080/713667453

220. Launders N, Kirsh L, Osborn DPJ, Hayes JF. The temporal relationship between severe mental illness diagnosis and chronic physical comorbidity: a UK primary care cohort study of disease burden over 10 years. Lancet Psychiatry. 2022. doi:10.1016/S2215-0366(22)00225-5

221. NHS England. NHS Mental Health Implementation Plan 2019/20 – 2023/24. 2019.

222. World Health Organization. Addressing comorbidity between mental disorders and major noncommunicable diseases. Copenhagen: WHO Regional Office for Europe; 2017.

223. Cheng HG, Phillips MR. Secondary analysis of existing data: opportunities and implementation. Shanghai Arch Psychiatry. 2014;26(6):371-5. doi:10.11919/j.issn.1002-0829.214171

224. Jackson RG, Patel R, Jayatilleke N, Kolliakou A, Ball M, Gorrell G, et al. Natural language processing to extract symptoms of severe mental illness from clinical text: the Clinical Record Interactive Search Comprehensive Data Extraction (CRIS-CODE) project. BMJ Open. 2017;7(1). doi:10.1136/bmjopen-2016-012012

225. NIHR Maudsley Biomedical Research Centre. CRIS Natural Language Processing Applications Library 2021 [cited 2021, 25 Jun]. Available from: https://maudsleybrc.nihr.ac.uk/facilities/clinical-record-interactive-search-cris/cris-natural-language-processing/.

226. Carson L, Jewell A, Downs J, Stewart R. Multisite data linkage projects in mental health research. Lancet Psychiatry. 2020;7(10). doi:10.1016/S2215-0366(20)30375-8

227. NIHR Maudsley Biomedical Research Centre. CRIS Data Linkages [cited 2022, 26 Feb]. Available from: https://www.maudsleybrc.nihr.ac.uk/facilities/clinical-record-interactive-search-cris/cris-data-linkages/.

228. NHS Digital. Hospital Episode Statistics (HES) [cited 2022, 27 Feb]. Available from: https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/hospital-episode-statistics.

229. Marks I. Overcoming obstacles to routine outcome measurement: The nuts and bolts of implementing clinical audit∗. Br J Psychiatry. 1998;173(4):281-6. doi:10.1192/bjp.173.4.281

230. Department of Health and Social Care. Payment by Results: Guidance for 2012-13. 2012.

231. Twomey C, Prina AM, Baldwin DS, Das-Munshi J, Kingdon D, Koeser L, et al. Utility of the Health of the Nation Outcome Scales (HoNOS) in Predicting Mental Health Service Costs for Patients with Common Mental Health Problems: Historical Cohort Study. PLoS ONE. 2016;11(11). doi:10.1371/journal.pone.0167103

232. Luo W, Harvey R, Tran T, Phung D, Venkatesh S, Connor JP. Consistency of the Health of the Nation Outcome Scales (HoNOS) at inpatient-to-community transition. BMJ Open. 2016;6(4). doi:10.1136/bmjopen-2015-010732

233. CRIS Network. Welcome to the CRIS Network [cited 2021, 07 May]. Available from: https://crisnetwork.co/.

234. Dalton-Locke C, Marston L, McPherson P, Killaspy H. The Effectiveness of Mental Health Rehabilitation Services: A Systematic Review and Narrative Synthesis. Front Psychiatry. 2021;11. doi:10.3389/fpsyt.2020.607933

235. Marsden E, Torgerson CJ. Single group, pre-and post-test research designs: Some methodological concerns. Oxford Review of Education. 2012;38(5):583-616. doi:10.1080/03054985.2012.731208

236. Austin PC. An Introduction to Propensity Score Methods for Reducing the Effects of Confounding in Observational Studies. Multivariate Behav Res. 2011;46(3):399-424. doi:10.1080/00273171.2011.568786

237. Hariton E, Locascio JJ. Randomised controlled trials—the gold standard for effectiveness research. BJOG: An International Journal of Obstetrics and Gynaecology. 2018;125(13). doi:10.1111/1471-0528.15199

238. Rosenbaum PR, Rubin DB. The central role of the propensity score in observational studies for causal effects. Biometrika. 1983;70:41-55. doi:doi:10.1093/biomet/70.1.41

239. Austin P, Email Austin P, peter, austin@ices, on, ca. A critical appraisal of propensity-score matching in the medical literature between 1996 and 2003. Stat Med. 2008;27(12):2037-49. doi:http://dx.doi.org/10.1002/sim.3150

240. Thoemmes FJ, Kim ES. A systematic review of propensity score methods in the social sciences. Multivariate Behav Res. 2011;46:90-118. doi:10.1080/00273171.2011.540475

241. Yao XI, Wang X, Speicher PJ, Hwang ES, Cheng P, Harpole DH, et al. Reporting and Guidelines in Propensity Score Analysis: A Systematic Review of Cancer and Cancer Surgical Studies. JNCI: Journal of the National Cancer Institute. 2017;109(8). doi:10.1093/jnci/djw323

242. Erlangsen A, Lind BD, Stuart EA, Qin P, Stenager E, Larsen KJ, et al. Short-term and long-term effects of psychosocial therapy for people after deliberate self-harm: a register-based, nationwide multicentre study using propensity score matching. Lancet Psychiatry. 2015;2(1):49-58. doi:10.1016/S2215-0366(14)00083-2

243. Roy AD. Some thoughts on the distribution of earnings. Oxford Economic Papers. 1951;3(2):135-46.

244. Rubin DB. Assignment to treatment group on the basis of a covariate. Journal of Educational Statistics. 1977;2(1):1-26. doi:10.3102/10769986002001001

245. Caliendo M, Kopeinig S. Some practical guidance for the implementation of propensity score matching. Journal of Economic Surveys. 2008;22(1):31-72. doi:10.1111/j.1467-6419.2007.00527.x

246. Beal SJ, Kupzyk KA. An introduction to propensity scores: What, when, and how. The Journal of Early Adolescence. 2014;.34(1). doi:10.1177/0272431613503215

247. StataCorp. Stata 17 Base Reference Manual. College Station, Texas: Stata Press; 2021.

248. Rosenbaum PR. Optimal Matching for Observational Studies. J Am Stat Assoc. 1989;84(408):1024-32. doi:10.2307/2290079

249. Smith JA, Todd PE. Does matching overcome LaLonde's critique of nonexperimental estimators? Journal of Econometrics. 2005;125(1-2):305-53. doi:10.1016/j.jeconom.2004.04.011

250. Rosenbaum PR, Rubin DB. The bias due to incomplete matching. Biometrics. 1985:103-16. doi:10.2307/2530647

251. Benedetto U, Head SJ, Angelini GD, Blackstone EH. Statistical primer: propensity score matching and its alternatives. European Journal of Cardio-Thoracic Surgery. 2018;53(6):1112-7. doi:10.1093/ejcts/ezy167

252. Austin P. Balance diagnostics for comparing the distribution of baseline covariates between treatment groups in propensity-score matched samples. Stat Med. 2009;28(25):3083-107. doi:10.1002/sim.3697

253. Ahmed A, Perry GJ, Fleg JL, Love TE, Goff JDC, Kitzman DW. Outcomes in ambulatory chronic systolic and diastolic heart failure: a propensity score analysis. American Heart Journal. 2006;152:956-66. doi:10.1016/j.ahj.2006.06.020

254. Ahmed A, Husain A, Love TE, Gambassi G, Dell'Italia LJ, Francis GS, et al. Heart failure, chronic diuretic use, and increase in mortality and hospitalization: an observational study using propensity score methods. European Heart Journal. 2006;27:1431-9. doi:10.1093/eurheartj/ehi890

255. Rosenbaum PR, Rubin DB. Reducing Bias in Observational Studies Using Subclassification on the Propensity Score. J Am Stat Assoc. 1984;79(387):516-24. doi:10.2307/2288398

256. NICE. Psychosis and schizophrenia in adults: prevention and management. Clinical guideline [CG178]. London, England; 2014.

257. Holmqvist KL, Holmefur M. The ADL taxonomy for persons with mental disorders - adaptation and evaluation. Scand J Occup Ther. 2019;26(7):524-34. doi:10.1080/11038128.2018.1469667

258. King G, Nielsen R. Why propensity scores should not be used for matching. Political Analysis. 2019;27(4):435-54. doi:10.1017/pan.2019.11

259. NIHR Maudsley Biomedical Research Centre. CRIS: Publications 2021 [cited 2021, 25 June]. Available from: https://www.maudsleybrc.nihr.ac.uk/facilities/clinical-record-interactive-search-cris/cris-publications/.

260. Leff J, Szmidla A. Evaluation of a special rehabilitation programme for patients who are difficult to place. Soc Psych Psych Epid. 2002;37(11):532-6. doi:10.1007/s00127-002-0578-z

261. McPherson P, Lloyd-Evans B, Dalton-Locke C, Killaspy H. A Systematic Review of the Characteristics and Efficacy of Recovery Training for Mental Health Staff: Implications for Supported Accommodation Services. Front Psychiatry. 2021;12. doi:10.3389/fpsyt.2021.624081

262. Priebe S, Huxley P, Knight S, Evans S. Application and results of the Manchester Short Assessment of Quality of Life (MANSA). Int J Soc Psychiatry. 1999;45(1):7-12. doi:10.1177/002076409904500102

263. Parker G, Rosen A, Emdur N, Hadzi-Pavlov D. The Life Skills Profile: psychometric properties of a measure assessing function and disability in schizophrenia. Acta Psychiatrica Scandinavica. 1991;83(2):145-52. doi:10.1111/j.1600-0447.1991.tb07381.x

264. Bredski J, Forsyth K, Mountain D, Harrison M, Irvine L, Maciver D. What in-patients want: a qualitative study of what's important to mental health service users in their recovery (Wayfinder Partnership). Mental Health Review Journal. 2015. doi:10.1108/MHRJ-02-2014-0003

265. Nosek BA, Errington TM. What is replication? PLoS Biology. 2020;18(3). doi:10.1371/journal.pbio.3000691

266. Camerer CF, Dreber A, Holzmeister F, Ho T-H, Huber J, Johannesson M, et al. Evaluating the replicability of social science experiments in Nature and Science between 2010 and 2015. Nature Human Behaviour. 2018;2(9):637-44. doi:10.1038/s41562-018-0399-z

267. Pashler H, Wagenmakers EJ. Editors' introduction to the special section on replicability in psychological science: A crisis of confidence? Perspectives on Psychological Science. 2012;7(6):528-30. doi:10.1177/1745691612465253

268. Devlin H. Attempt to replicate major social scientific findings of past decade fails: The Guardian; 2018 [cited 2022, 16 Feb]. Available from: https://www.theguardian.com/science/2018/aug/27/attempt-to-replicate-major-social-scientific-findings-of-past-decade-fails.

269. Piper K. Science has been in a "replication crisis" for a decade. Have we learned anything? : Vox; 2020 [cited 2022, 15 Feb]. Available from: https://www.vox.com/future-perfect/21504366/science-replication-crisis-peer-review-statistics.

270. Burchett HE, Kneale D, Blanchard L, Thomas J. When assessing generalisability, focusing on differences in population or setting alone is insufficient. Trials. 2020;21(1):1-4. doi:10.1186/s13063-020-4178-6

271. Downs JM, Ford T, Stewart R, Epstein S, Shetty H, Little R, et al. An approach to linking education, social care and electronic health records for children and young people in South London: a linkage study of child and adolescent mental health service data. BMJ open. 2019;9(1). doi:10.1136/bmjopen-2018-024355

Appendices

Appendix A: The two C&I CRIS structured fields for accommodation, the possible values, and their categories

Demographics field value 'accommodation_status_desc'	**CPA field value 'cpa_accommodation_desc'**	**Category**
CH00 Accommodation with other	Accommodation with other (not specialist mental health) care support	Other
CH01 Foyer - accommodation for young people aged 16-25 who are homeless or in housing need	Foyer - accommodation for young people aged 16-25 who are homeless or in housing need	Other
CH02 Refuge	Refuge	Other
CH03 Non-Mental Health Registered Care Home	Non-Mental Health Registered Care Home	Other
CH09 Other accommodation with care and support	Other accommodation with care and support (not specialist mental health)	Other
CJ00 Accommodation with criminal justice support	Accommodation with criminal justice support	Criminal justice
CJ01 Bail/Probation hostel	Bail/Probation hostel	Criminal justice
CJ02 Prison	Prison	Criminal justice
CJ03 Young Offenders Institute	Young Offenders Institution	Criminal justice
CJ09 Other accommodation with criminal justice support such as ex-offender support	Other accommodation with criminal justice support such as ex-offender support	Criminal justice
…	Detention Centre	Criminal justice
HM00 Homeless	Homeless	Homeless/Temporary
HM01 Rough sleeper	Rough sleeper	Homeless/Temporary
HM02 Squatting	Squatting	Homeless/Temporary
HM03 Night shelter/emergency hostel/Direct access hostel	Night shelter/emergency hostel/Direct access hostel	Homeless/Temporary
HM04 Sofa surfing	Sofa surfing	Homeless/Temporary
HM05 Placed in temporary accommodation by Local Authority	Placed in temporary accommodation by Local Authority	Homeless/Temporary

HM06 Staying with friends/family as a short term guest	Staying with friends/family as a short term guest	Homeless/Temporary
HM07 Other homeless	Other homeless	Homeless/Temporary
HS00 Acute/long stay healthcare residential facility/hospital	Acute/long stay healthcare residential facility/hospital	Hospital
HS01 NHS acute psychiatric ward	NHS acute psychiatric ward	Hospital
HS02 Independent hospital/clinic	Independent hospital/clinic	Hospital
HS03 Specialist rehabilitation/recovery	Specialist rehabilitation/recovery	Hospital
HS04 Secure psychiatric unit	Secure psychiatric unit	Hospital
HS05 Other NHS facilities/hospital	Other NHS facilities/hospital	Hospital
HS09 Other acute/long stay healthcare residential facility/hospital	Other acute/long stay healthcare residential facility/hospital	Hospital
MA00 Mainstream Housing	Mainstream Housing	Mainstream housing
MA01 Owner occupier	Owner occupier	Mainstream housing
MA02 Settled mainstream housing with family/friends	Settled mainstream housing with family/friends	Mainstream housing
MA03 Shared ownership scheme	Shared ownership scheme e.g. Social Homebuy Scheme	Mainstream housing
MA04 Tenant - Local Authority/Arms Length Management Organisation/Registered Landlord	Tenant - Local Authority/Arms Length Management Organisation/Registered Landlord	Mainstream housing
MA05 Tenant - Housing Association	Tenant - Housing Association	Mainstream housing
MA06 Tenant - private landlord	Tenant - private landlord	Mainstream housing
MA09 Other mainstream housing	Other mainstream housing	Mainstream housing
MH00 Accommodation with mental healthcare support	Accommodation with mental healthcare support	Mental health supported
MH01 Supported accommodation	Supported accommodation	Mental health supported
MH02 Supported lodgings	Supported lodgings	Mental health supported
MH03 Supported group home	Supported group home	Mental health supported
MH04 Mental Health Registered Care Home	Mental Health Registered Care Home	Mental health supported

MH09 Other accommodation with mental healthcare and support	Other accommodation with mental healthcare and support	Mental health supported
ML00 Mobile accommodation	Mobile accommodation	Other
NULL	NOT RECORDED	Not recorded or unknown
OC96 Not elsewhere classified	Not elsewhere classified	Not recorded or unknown
OC97 Not specified	UNKNOWN	Not recorded or unknown
OC98 Not applicable	…	Not recorded or unknown
OC99 Not known	Not known	Not recorded or unknown
SH00 Sheltered Housing	Sheltered Housing	Not recorded or unknown
SH01 Sheltered housing for older persons	Sheltered housing for older persons	Not recorded or unknown
SH02 Extra care sheltered housing	Extra care sheltered housing	Not recorded or unknown
SH03 Nursing Home for older persons	Nursing Home for older persons	Not recorded or unknown
SH09 Other sheltered housing	Other sheltered housing	Not recorded or unknown

Appendix B: Search results for the CPA accommodation structured field

Type of accommodation*	Total number ever recorded†	Total distinct individuals per type of accommodation‡
Mental health supported	5152	1635
Not recorded or unknown	31929	9545
Mainstream housing	19051	5632
Homeless/Temporary	1288	816
Nursing home / Sheltered housing	548	303
Hospital	1065	480
Other	270	210
Criminal justice	105	81
TOTAL	59408	18702

Date range for search results: 01-Jan-2008 to 31-Dec-2017.

*There are a total of 50 values for this field in the CIFT Research Database. They have been grouped here with appropriate labels for clarity. For example, the value 'Mental health supported' consists of the following database values: 'MH00 Accommodation with mental healthcare support', 'MH01 Supported accommodation', 'MH02 Supported lodgings', 'MH03 Supported group home', 'MH04 Mental Health Registered Care Home' and 'MH09 Other accommodation with mental healthcare and support'. See Appendix A for the full list of original values and their grouping term.

†Individuals can appear for more than one type and within the same type more than once.

‡Individuals can appear for more than one type but only once within the same type.

Appendix C: Search results for the demographics accommodation structured field

Type of accommodation*	Total number ever recorded†	Total distinct individuals per type of accommodation‡
Mental health supported	2179	882
Not recorded or unknown	36577	17899
Mainstream housing	20587	9087
Homeless/Temporary	4101	1492
Nursing home / Sheltered housing	561	267
Hospital	373	159
Other	521	225
Criminal justice	166	72
TOTAL	65065	30083

Date range for search results: 01-Jan-2008 to 31-Dec-2017.

*There are a total of 50 values for this field in the CIFT Research Database. They have been grouped here with appropriate labels for clarity. For example, the value 'Mental health supported' consists of the following database values: 'MH00 Accommodation with mental healthcare support', 'MH01 Supported accommodation', 'MH02 Supported lodgings', 'MH03 Supported group home', 'MH04 Mental Health Registered Care Home' and 'MH09 Other accommodation with mental healthcare and support'. See Appendix A for the full list of original values and their grouping term.

†Individuals can appear for more than one type and within the same type more than once.

‡Individuals can appear for more than one type but only once within the same type.

Appendix D: Systematic review search strategy

Final search Ovid - MEDLINE		
LINE	SEARCH	Results 13/06/2019
1	Exp Mental Disorders/	1176937
2	exp Mental Health/	34013
3	((psycho* or psychiat* or mental*) adj (illness* or disorder* or problem* or disease* or disab* or health or well being or wellbeing)).tw. *[tw= search in: title, abstract]*	217487
4	(severe mental illness or serious mental illness).tw.	5455
5	schizo*.tw.	120434
6	or/1-5	1295851
7	Hospitals, Psychiatric/	24808
8	Psychiatric Rehabilitation/	287
9	Community Mental Health Centers/	2887
10	Mental Health Services/	31879
11	((community or inpatient or in-patient or hospital or service) adj3 rehab*).tw.	10525
12	Residential facilities/	5288
13	Group homes/	947
14	Residential treatment/	3019
15	(((support* or shelter* or board* or group or resident*) adj (hous* or home* or accom* or living or lodg* or tenanc* or care or support* or rehab*)) or hostel or ((floating or visiting) adj (support or outreach))).tw.	25088
16	or/7-15	99197
17	exp hospitalization/	221518
18	Patient Discharge/	27099
19	mental health recovery/	71
20	patient readmission/	14887
21	(admission* or re?admission*).tw.	187886
22	bed adj day*.tw.	1838
23	length of stay.tw.	41893
24	(patient adj (discharge* or recovery)).tw.	2751
25	(independent) adj (accom* or living).tw.	2183
26	((less or lower) adj3 accom*).tw.	2579
27	(more adj3 accom*).tw.	2741
28	(Move on or moveon or move on or moved on or moved-on).tw.	1338
29	or/17-28	371403
30	6 and 16 and 29	9350
31	Limit 30 to English language	8146
32	Limit 31 to yr="2000 -Current"	3884

Final search Ovid - EMBASE		
LINE	SEARCH	Results 13/06/2019
1	exp *Mental Disease/	1276960
2	exp *Mental Health/	39863
3	((psycho* or psychiat* or mental*) adj (illness* or disorder* or problem* or disease* or disab* or health or well being or wellbeing)).tw. *[tw= search in: title, abstract]*	337402
4	(severe mental illness or serious mental illness).tw.	8287
5	schizo*.tw.	170269
6	or/1-5	1503910
7	Mental hospital/	23137
8	psychosocial rehabilitation/	1285
9	Community Mental Health Center/	2887
10	Mental Health Service/	52247
11	((community or inpatient or in-patient or hospital or service) adj3 rehab*).tw.	19951
12	Residential home/	6719
13	Residential care/	11363
14	(((support* or shelter* or board* or group or resident*) adj (hous* or home* or accom* or living or lodg* or tenanc* or care or support* or rehab*)) or hostel or ((floating or visiting) adj (support or outreach))).tw.	45102
15	or/7-14	152673
16	exp hospitalization/	333443
17	mental health recovery/	165
18	hospital discharge/	111465
19	hospital readmission/	53312
20	admission* or re?admission*.tw.	458669
21	bed adj day*.tw.	3667
22	length of stay.tw.	92195
23	(patient adj (discharge* or recovery)).tw.	5520
24	(independent) adj (accom* or living).tw.	3518
25	((less or lower) adj3 accom*).tw.	3728
26	(more adj3 accom*).tw.	4061
27	(Move on or moveon or move on or moved on or moved-on).tw.	2134
28	or/16-27	856989
29	6 and 15 and 28	9789
30	Limit 29 to English language	8719
31	Limit 30 to yr="2000 -Current"	6800

Final search Ovid - PsycINFO		
LINE	SEARCH	Results 13/06/2019
1	Exp Mental Disorders/	816545
2	exp Mental Health/	60893
3	((psycho* or psychiat* or mental*) adj (illness* or disorder* or problem* or disease* or disab* or health or well being or wellbeing)).tw. *[tw= search in: title, abstract]*	332392
4	(severe mental illness or serious mental illness).tw.	8518
5	schizo*.tw.	126327
6	or/1-5	1017298
7	Psychiatric hospitals/	7723
8	Psychosocial Rehabilitation/	3977
9	Community Mental Health Centers/	2746
10	Mental Health Services/	33106
11	((community or inpatient or in-patient or hospital or service) adj3 rehab*).tw.	4883
12	Residential Care Institutions/	10250
13	Group homes/	1085
14	(((support* or shelter* or board* or group or resident*) adj (hous* or home* or accom* or living or lodg* or tenanc* or care or support* or rehab*)) or hostel or ((floating or visiting) adj (support or outreach))).tw.	15543
15	or/7-14	72471
16	exp hospitalization/	21936
17	(admission* or re?admission*).tw.	38174
18	bed adj day*.tw.	304
19	length of stay.tw.	4974
20	(patient adj (discharge* or recovery)).tw.	455
21	(independent) adj (accom* or living).tw.	2862
22	((less or lower) adj3 accom*).tw.	620
23	(more adj3 accom*).tw.	1463
24	(Move on or moveon or move on or moved on or moved-on).tw.	1519
25	or/16-24	61633
26	6 and 15 and 25	3922
27	Limit 26 to English language	3615
28	Limit 27 to yr="2000 -Current"	2258

Final search EBSCOhost – CINAHL Plus		
LINE	SEARCH	Results 14/06/2019
1	(MM "Mental Disorders+")	373084
2	(MH "Mental Health")	30797
3	((psycho* or psychiat* or mental*) W0 (illness* or disorder* or problem* or disease* or disab* or health or well being or wellbeing)) *[search in: Abstract, Author, Keywords, Classification Codes, Subjects, Title and Translated Title]*	210998
4	(severe mental illness or serious mental illness)	5356
5	schizo*	29418
6	S1 OR S2 OR S3 OR S4 OR S5	503105
7	MH "Hospitals, Psychiatric"	6238
8	MH "Psychiatric Units"	2325
9	MH "Psychiatric Service"	809
10	MH "Rehabilitation, Psychosocial+"	4760
11	MH "Community Mental Health Services+"	10953
12	MH "Psychiatric Patients"	10806
13	MH "Inpatients"	75089
14	((community OR inpatient OR hospital) W3 rehab*)	6546
15	MH "Residential Care+"	6873
16	MH "Residential Facilities+"	29117
17	MH "Psychiatric Home Care"	217
18	(((support* OR shelter* OR board* OR group OR resident*) W0 (hous* OR home* OR accom* OR living OR lodg* OR tenanc* OR care OR support* OR rehab*)) OR hostel OR ((floating OR visiting) W0 (support OR outreach)))	20739
19	S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18	151383
20	(MH "Hospitalization+")	88127
21	(admission* OR readmission* OR re-admission* OR (bed W0 day*) OR "length of stay")	118825
22	MH "Discharge Planning+"	4641
23	MH "After Care"	11844
24	(patient W0 (discharge* OR recovery))	21358
25	((independent) W0 (accom* or living))	1994
26	((less or lower) W3 accom*)	216
27	(more W3 accom*)	380
28	(Move on or moveon or move on or moved on or moved-on)	25446
29	S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28	241689
30	S6 AND S19 AND S29	5952
31	S6 AND S19 AND S29 **Limiters** - Publication Year: 2000-2019; English Language	4916

Final search Web of Science		
LINE	SEARCH	Results 14/06/2019
1	TS=((psycho* or psychiat* or mental*) NEAR/0 (illness* or disorder* or problem* or disease* or disab* or health or "well being" or wellbeing)) *[TS = search in: Title, Abstract, Author Keywords, Keywords Plus]*	344890
2	TS=(severe mental illness or serious mental illness)	16489
3	TS=schizo*	220551
4	#3 OR #2 OR #1	525724
5	TS=((community OR inpatient OR hospital) NEAR/3 rehab*)	13344
6	TS=(((support* OR shelter* OR board* OR group OR resident*) NEAR/0 (hous* OR home* OR accom* OR living OR lodg* OR tenanc* OR care OR support* OR rehab*)) OR hostel OR ((floating OR visiting) NEAR/0 (support OR outreach)))	43957
7	#6 OR #5	57133
8	TS=(admission* OR readmission* OR re-admission* OR (bed NEAR/0 day*) OR "length of stay")	241565
9	TS=(patient NEAR/0 (discharge* OR recovery))	8721
10	TS=((independent) NEAR/0 (accom* or living))	3818
11	TS=((less or lower) NEAR/3 accom*)	12302
12	TS=(more NEAR/3 accom*)	14952
13	TS=(Move on or moveon or move on or moved on or moved-on)	366610
14	#13 OR #12 OR #11 OR #10 OR #9 OR #8	642186
15	#14 AND #7 AND #4	533
16	#14 AND #7 AND #4 Limiters - Publication Year: 2000-2019; English Language	410

Final search Cochrane Library		
LINE	SEARCH	Results 14/06/2019
1	MeSH descriptor: [Mental Disorders] explode all trees	64650
2	MeSH descriptor: [Mentally Ill Persons] this term only	46
3	MeSH descriptor: [Mental Health] this term only	1282
4	((psycho* or psychiat* or mental*) NEAR/0 (illness* or disorder* or problem* or disease* or disab* or health or "well being" or wellbeing)):ti,ab,kw	86
5	(severe mental illness or serious mental illness):ti,ab,kw	2430
6	schizo*:ti,ab,kw	16750
7	#1 OR #2 OR #3 OR #4 OR #5 OR #6	75729
8	MeSH descriptor: [Hospitals, Psychiatric] this term only	237
9	MeSH descriptor: [Psychiatric Rehabilitation] this term only	32
10	MeSH descriptor: [Rehabilitation Centers] explode all trees	653
11	MeSH descriptor: [Community Mental Health Centers] explode all trees	109
12	MeSH descriptor: [Community Mental Health Services] this term only	686
13	MeSH descriptor: [Psychiatric Department, Hospital] this term only	95
14	((community OR inpatient OR hospital) NEAR/3 rehab*):ti,ab,kw	2915
15	MeSH descriptor: [Residential Treatment] this term only	153
16	MeSH descriptor: [Residential Facilities] explode all trees	1628
17	MeSH descriptor: [Group Homes] this term only	44
18	(((support* OR shelter* OR board* OR group OR resident*) NEAR/0 (hous* OR home* OR accom* OR living OR lodg* OR tenanc* OR care OR support* OR rehab*)) OR hostel OR ((floating OR visiting) NEAR/0 (support OR outreach))):ti,ab,kw	108253
19	#8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18	113181
20	MeSH descriptor: [Hospitalization] explode all trees	13019
21	MeSH descriptor: [Mental Health Recovery] this term only	3
22	(admission* or re?admission*):ti,ab,kw	5139
23	(bed NEAR/0 day*):ti,ab,kw	2
24	(length of stay):ti,ab,kw	22443
25	(patient NEAR/0 (discharge* or recovery)):ti,ab,kw	3
26	(independent) NEAR/0 (accom* or living):ti,ab,kw	0
27	((less or lower) NEAR/3 accom*):ti,ab,kw	246
28	(more NEAR/3 accom*):ti,ab,kw	238
29	(Move on or moveon or move on or moved on or moved-on):ti,ab,kw	4205
30	#20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29	35704
31	#7 AND #19 AND #30	786
32	#7 AND #19 AND #30 Limiters - Publication Year: 2000-2019, in Trials	524

Final search: Databases combined – 14/06/2019	
Database	**Results**
Medline	3923
Embase	6806
PsycINFO	2259
CINAHL Plus	4916
Web of Science	410
Cochrane	524
Total	18838
De-duplicated total	13685

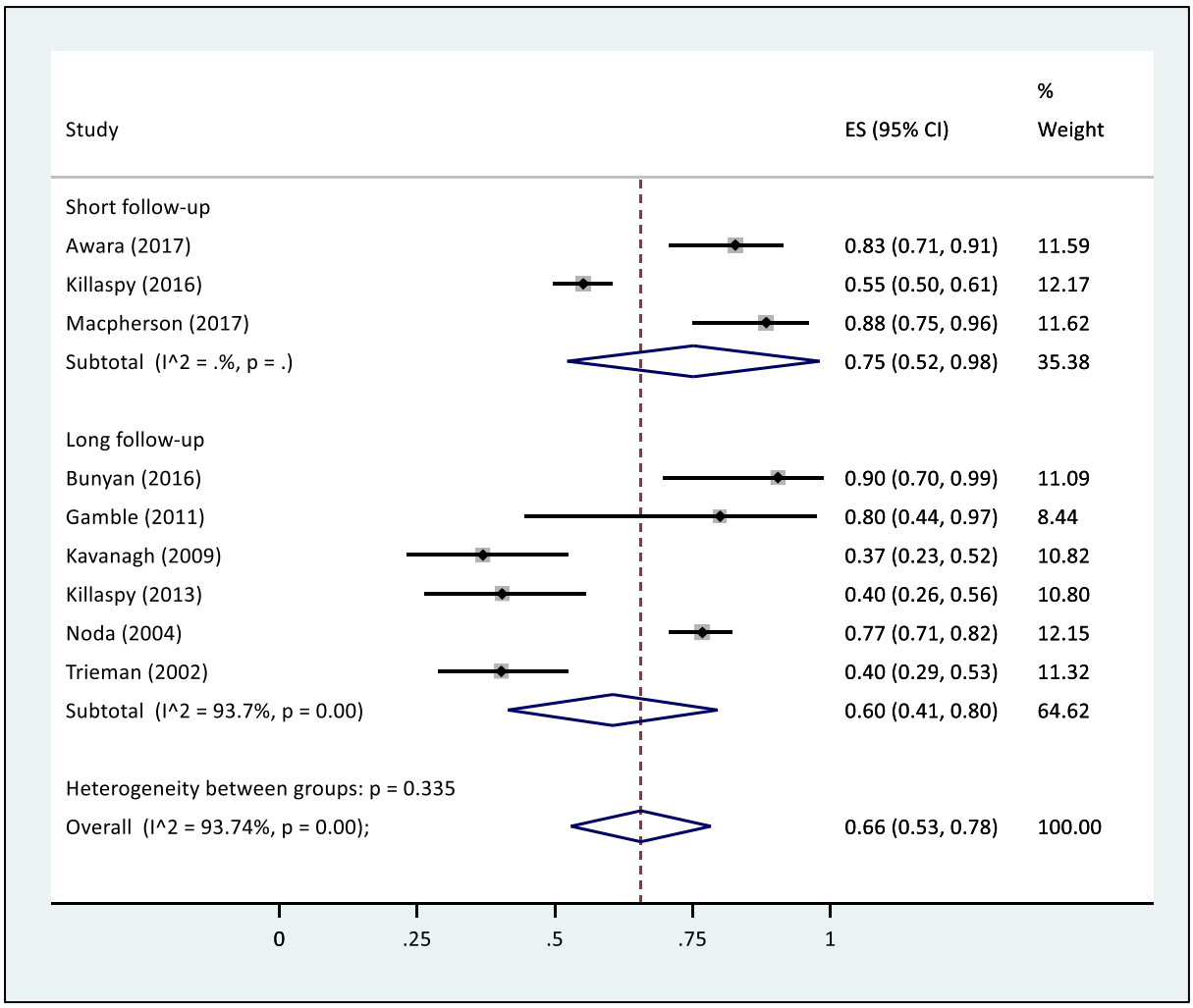
Relevance check		
Author, year and title of known paper	**Paper included in results?**	**Notes**
Bunyan et al. 2016: 'In-patient rehabilitation: clinical outcomes and cost implications'	YES	-
Killaspy and Zis, 2013: 'Predictors of outcomes for users of mental health rehabilitation services: a 5-year retrospective cohort study in inner London, UK'	YES	-
Killaspy et al. 2016: REAL cohort study – 'Clinical outcomes and costs for people with complex psychosis; a naturalistic prospective cohort study of mental health rehabilitation service users in England'	YES	-
Lavelle et al. 2007: 'Mental Health Rehabilitation and Recovery Services in Ireland: A multicentre study of current service provision, characteristics of service users and outcomes for those with and without access to these services'	NO	Paper not published in peer reviewed journals. Searched http://www.opengrey.eu/ (23/06/2019), and also does not appear in this database.
Kelbrick et al. 2016: 'Evaluating outcomes in an adult inpatient psychiatric rehabilitation unit'	YES	-
Killaspy et al. 2019: QuEST cohort study – 'Predictors of moving on from mental health supported accommodation in England: national cohort study'	YES	-
Trieman, N. and Leff, J. (2002): 'Longterm outcome of long-stay psychiatric in-patients considered unsuitable to live in the community: TAPS Project'	YES	-

Updated search: Databases combined – 09/07/2020	
Database	**Results**
Medline	113
Embase	214
PsycINFO	108
CINAHL Plus	294
Web of Science	75
Cochrane	104
Total	908
De-duplicated total	813

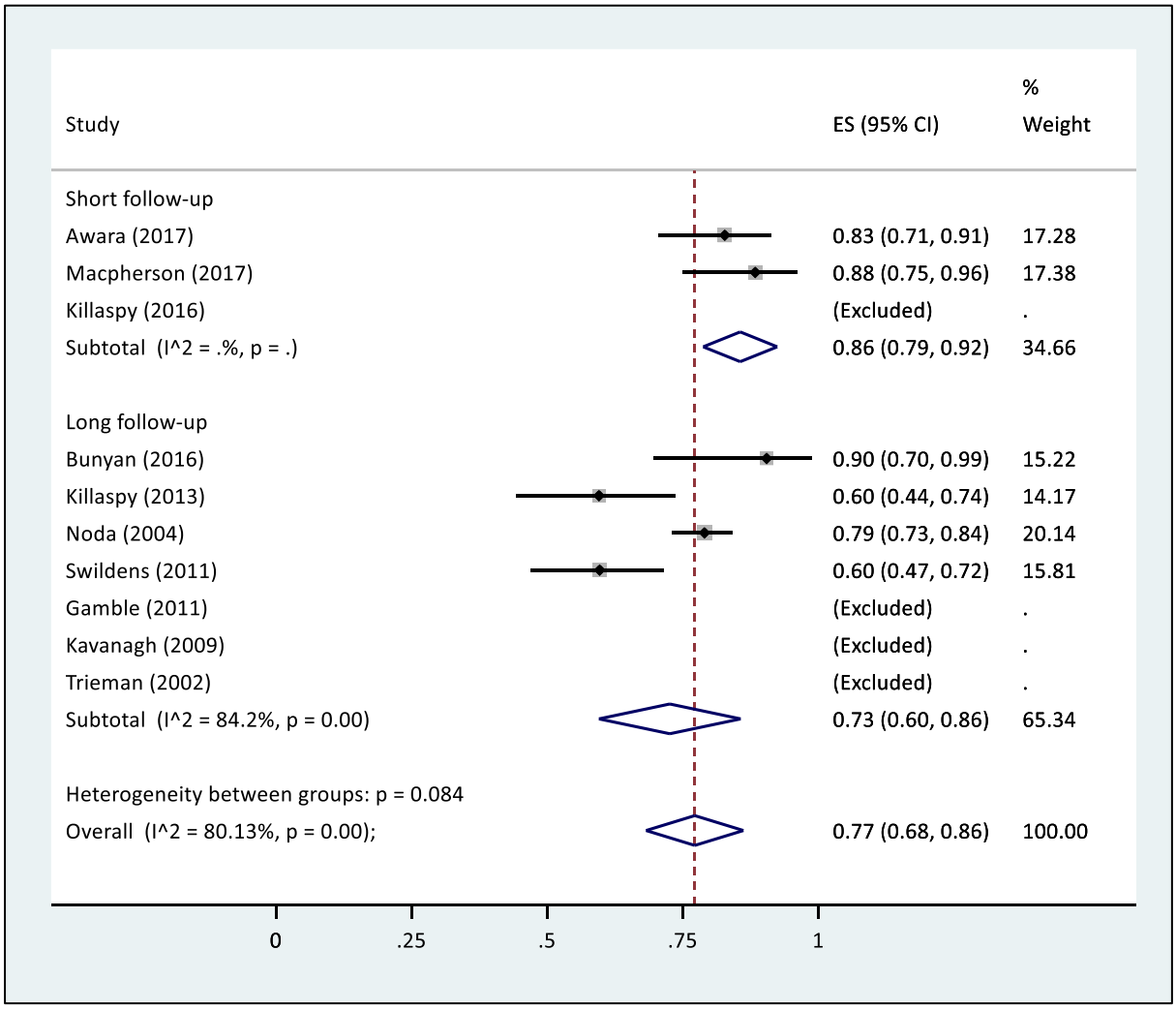
Inclusion/Exclusion criteria:	
Include:	
Study design	Quantitative studies published in peer reviewed journals.
Population	>49% sample people with longer term SMI (psychosis/bipolar).
Inter-vention	Care provision of intervention/service is sufficiently described and is consistent with the 'psychiatric rehabilitation' ethos. I.e. comprised of longer term (mean or median = >6mo), holistic (biopsychosocial), person-centred care based on rehabilitation principles (increased QoL, community integration, progress to greater independence / ADLs and greater autonomy). The service/intervention should specifically provide for people with longer term SMI, they may be structured using a 'case management' (care coordination) approach and work collaboratively with other healthcare services. The intervention/service should be recognisable as one of the following: an inpatient rehab unit, a community rehab unit, a community rehab team (including CMHT with rehab focus) or a supported accommodation service (residential care, supported housing, floating outreach). Studies which are trialling an intervention but using a rehab service as TAU/control.
Outcome	Psychiatric hospitalisation during/post intervention (>3month FU post hospital discharge), and/or discharge or move on rate from intervention service, and/or tenure of community placement/residency.
Exclude:	
Study design	Qualitative studies, case reports, reviews, guidelines, protocols, commentaries, editorials, poster abstracts, conference abstracts, non-English language.
Population	People with first episode psychosis, mood/affective disorder, dementia or learning disability. Samples with mean or median = <18 or >64.
Inter-vention	Insufficient information. Acute (crisis) services (<6mo), forensic services, assertive community treatment/outreach / intensive case management, early intervention in psychosis, nursing homes, non-mh focus (e.g. drug/alcohol treatment).
Outcome	-

Appendix E: Systematic review meta-analyses

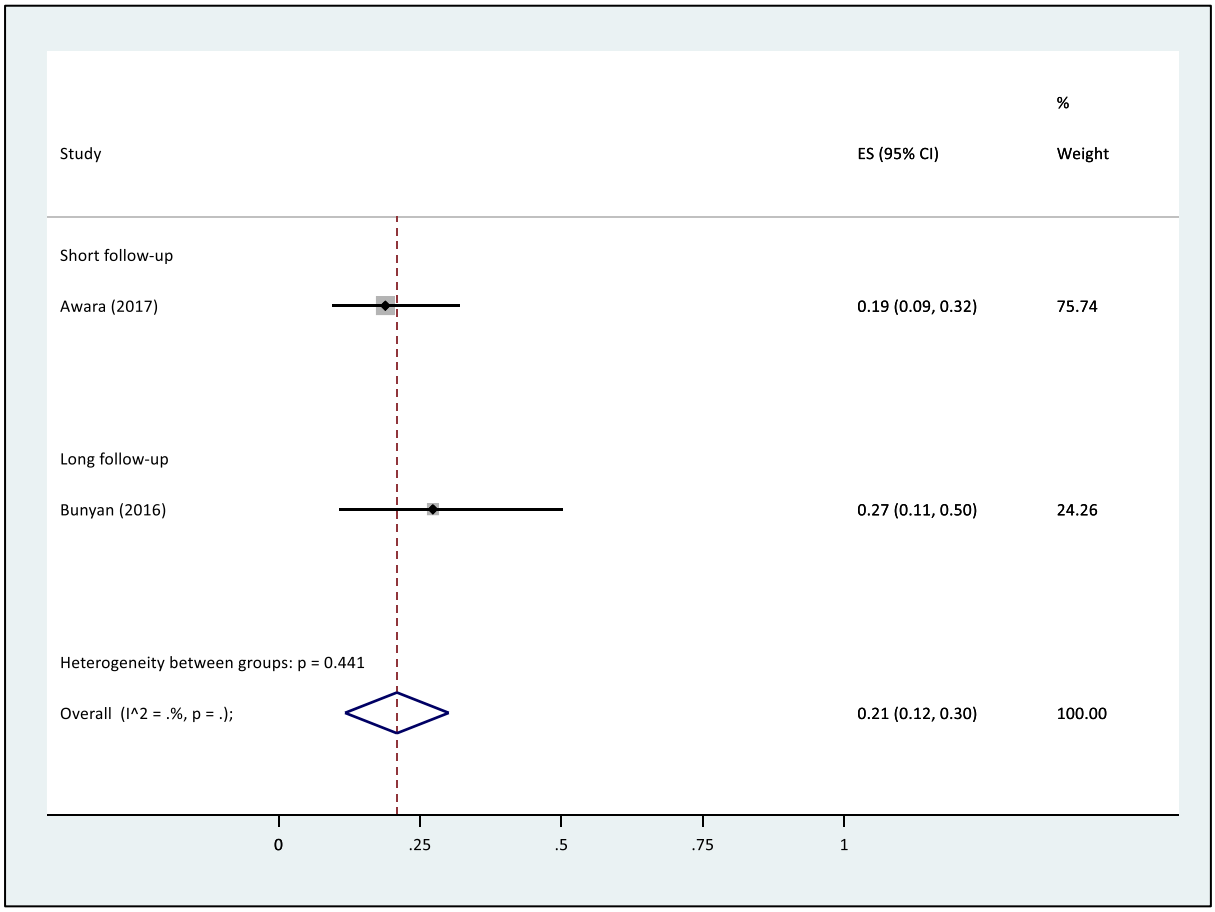
Inpatient services: Positive move



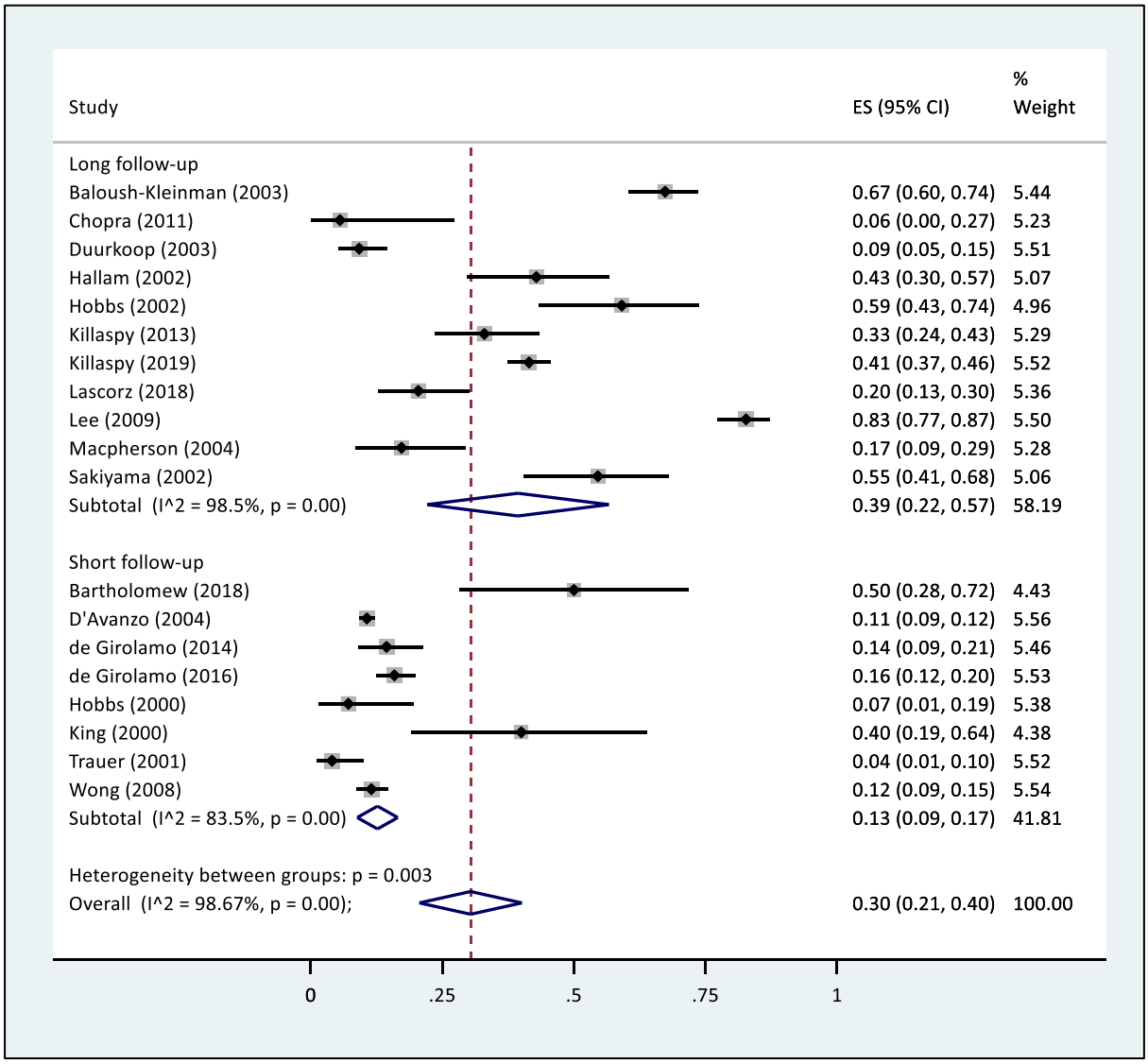
Inpatient services: Maintained placement



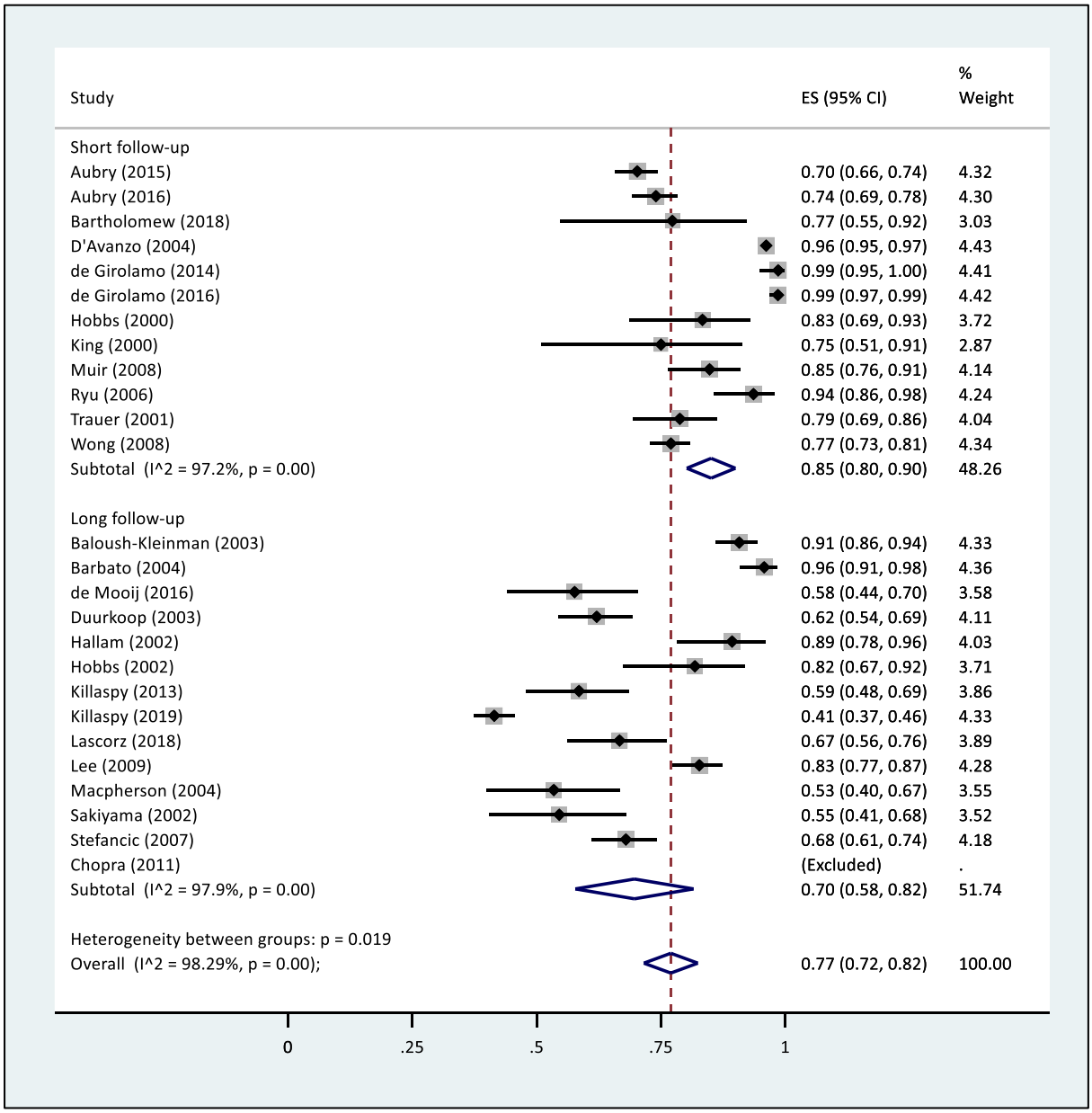
Inpatient services: Hospitalisation



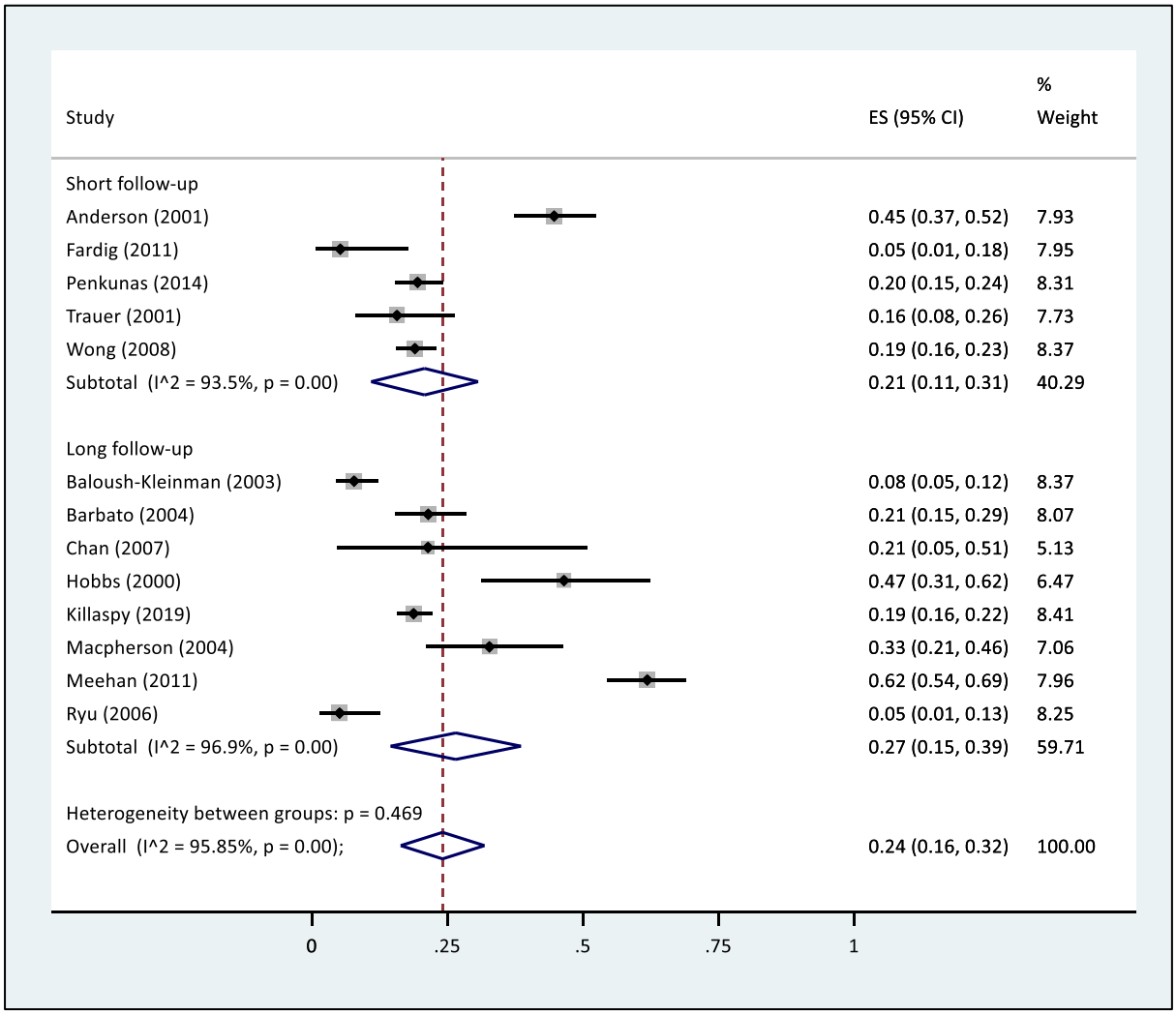
Community services: Positive move



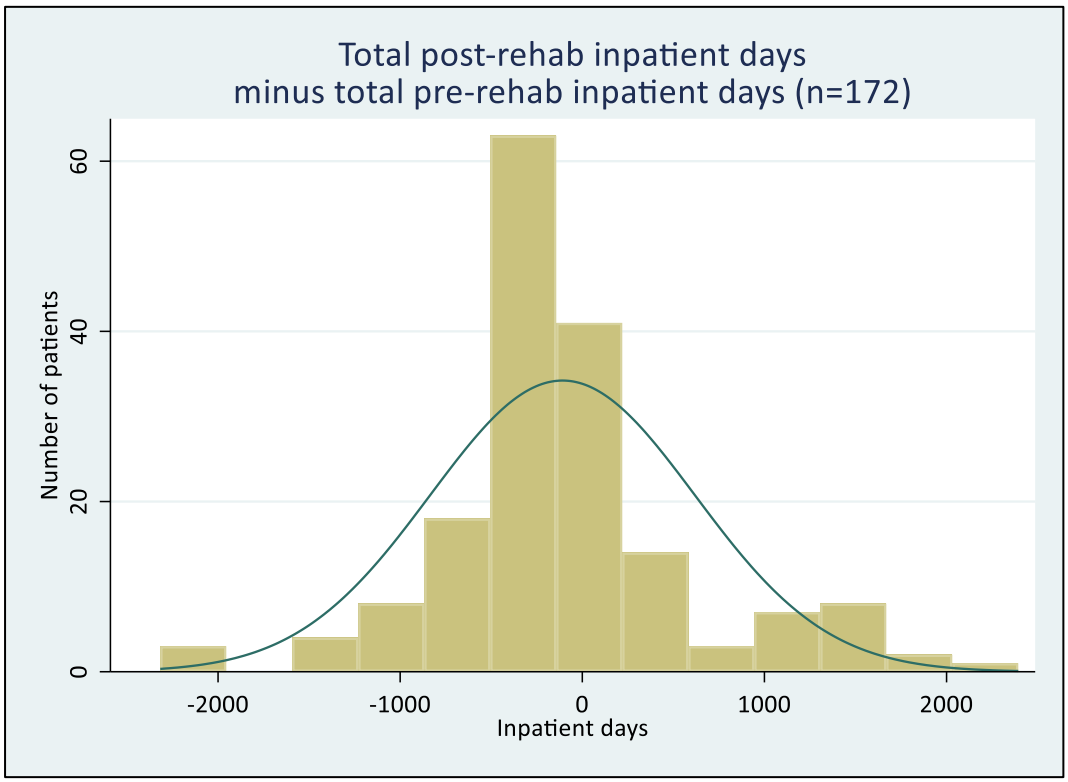
Community services: Maintained placement

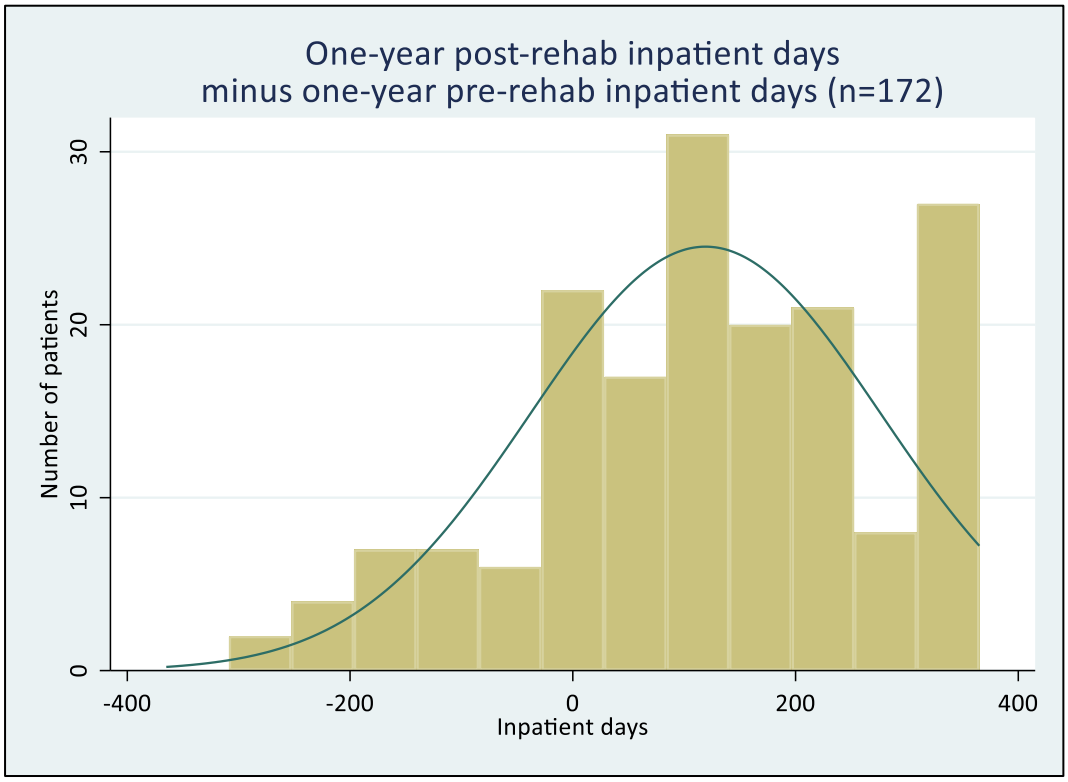


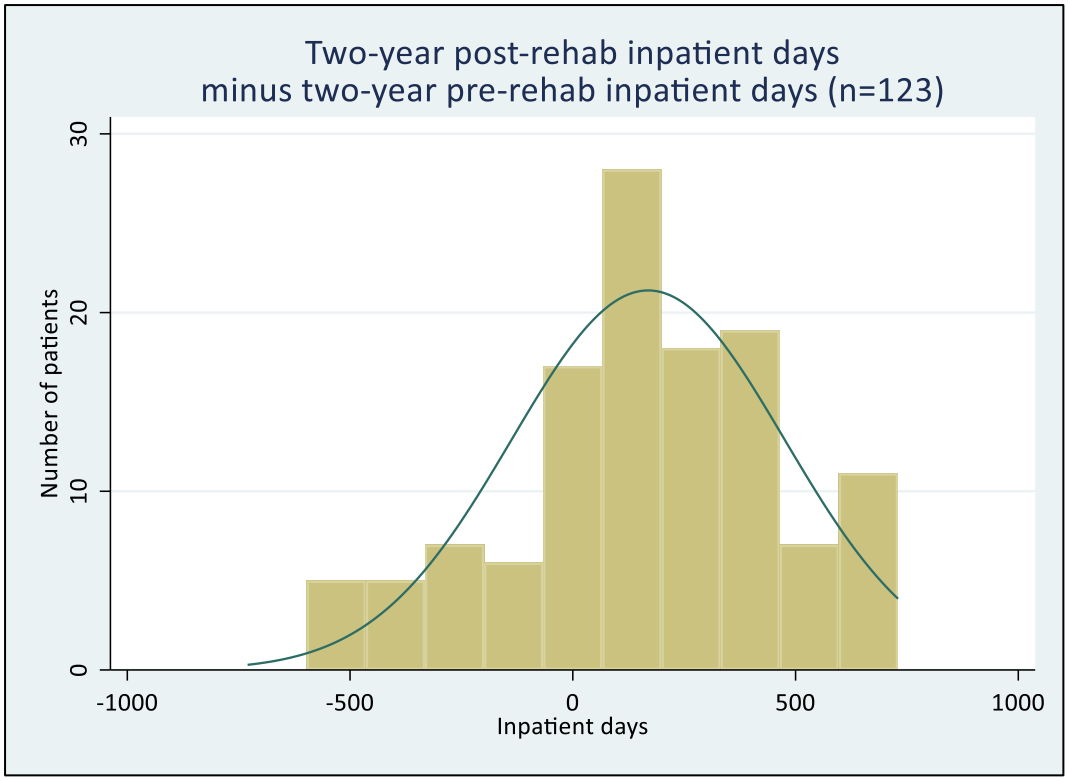
Community services: Hospitalisation

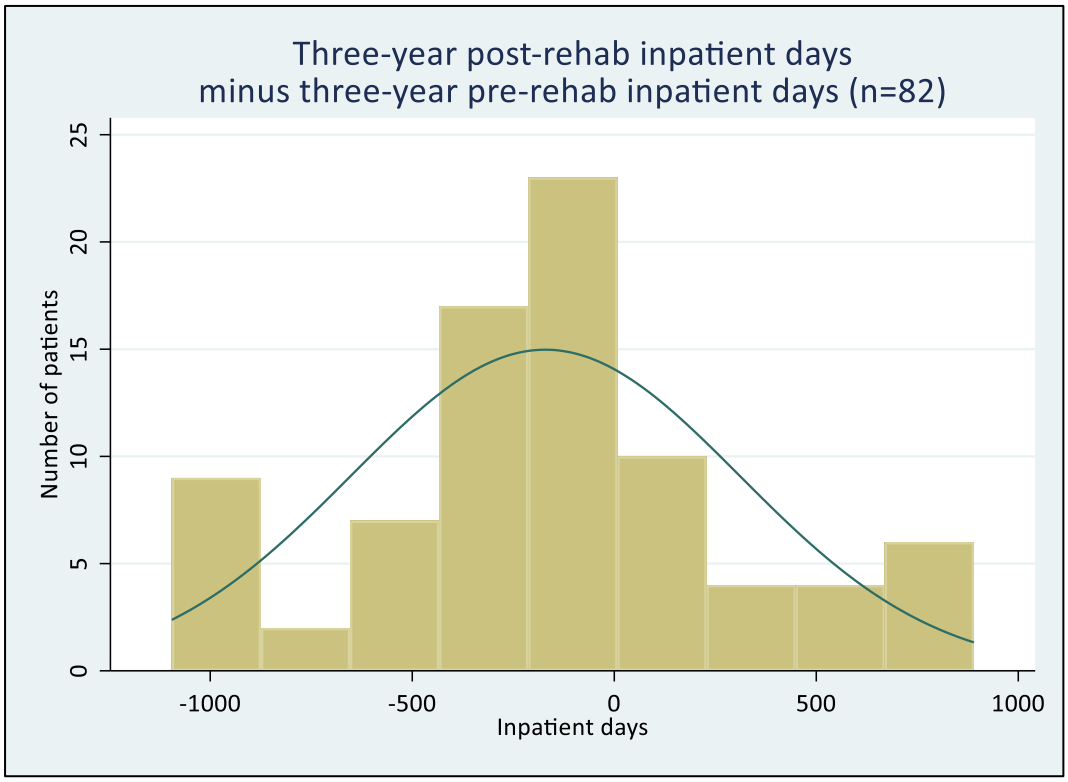


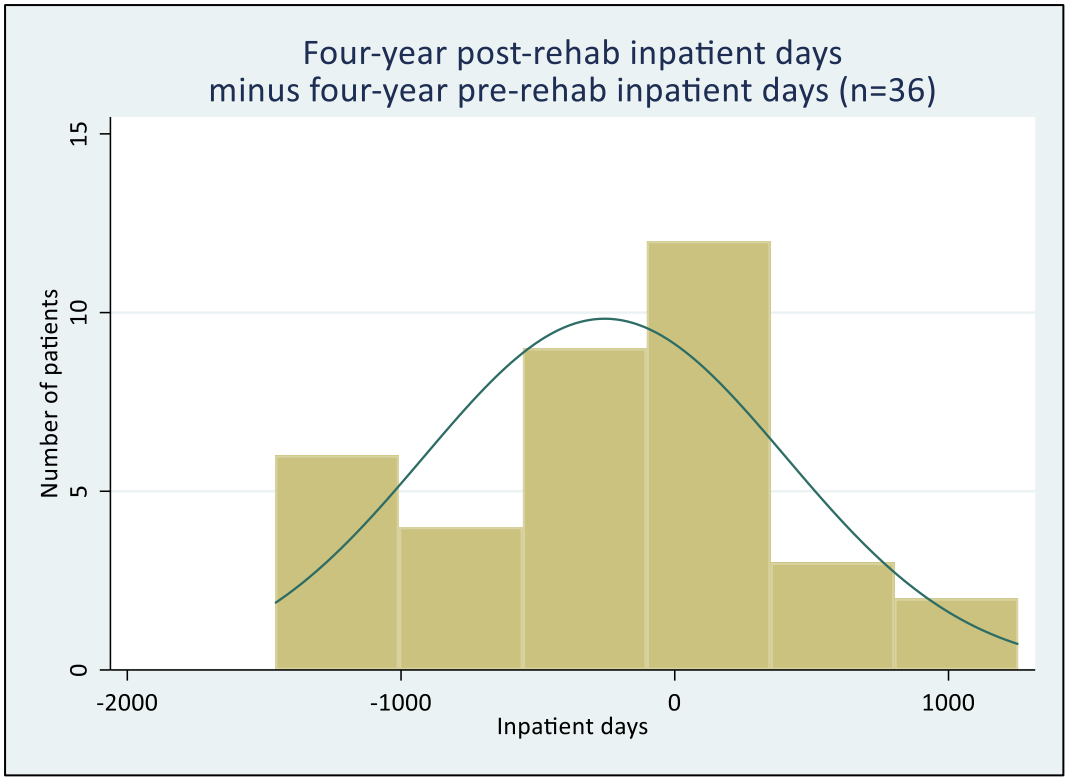
Appendix F: Histograms of the difference in inpatient days before and after a mental health inpatient rehabilitation admission






Two-year post-rehab inpatient days
minus two-year pre-rehab inpatient days (n=123)
Number of patients
0
10
20
30
-1000
-500
0
500
1000
Inpatient days


Three-year post-rehab inpatient days
minus three-year pre-rehab inpatient days (n=82)
Number of patients
0
5
10
15
20
25
-1000
-500
0
500
1000
Inpatient days


Four-year post-rehab inpatient days
minus four-year pre-rehab inpatient days (n=36)
Number of patients
0
5
10
15
-2000
-1000
0
1000
Inpatient days

Appendix G: Chapter 4: UCL declaration form for including work which has already been published

1. For a research manuscript that has already been published (if not yet published, please skip to section 2)**:**		
a) Where was the work published? (e.g. journal name)	PLoS ONE	
b) Who published the work? (e.g. Elsevier/Oxford University Press):	Public Library of Science	
c) When was the work published?	20/08/2020	
d) Was the work subject to academic peer review?	Yes	
e) Have you retained the copyright for the work?	Yes	
[If no, please seek permission from the relevant publisher and check the box next to the below statement]: *I acknowledge permission of the publisher named under 1b to include in this thesis portions of the publication named as included in 1a.*		
2. For a research manuscript prepared for publication but that has not yet been published (if already published, please skip to section 3)**:**		
a) Has the manuscript been uploaded to a preprint server? (e.g. medRxiv):	Please select.	**If yes, which server?** Click or tap here to enter text.
b) Where is the work intended to be published? (e.g. names of journals that you are planning to submit to)	Click or tap here to enter text.	
c) List the manuscript's authors in the intended authorship order:	Click or tap here to enter text.	
d) Stage of publication	Please select.	
3. For multi-authored work, please give a statement of contribution covering all authors (if single-author, please skip to section 4)**:**		
CD-L, HK and JT conceived and designed the study. CD-L developed and carried out the searches with supervision from JT and NW. All authors were involved in the interpretation of the data. CD-L drafted the manuscript which was reviewed and revised by all authors. All authors approved the final version of the manuscript and agreed their accountability in ensuring that any questions related to the accuracy or integrity of any part of the work were appropriately investigated and resolved.		
4. In which chapter(s) of your thesis can this material be found?		
Chapter 4		
5. e-Signatures confirming that the information above is accurate (this form should be co-signed by the supervisor/ senior author unless this is not appropriate, e.g. if the paper was a single-author work):		

Candidate:	Christian Dalton-Locke	**Date:**	14/07/2022
Supervisor/ Senior Author (where appropriate)**:**	Helen Killaspy	**Date:**	14/07/2022

Appendix H: Chapter 5: UCL declaration form for including work which has already been published

1. For a research manuscript that has already been published (if not yet published, please skip to section 2)**:**		
a) Where was the work published? (e.g. journal name)	Frontiers in Psychiatry	
b) Who published the work? (e.g. Elsevier/Oxford University Press):	Frontiers	
c) When was the work published?	13/01/2021	
d) Was the work subject to academic peer review?	Yes	
e) Have you retained the copyright for the work?	Yes	
[If no, please seek permission from the relevant publisher and check the box next to the below statement]: *I acknowledge permission of the publisher named under 1b to include in this thesis portions of the publication named as included in 1a.*		
2. For a research manuscript prepared for publication but that has not yet been published (if already published, please skip to section 3)**:**		
a) Has the manuscript been uploaded to a preprint server? (e.g. medRxiv):	Please select.	**If yes, which server?** Click or tap here to enter text.
b) Where is the work intended to be published? (e.g. names of journals that you are planning to submit to)	Click or tap here to enter text.	
c) List the manuscript's authors in the intended authorship order:	Click or tap here to enter text.	
d) Stage of publication	Please select.	
3. For multi-authored work, please give a statement of contribution covering all authors (if single-author, please skip to section 4)**:**		
CD-L, HK and JT conceived and designed the study. CD-L developed and carried out the searches with supervision from JT and NW. All authors were involved in the interpretation of the data. CD-L drafted the manuscript which was reviewed and revised by all authors. All authors approved the final version of the manuscript and agreed their accountability in ensuring that any questions related to the accuracy or integrity of any part of the work were appropriately investigated and resolved.		
4. In which chapter(s) of your thesis can this material be found?		
Chapter 5		
5. e-Signatures confirming that the information above is accurate (this form should be co-signed by the supervisor/ senior author unless this is not appropriate, e.g. if the paper was a single-author work):		

Candidate:	Christian Dalton-Locke	**Date:**	14/07/2022
Supervisor/ Senior Author (where appropriate)**:**	Helen Killaspy	**Date:**	14/07/2022