What is the evidence for the need for specialist treatment of people with acquired brain injury in secure psychiatric services?

Protocol for a systematic review

Final Protocol

6.1.20

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Date completed	6th January 2020
Source of funding	This report was commissioned by the Department of Health and Social Care via the NIHR HS&DR programme as a review project within NIHR HS&DR programme project number 16/47/22.
Role of funder/institution in protocol creation	This protocol was informed by information provided by the Department of Health and Social Care.
Declared competing interests of the authors	None.
Rider on responsibility for document	The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health. Any errors are the responsibility of the authors.
PROSPERO registration number	None.

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1 Background

1.1 Adult secure services in the UK

Adult medium and low secure services provide care and treatment for men and women with mental and/or neurodevelopment disorders who are liable to be detained under the Mental Health Act (MHA) 1983, and whose risk of harm to others and risk of escape from hospital cannot be managed safely within other mental health settings.[1]

The secure psychiatric care pathway can be complex and there are many interdependencies with other services and organisations. Patients will typically have complex chronic mental illnesses and/or disorders, including neurodevelopmental disorders, which are linked to offending or seriously harmful behaviour. Some patients will be involved with the criminal justice system, courts and prison, and may have Ministry of Justice restrictions imposed.

Secure services provide a comprehensive range of evidence-based care and treatment provided by practitioners, expert in the field of forensic mental health. A range of specialist treatment programmes are available, delivered either individually or within groups. However, the specific needs or diagnoses catered for by different services or centres varies considerably. The aim of treatment for each individual will be to safely return to either (a) the community, (b) to a lower level of security or into non-secure services, or (c) to prison.

1.2 Acquired brain injury

An acquired brain injury (ABI) "…is a form of brain injury that an individual sustains, or 'acquires', after birth; individuals are not born with the injury as a result of congenital or genetic disorders" and can be separated into two types: traumatic brain injuries (TBI) are "sustained as a result of some form of impact to the head", whilst non-traumatic brain injuries (nTBI) are of internal causation and "…as a result of medical occurrences such as having a stroke, a brain tumour, or meningitis".[2]

1.5 million people within the UK are currently living with a disability resulting from a brain injury.[3] Depending on the location and severity of the injury, people living with an ABI can experience a variety of difficulties, which can be divided into four broad categories; physical, communicative, cognitive and behavioural/emotional.[4] People living with a brain injury are more likely to experience mental health difficulties,[5] are at increased risk of engaging in offending behaviour or drug use and present a higher risk of harm to others and/or themselves.[3] It is estimated that over 60 per cent of the UK prison population have a brain injury.[6]

1.3 Provision of specialist acquired brain injury services

Delivering services for people with an ABI can be complex as differences in the aetiology and severity of the injury can lead to variations in level of functioning and range of potential needs across different individuals.[7]

Recovery from an ABI can occur over many months or even years. The 'slinky model' of rehabilitation indicates that patients require different services and levels of support depending on the stage of their recovery.[8] This support ranges from specialist rehabilitation as a post-acute inpatient, stepping down to services provided by community-based rehabilitation services then on to longer-term community support, including specialist case management.

The level of support available from families and the structure of local service provision can vary considerably. This may mean that whilst the longer-term needs of people living with ABI can be met through community based-services, the needs of individuals with severe difficulties may mean secure services are best equipped to reduce the risk of harm the patient presents to themselves and/or others, whilst supporting them to achieve their individual rehabilitation goals.

1.3.1 Secure acquired brain injury services within the UK

A discussion paper commissioned by NHS England to review specialist secure service provision for adults with ABI indicates that NHS England currently commissions 76 secure ABI beds in total (47 medium secure and 33 low secure beds), across 3 providers at 3 hospital sites in the North West and East Midlands.[9] All of these beds are for male occupancy and there is currently no specialist ABI high-secure provision. There are "…significant differences in the sources of admission across the three providers of secure ABI services which may relate to differences in the pathway, differences in the nature of provision being offered, and differences in the referrals and access assessment process across the country".[9]

In September 2017, 70 individuals were using secure ABI services within the UK. Over a 30 month period, 60 patients were discharged, whilst 70 were admitted with an average of 1-2 admissions per month, with the highest proportion of accepted referrals stemming from prison, courts or the police.[9] Only 55% of referrals to low and medium secure services were accepted, with 53% of all patients passing through low-secure and 67% within medium-secure services were on criminal sections of the Mental Health Act (1983).[9]

Only 75% of the patients progressing through ABI secure services during a thirty month period had a recorded ABI diagnosis. Of the patients without an ABI diagnosis, the most common primary diagnosis was '*Schizophrenia, schizotypal and delusional disorders'*.[9] Currently referral to specialist ABI secure services has been based upon the care needs, available treatment and level of security required by the individual patient.[10]

1.4 Context of this review

The Adult Secure Mental Health Service Review (MHSR) seeks to ensure that individuals who require support from secure services can do so close home, in the least restrictive environment appropriate to their needs.[11] It is intended that the provision of secure services will be also be aligned with non-secure inpatient services, community services and prison mental health services.

Currently ABI secure service landscape is a product of local, organic development rather than a national strategy, resulting in variation in service provision across local sites with no agreement on what appropriate referral and treatment pathways or patient outcomes should be for patients with an ABI who access secure services. To inform the MHSR, the Clinical Reference Group recommended that more focused piece of work focusing on the existing evidence-base for the provision of secure ABI is required.

1.5 Overall aims and objectives of the review

This review aims to summarise and synthesise evidence that can inform the arrangements for the specialist care of adults with ABI who may require secure psychiatric services. This overarching interest can be broken down into three specific research questions:

1) Is there evidence to support the differentiation between different groups of adult patients with ABI as a criterion influencing the most appropriate care setting for treatment of adults with ABI?

2) Is there evidence to support the use of diagnostic, disease- or symptom-severity assessment criteria in influencing the most appropriate setting for care and treatment of adults with ABI?

3) Is there evidence to support the use of risk assessment criteria in influencing the most appropriate setting for care and treatment of adults with ABI?

By seeking to identify evidence relating to these specific research questions we hope the review can directly inform service development and commissioning in the NHS within England. This review should also help determine the need for commissioning further research. This may be a call for primary research to increase evidence about the use of specialist services, or for other evidence syntheses to make sense of the available evidence.

2 Methods

2.1 Identification of studies

We will identify relevant studies by:

- searching an appropriate selection of bibliographic databases
- checking reference lists of included studies and topically relevant systematic reviews
- liaising with stakeholders
- searching conference proceedings of relevant conferences
- searching trials registries
- searching relevant websites

We will also conduct targeted searches for relevant studies carried out at or linked by citation chain to the three specialist secure service providers in the UK, including:

- forward citation searching of included studies conducted at UK specialist secure services
- searching for studies conducted at UK specialist secure services by using the author affiliation search function in Scopus
- contacting authors of relevant studies conducted at UK specialist secure services

The bibliographic database search strategy will be developed using MEDLINE via Ovid by an information specialist (SB) in consultation with the review team and stakeholders. It will consist of two sub-strands, including (1) identification of studies of ABI that explicitly mention a relevant care setting (i.e. secure, forensic or in-patient psychiatric care), and (2) identification studies that do not explicitly mention a relevant care setting but do mention assessment or diagnosis of ABI and behavioural symptoms associated with ABI. Our test searches using MEDLINE and PsycINFO indicate that this approach is the most effective way of retrieving relevant papers identified during background reading and scoping searches.

Search terms will be derived from the titles, abstracts and indexing terms (e.g. MeSH in MEDLINE) of known relevant studies, and supplemented with terminology derived from relevant websites (such as the Headway website [https://www.headway.org.uk/]) and pre-existing systematic reviews of acquired brain injury. Throughout this process careful attention will be given to ensuring an appropriate balance of specificity (i.e. minimising the retrieval of irrelevant studies) and sensitivity (i.e. retrieval of all relevant studies). Stakeholders will be consulted to provide feedback on the appropriateness of search terms. The search results will be date limited from 2000 to-date of search and to English-language studies.

The final bibliographic database search will be translated for use in a selection bibliographic databases including (listed in alphabetical order of provider):

CINAHL (via EBSCO)

Health Management Information Consortium (via Ovid)

MEDLINE (via Ovid)

MEDLINE In-Process & Other Non-Indexed Citations (via Ovid)

PsycINFO (via Ovid)

Social Policy and Practice (via Ovid)

ASSIA (via ProQuest)

The databases have been selected according to their topical relevance to our review, and their performance at retrieving known relevant studies during the search strategy development stage. A provisional search strategy for MEDLINE can be seen in Appendix 1.

We will also search trials registries for ongoing studies including:

ClinicalTrials.gov

WHO ITRCP Search Portal

The reference lists of included studies and topically relevant systematic reviews will be manually inspected. Forward citation searching of studies conducted at UK specialist secure services and author affiliation searches will be conducted using Scopus.

The conference proceedings of the United Kingdom Acquired Brain Injury Form (UKABIF) annual conference from 3 years prior to date of search will be searched to identify relevant studies that are not yet in published form, pending successfully obtaining the proceedings from the conference website or organiser.

The websites of relevant organisations will be searched for unpublished studies or reports of interest, including the websites of:

Brain Injury Rehabilitation Trust (BIRT)

Centre for Mental Health

Headway

Mind

The Royal College of Psychiatrists

The United Kingdom Acquired Brain Injury Forum

2.1.1 Inclusion and exclusion criteria

The inclusion criteria and exclusion criteria, according to the PICoS[12] categories i.e. Patient/Population, phenomenon of Interest and Context to be applied to the studies identified through the search strategy are detailed below.

Participants/population:

Include if:

Participants are adults (aged 18 or over), to include those aged 16+ if in adult services. If participants below the age of 18 are included alongside users of adult secure services, the findings for those aged over 18 should be reported separately.

Participants have any diagnosed acquired brain injury, as defined above, which may include injury acquired through any cause including, but not limited to:

- Trauma – head injury or surgical damage
- Vascular accident e.g. stroke
- Cerebral anoxia

- Other toxic or metabolic insult (e.g. hypoglycaemia)
- Infection (e.g. meningitis) or inflammation

Participants are placed in, eligible for referral to, or being assessed for eligibility for referral to secure psychiatric services, even if the study does not explicitly look at where people are referred. If the study does not look at where people are referred, look for challenging behaviours that indicate that secure services might be appropriate, including:

adjustment;
aggression;
antisocial behaviour;
antisocial personality;
behavioural dysregulation;
criminal behaviour;
dysexecutive syndrome;
emotional functioning;
emotional lability;
empathy;
impulsivity;
inappropriate sexual behaviour;
interpersonal behaviour;
major depressive disorder;
obsessive compulsive disorder;
personality disorders;
physical assault;
phobia;
post-traumatic stress disorder syndrome;
psychological distress;
suicidality;
substance abuse;
violence.

Participants are in any setting, including within the community.

Where participants with an ABI are one subgroup within a study including participants with multiple diagnosis, but where the study's findings are reported separately for those with an ABI.

Exclude if:

Participants do not have a diagnosis of ABI. Participants are aged under 18, or receiving support from adolescent services.

Participants have a diagnosis of a progressive, degenerative disease such as MS or a disease associated with aging, such as Parkinson's disease or a dementia (e.g. Alzheimer's disease).

Participants are described as living with an intellectual or learning disability/difficulty without clear indication that these difficulties arose from an ABI.

Phenomenon of Interest:

Evidence should be relevant to at least one of the three research questions. This may encompass:

- Evidence seeking to establish the value of testing, assessment or patient classification procedures (e.g. psychometric, scans, risk assessments etc.) to predict the needs of people living with an ABI who require/may benefit from support within a secure settings.

Psychometric evaluations of assessment tools must consider some aspects of both reliability and validity in order to be included.

Geographical Scope

We are primarily interested in research conducted within the UK. We will also include studies that are conducted in other high-income countries deemed to have a similar system of service provision to the UK. The inclusion of studies from other countries will be decided on a case by case basis following consultation with our stakeholders.

Study design

Include if:

Any study design which contains evidence relevant to review questions 1 to 3. This may include, but is not limited to:

- Systematic reviews

- Empirical studies that have collected quantitative data (e.g. about tests, assessments, classification systems)

Exclude if:

Commentaries, opinion pieces and editorials

Case studies of individual patients

Epidemiological studies e.g. studies that take an epidemiological approach to understand comorbidities associated with an ABI

Date of publication

From 2000 to date.

2.1.2 Process for applying inclusion criteria

As an initial calibration exercise of inclusion judgments and the clarity of our inclusion criteria, all reviewers will apply inclusion and exclusion criteria to a sample (e.g. n=100) of search results. Decisions will be discussed in a face to face meeting to ensure consistent application of criteria. Where necessary inclusion and exclusion criteria will be revised to reflect reviewer interpretation and judgement.

The revised inclusion and exclusion criteria will then be applied to the title and abstract of each identified citation independently by two reviewers. Disagreements will be resolved through discussion. Items without an abstract will be put through for full text screening.

The full text of each source will be assessed independently for inclusion by two reviewers. Disagreements will be settled by discussion with a third reviewer if necessary. We will also liaise with stakeholders to ensure that our application of inclusion and exclusion criteria is consistent with their expert understanding, e.g. which studies are set in relevant secure settings, and which studies measure behaviours that indicate the need for secure services.

EPPI Reviewer and Endnote X8 software will be used to support study selection. A PRISMA-style flowchart will be produced to detail the study selection process and reasons for exclusion of each full-text paper will be reported.[13]

2.2 Data extraction

Summary data will be extracted for each study by one reviewer and checked by a second reviewer. This data will include: study author, title and date of publication; country where the study was conducted; study design, aims; research question(s) to which the study relates; relevant sample characteristics such as sample size, age, gender and ethnicity; details of

any interventions and comparator, if relevant; details of outcome measures and data collected.

2.3 Study quality appraisal strategy

Principles of quality assessment will be applied to each included paper and discussed narratively.[14]

2.4 Evidence synthesis

Based on preliminary scoping, we believe the most appropriate strategy will be to narratively describe the studies that are included. We will describe the extent to which the evidence is able to address to research questions.

2.5 Stakeholder involvement

Stakeholder involvement will be incorporated within this review. Representatives from NHS England will be consulted on the development of the protocol, screening of studies for inclusion, resolution of disagreements and involved with making sense of preliminary results and preparation of the final report and any other outputs.

3 Dissemination plans

A final report will be produced for NHS England and published in the NIHR Journals Library. Additional publications may be sought, depending on the extent of evidence identified.

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Appendix 1. Search strategy

MEDLINE (Ovid) search strategy

1. ((brain or forebrain) adj3 (aneurysm* or damage or edema or h?emorrhage* or infarction* or injur* or oedema or swell* or trauma* or wound*)).tw.
2. concussion*.tw.
3. ((cerebr* or crani* or intercrani* or intracrani* or capitis) adj3 (atrophy or contusion* or damage or edema or h?emorrhage* or infarction* or injur* or laceraton* or oedema or swell* or trauma*)).tw.
4. exp Craniocerebral Trauma/
5. (head adj3 (bleed* or damage or fractur* or injur* or swell* or trauma* or wound*)).tw.
6. or/1-5
7. (bleed* adj3 (brain or cerebr* or crani* or intercrani* or intracrani* or capitis)).tw.
8. "blow to the head".tw.
9. (brain adj3 (cancer* or carcinoma* or neoplasm* or tumo?r*)).tw.
10. exp Brain Neoplasms/
11. ("cortical pseudolaminar necrosis" or "laminar necrosis").tw.
12. ((coup or contrecoup) adj3 injur*).tw.
13. "diffuse axonal injur*".tw.
14. "eggshell fracture*".tw.
15. (encephalopathy or encephalomalacia).tw.
16. "extracranial CNS injur*".tw.
17. "hypoxic isch?emic injury".tw.
18. ((intracerebral or intracranial) adj1 (bleeding or h?emorrhage or injur*)).tw.
19. (intraparenchymal adj1 (bleed* or haemorrhage* or hemorrhage* or tear*)).tw.
20. "intraventricular h?ematoma".tw.
21. "leptomeningeal cyst*".tw.
22. ("neurologic injur*" or neuropathology).tw.
23. neuropathology/
24. "second impact syndrome".tw.
25. (skull adj1 fracture).tw.
26. (stroke or "cerebro vascular accident*" or "cerebrovascular accident*" or "cerebral ischaemia").tw.
27. exp Stroke/
28. exp Brain Ischemia/
29. "subarachnoid h?ematoma".tw.
30. (subdural adj1 (h?ematoma or hygroma)).tw.
31. or/7-30
32. 6 or 31
33. (secure adj3 (care or healthcare or hospital* or "mental health" or service* or unit* or ward*)).tw.
34. (forensic adj3 (care or healthcare or hospital* or "mental health" or "occupational therap*" or psyc* or service* or unit* or ward*)).tw.
35. Forensic Psychiatry/
36. forensic psychology/

37. (locked adj3 (care or healthcare or hospital* or "mental health" or rehab* or service* or unit* or ward*)).tw.
38. ("in reach" adj3 (hospital or service*)).tw.
39. (psychiatric adj3 (admission* or care or department* or healthcare or hospital* or rehab* or service* or setting* or unit* or ward*)).tw.
40. (("neuro rehab*" or neurorehab* or neuropsyc* or neurobehav*) adj3 (admission* or care or department* or healthcare or hospital* or rehab* or service* or setting* or unit* or ward*)).tw.
41. Hospitals, Psychiatric/
42. Psychiatric Department, Hospital/
43. ("mental health" adj3 (admission* or care or department* or hospital* or rehab* or service* or setting* or unit* or ward*)).tw.
44. Mental Health Services/
45. or/33-44
46. 32 and 45
47. ((diagnos* or "disease severity" or psyc* or referral* or risk* or screening) adj2 (assessment or criter* or decision* or questionnaire* or test* or tool*)).tw.
48. (assessment adj2 (criter* or decision* or questionnaire* or referral* or symptom* or tool*)).tw.
49. (sensitiv* or accura* or "predictive value" or prediction*).tw.
50. (validat* adj2 (scale* or index*)).tw.
51. "Sensitivity and Specificity"/
52. Diagnosis/
53. "Severity of Illness Index"/
54. psychometric*.tw.
55. or/47-54
56. ("challeng* behav*" or aggressive* or aggression or violent* or violence).tw.
57. Violence/di, pc [Diagnosis, Prevention & Control]
58. Social Behavior Disorders/di, pc [Diagnosis, Prevention & Control]
59. (illegal* or legal* or crime or criminal* or offender*).tw.
60. Crime/pc, px [Prevention & Control, Psychology]
61. (memory adj2 (disorder* or loss or impair*)).tw.
62. Memory Disorders/di [Diagnosis]
63. or/56-62
64. 32 and 55 and 63
65. 46 or 64
66. limit 65 to (english language and yr="2000 -Current")