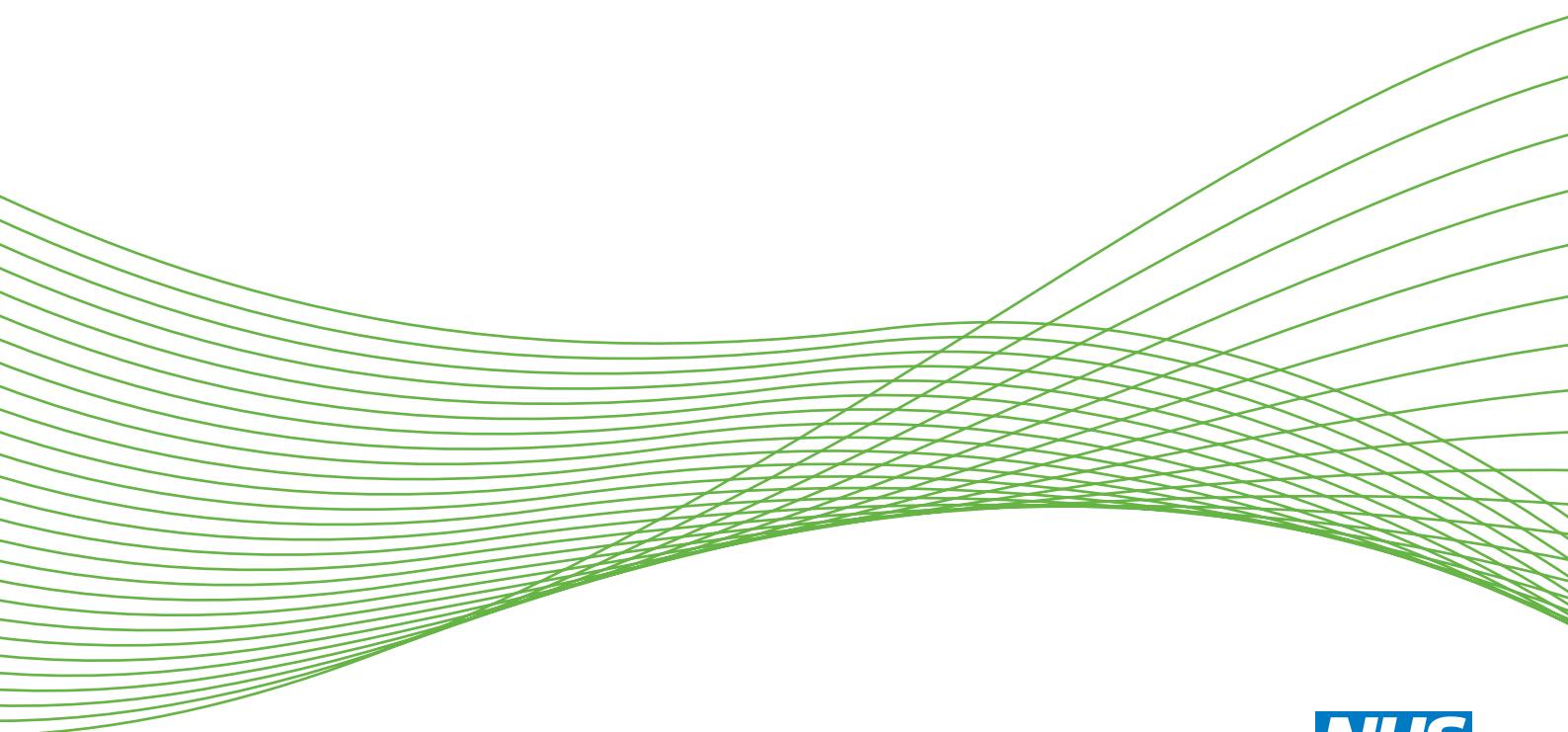


## Researching outcomes from forensic services for people with intellectual or developmental disabilities: a systematic review, evidence synthesis and expert and patient/carer consultation

*Catrin Morrissey, Nicole Geach, Regi Alexander, Verity Chester, John Devapriam, Conor Duggan, Peter E Langdon, Bill Lindsay, Jane McCarthy and Dawn-Marie Walker*





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## Abstract

# Researching outcomes from forensic services for people with intellectual or developmental disabilities: a systematic review, evidence synthesis and expert and patient/carer consultation

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**Background:** Inpatient services for people with intellectual and other types of developmental disabilities (IDD) who also have forensic or risk issues are largely provided in secure hospitals. Although this is a health service sector with high levels of expenditure, there is limited empirical information on patient outcomes from such services. In order for a future substantive longitudinal outcomes study in forensic IDD services to be informed and feasible, more needs to be understood about the outcome domains that are of relevance and importance and how they should be measured. A preliminary series of studies was therefore undertaken.

**Objectives:** To synthesise evidence in relation to the outcome domains that have been researched in the existing literature from hospital and community forensic services for people with IDD, within the broad domains of service effectiveness, patient safety and patient experience. To identify a definitive framework of outcome domains (and associated measures and indicators) based both on this research evidence and on the views of patients, carers and clinicians. To synthesise the information gathered in order to inform design of future multisite longitudinal research in the sector.

**Design:** Three linked studies were conducted. Stage 1 was a systematic review and evidence synthesis of outcome domains and measures as found within the forensic IDD literature. Stage 2 was a consultation exercise with 15 patients with IDD and six carers. Stage 3 was a modified Delphi consensus exercise with 15 clinicians and experts using the information gathered at stages 1 and 2.

## ABSTRACT

**Results:** At stage 1, 60 studies that researched a range of outcomes in forensic IDD services were identified from the literature. This resulted in the construction of an initial framework of outcome domains. The consultation with patients and carers at stage 2 added to these framework domains that related particularly to carer experience and the level of support post discharge in the community. The Delphi process at stage 3 confirmed the validity of the resulting framework for clinician. This survey also identified the outcome measures preferred by clinicians and those that are currently utilised in services. Thus, indicators of appropriate measures in some important domains were identified, although there was a paucity of measures in other domains.

**Conclusions:** Together, these three linked studies led to the development of an evidence-based framework of key outcome domains and subdomains. A provisional list of associated measures and indicators was developed, although with the paucity of measures in some domains development of specific indicators may be required. With further refinement this could eventually be utilised by services and commissioners for comparative purposes, and in future empirical research on outcomes in forensic IDD services. An outline research proposal closely linked to recent policy initiatives was proposed. Limitations of the study include the relatively small number of carers and patients and range of experts consulted.

**Future work:** This would comprise a national longitudinal study tracking IDD in patients through hospitalisation and discharge.

**Study registration:** This study is registered as PROSPERO CRD42015016941.

**Funding:** The National Institute for Health Research Health Services and Delivery Research programme.

# Contents

<b>List of tables</b>	<b>ix</b>
<b>List of figures</b>	<b>xi</b>
<b>List of boxes</b>	<b>xiii</b>
<b>List of abbreviations</b>	<b>xv</b>
<b>Plain English summary</b>	<b>xvii</b>
<b>Scientific summary</b>	<b>xix</b>
<b>Chapter 1 Introduction and background</b>	<b>1</b>
Research group	1
Aims of the research	1
Overview of design	2
This report	2
Note on terminology	2
<b>Chapter 2 Stage 1: systematic literature review of outcome domains researched in forensic intellectual/developmental disabilities services</b>	<b>3</b>
Research questions/objectives of the review	3
Review methods	3
<i>Search strategy</i>	3
<i>Inclusion and exclusion criteria</i>	3
<i>Study selection</i>	4
<i>Data extraction</i>	5
<i>Hierarchy of evidence</i>	5
<i>Analysis</i>	5
Results of the review	5
Discussion: analysis of outcome domains and measures	17
<i>Domain 1: effectiveness</i>	17
<i>Domain 2: patient safety</i>	21
<i>Domain 3: patient experience</i>	21
Conclusions	22
<b>Chapter 3 Stage 2: patient and carer consultation groups</b>	<b>23</b>
Aim	23
Consultation methodology	23
Findings	24
<i>Effectiveness domain</i>	25
<i>Patient safety domain</i>	29
<i>Patient (and carer) experience domain</i>	30
Conclusions	33
<b>Chapter 4 Stage 3: Delphi survey of professionals</b>	<b>35</b>
Aims	35
Method	35

<i>Participants</i>	35
<i>Procedure</i>	35
<i>Analysis</i>	36
Results	36
<i>Characteristics of participants</i>	36
<i>Ratings</i>	37
<i>Top five outcomes</i>	37
<i>Suggested measures/indicators</i>	37
Discussion	37
<i>What are the most important/highest priority outcomes?</i>	39
<i>Additional subdomains</i>	40
<i>Current use of outcome measures</i>	40
<i>Additional issues raised</i>	42
Conclusions	43
<b>Chapter 5 Synthesis of findings and conclusions for future research</b>	<b>45</b>
Overview	45
Final framework of outcome domains	45
Long list of indicators	45
Current policy context	47
Recommendations for future research	47
Limitations	48
Final remarks	49
Dissemination strategy	49
<b>Acknowledgements</b>	<b>51</b>
<b>References</b>	<b>53</b>
<b>Appendix 1 Search strategy</b>	<b>59</b>
<b>Appendix 2 Inclusion and exclusion criteria</b>	<b>65</b>
<b>Appendix 3 Screening tool and data extraction form</b>	<b>67</b>
<b>Appendix 4 Patient and carer information for consultation groups</b>	<b>71</b>
<b>Appendix 5 Topic guides for consultation groups</b>	<b>75</b>
<b>Appendix 6 Delphi information sheet and round 1 questionnaire</b>	<b>81</b>
<b>Appendix 7 Delphi round 2 questionnaire</b>	<b>91</b>
<b>Appendix 8 Provisional 'long list' of measures/indicators</b>	<b>97</b>
<b>Appendix 9 Summary of research for public and patient involvement dissemination</b>	<b>101</b>

# List of tables

<b>TABLE 1</b> Summary of studies presenting data on the effectiveness outcome domain (cohort studies)	7
<b>TABLE 2</b> Summary of studies presenting data on the effectiveness outcome domain (cross-sectional studies)	12
<b>TABLE 3</b> Summary of studies presenting data on the patient safety outcome domain (cohort studies)	15
<b>TABLE 4</b> Summary of studies presenting data on the patient safety outcome domain (cross-sectional studies)	16
<b>TABLE 5</b> Summary of studies presenting data on the patient experience outcome domain (cohort studies)	16
<b>TABLE 6</b> Summary of studies presenting data on the patient experience outcome domain (cross-sectional studies)	17
<b>TABLE 7</b> Framework of outcome domains and subdomains (stage 1)	18
<b>TABLE 8</b> Average ratings for each subdomain	38
<b>TABLE 9</b> Frequency of participants who rated each subdomain as the top five most important (%)	39
<b>TABLE 10</b> Percentage of respondents who reported using each measure/indicator routinely in their service(s) (round 1: $n = 17$ )	41
<b>TABLE 11</b> Final framework of outcome domains	46



# List of figures

<b>FIGURE 1</b> Flow chart of study selection process	<b>6</b>
<b>FIGURE 2</b> Area of work	<b>36</b>
<b>FIGURE 3</b> Type of role	<b>37</b>
<b>FIGURE 4</b> Type of service currently working in	<b>37</b>



## List of boxes

**BOX 1** Framework of outcome domains following stage 2 **24**

**BOX 2** Highest priority subdomains (rating and 'top five' method combined) **40**



## List of abbreviations

ASD	autistic spectrum disorder	LD	learning disability
CROM	clinician-rated outcome measure	NIHR	National Institute for Health Research
EPS	Emotional Problem Scales	PCL-R	Psychopathy Checklist Revised
EssenCES	Essen Climate Evaluation Scale	PCL-SV	Psychopathy Checklist Screening Version
FIDD	forensic intellectual and developmental disabilities	PDF	portable document format
HCR-20	Historical, Clinical Risk 20	PRN	pro re nata
HoNOS	Health of the Nation Outcome Scales	PROM	patient-reported outcome measure
IDD	intellectual and other types of developmental disabilities	VRAG	Violence Risk Appraisal Guide



## Plain English summary

People with intellectual and other types of developmental disabilities (IDD) (which may include autistic spectrum disorders) exhibit differences in cognitive functioning and day-to-day living skills that start in the developmental period. A small proportion of people with IDD can present with behaviour which cannot be safely managed in the community, and they may be detained in a secure hospital. Such hospitals, also called forensic hospitals or services, are high cost to the NHS, but little is known about patient outcomes from inpatient treatment. Research therefore needs to be undertaken in this area.

This project conducted preliminary work in preparation for a wider and more in-depth future project. We aimed to answer three questions:

1. What outcome 'domains' (areas) have been investigated in previous research on forensic services for people with IDD and how have they been measured?
2. What are the outcome domains that have most importance to users of such services and to their carers?
3. What do expert clinicians (e.g. psychologists, psychiatrists and nurses) consider are the most important outcome domains and measures?

We attempted to answer these questions by carrying out three linked studies:

1. a summary of the evidence from previously published research
2. consultation groups with patients with IDD from secure hospitals and their carers
3. an online survey of a panel of clinical experts.

Combining evidence from the three studies, we developed detailed categories of outcome domains and proposed ways of measuring these domains. With further refinement these could be used in future longitudinal outcomes research in forensic IDD services.



# Scientific summary

## Background

A small proportion of people with intellectual and other types of developmental disabilities (IDD) can present with behaviour that contravenes the law, or that is otherwise high risk, and cannot be safely managed in the community. These individuals typically present with a high degree of clinical complexity and may be detained for treatment in a secure hospital under the Mental Health Act 1983 (amended 2007) (Great Britain. *Mental Health Act*. London: The Stationery Office; 2007). Although it is a health service sector with high levels of expenditure, with the NHS currently funding around 1800 secure beds, there is limited empirical information on patient outcomes from such forensic mental health services for people with IDD. In order for a future substantive longitudinal outcomes study to be informed and feasible, more needs to be understood about the outcome domains that are of importance and how they should be measured. A preliminary series of studies was therefore undertaken.

## Objectives

- To synthesise evidence on the outcome domains that have been investigated in existing research from forensic services for people with IDD, in the broad domains of service effectiveness, patient safety and patient experience.
- To identify the views of patients in forensic IDD services and their carers on the outcome domains of most importance and relevance to them.
- To gain consensus on expert views on the outcome domains of most importance for use in future evaluation of forensic IDD services, based on the domains identified from the existing research and patient/carers views.
- To identify a framework of outcome domains (and potential associated measures and indicators) based on the research evidence and on the views of patients, carers and clinicians.
- To synthesise the information gathered in order to inform the design of a future longitudinal research project in the sector.

## Methods

Three linked studies were conducted:

- Stage 1: a systematic review of the literature pertaining to a range of forensic services for people with IDD, focusing specifically on the outcomes that have been researched. Searches of the following databases were conducted on 1 July 2015: MEDLINE, PsycINFO, EMBASE, Allied and Complementary Medicine, Health Management Information Consortium, the British Nursing Index and the Cumulative Index to Nursing and Allied Health Literature from inception to May 2015. Similar outcome domains and measures were clustered together in a qualitative synthesis.
- Stage 2: a series of consultation discussion groups with patients and carers.
- Stage 3: a modified online Delphi expert consensus process conducted over two rounds using the items generated at stages 1 and 2.

## Results

At stage 1, 60 studies that researched outcome domains in forensic IDD services (which included secure hospital-based and community-based services) were identified from the literature. This resulted in the construction of an initial framework of 31 outcome domains, under three superordinate domains.

The consultation with 15 patients and six carers at stage 2 added a number of domains to this framework, which particularly related to carer experience.

The Delphi process at stage 3 had 15 respondents at both round 1 and round 2; these were primarily clinicians in forensic IDD services. This process highlighted support for the validity of the framework and identified several key domains of most importance to clinicians. This survey also identified the outcome measures or indicators preferred by clinicians and those that are utilised currently in services. Both this survey and the systematic review identified a paucity of appropriate measures in some key domains, particularly in relation to treatment progress.

## **Conclusions**

Together, these three linked studies resulted in the consolidation of a framework of key outcome domains and subdomains. It also led to a long list of provisional associated measures and indicators for these domains. With further development, this could eventually be utilised both by services and commissioners and in any subsequent empirical longitudinal study of forensic IDD services.

### ***Implications for research***

The policy context in IDD at the present time is of importance when future research is concerned. The Transforming Care programme and related developments, including a national service model associated with reduction in IDD hospital bed numbers, require that secure hospitals treating people with IDD produce accurate and relevant outcome data, both during treatment and following discharge. This project has reviewed previous research on outcomes and clarified what a future outcome data set should look like. An outline research design is proposed.

## **Study registration**

This study is registered as PROSPERO CRD42015016941.

## **Funding**

Funding for this study was provided by the Health Services and Delivery Research programme of the National Institute for Health Research.

# Chapter 1 Introduction and background

People with intellectual and other types of developmental disabilities (IDD), such as autistic spectrum conditions, can face challenges with both adaptive behaviour and general intellectual functioning. As long-stay hospitals for those with IDD were closed from the 1980s onwards, forensic mental health services specifically for those with IDD have increased. These hospital services cater either for people with IDD who have committed criminal acts and are detained under Part III of the Mental Health Act,<sup>1</sup> or for those under civil sections whose violent or other challenging behaviour cannot be safely managed in the community. Typically, such patients present with a high level of clinical complexity.

A mapping exercise in 2012<sup>2</sup> indicated that in the combined NHS and independent sector there were 2393 high, medium and low secure funded beds in 10 strategic health authorities in England, with further access to locked and unlocked forensic rehabilitation beds. In addition, a number of specialised community IDD services provide for those with a forensic history. Inpatient secure beds in particular are high cost, and this is therefore a sector that involves high levels of health expenditure (estimated in 2012 to be £350–430M a year).

Within what we shall henceforth label as the forensic intellectual and developmental disabilities (FIDD) sector, it is notable that there is limited cross-service collation of empirical information on treatment and service outcomes, which in turn limits the ability to measure service effectiveness.<sup>2</sup> This area of service delivery is particularly pertinent in the context of the Department of Health's Transforming Care programme,<sup>3</sup> which aims to move care for people with IDD – including those who have offended – from hospitals to the community with the ultimate aim of closing many hospital beds (indeed, occupied secure beds have already reduced compared with 2012 figures).<sup>3</sup> There is a need to be able to accurately describe the outcomes nationally both for people treated within FIDD services and, in the longer term, those who are discharged from FIDD services, but this is not currently undertaken in a systematic way.

The Clinical Research Group in FIDD funded by the then Mental Health Research Network branch of the National Institute for Health Research (NIHR), which included the authors, considered the research needs in this area in 2013. As a starting point, we know that there are no agreed areas of outcome domains or routine measures employed in this sector. No systematic review has been published in relation to outcomes or outcome measures from such services and, therefore, little is known about the commonality of outcome measures across services. Neither outcome measures developed for mainstream mental health services (explored in a systematic review by Gilbody *et al.*)<sup>4</sup> nor those developed for mainstream forensic services (identified in a systematic review by Fitzpatrick *et al.*,<sup>5</sup> are necessarily appropriate for FIDD services. The current project therefore aimed to begin to address this existing gap in knowledge by conducting a preliminary study suitable for informing a future primary research project on FIDD service outcomes.

## Research group

The research steering group comprised academic and clinical experts in the FIDD field, a systematic review expert, a methodology expert and an 'expert by experience' (see *Acknowledgements*). The group met for two full-day meetings during the project.

## Aims of the research

The aims of the research were:

1. To systematically review empirical studies that relate to short- and long-term outcomes from FIDD services including secure, forensic rehabilitation and community forensic services. The review aimed

- specifically to synthesise the range of outcome domains studied and to identify specific measures that have been employed.
2. To consult a group of FIDD patients/carers regarding the outcome domains of most relevance to these groups of stakeholders.
  3. To obtain consensus on appropriate outcome domains and measures for FIDD services based on the expert opinions of professionals and providers.
  4. To synthesise the findings and develop a framework of outcomes in order to inform a large-scale primary research project.

## **Overview of design**

The preliminary study needed to examine the evidence from a range of perspectives and, therefore, three stages were planned. The first study was a systematic review and evidence synthesis of outcome domains and measures as found within the FIDD literature. The second was a consultation exercise with FIDD patients and carers and the third was a clinician and expert modified Delphi consensus exercise. The planned timescale of the research was short: May 2015 to February 2016.

## **This report**

This report is divided into four further substantive chapters. *Chapter 2* summarises the systematic review and evidence synthesis, which addresses aim 1. *Chapter 3* describes the patient and carer consultation, which addresses aim 2. *Chapter 4* describes the Delphi study of clinicians, which addresses aim 3. *Chapter 5* synthesises the studies and describes the direction for further research and evaluation of services.

## **Note on terminology**

In this report 'outcome domains' or 'subdomains' refer to specific areas of outcome. These are distinct from outcome 'measurements/indices', which refer to how these domains are indexed or measured. Thus, for example, within the patient experience superordinate domain, patient satisfaction would be an outcome subdomain and a patient satisfaction rating scale assessment would be an outcome measure for that domain, whereas the percentage of patients 'very satisfied' might be a specific indicator.

# Chapter 2 Stage 1: systematic literature review of outcome domains researched in forensic intellectual/developmental disabilities services

## Research questions/objectives of the review

The objective of the current review was to identify quantitative studies that examined either short- or long-term outcomes from FIDD service-level treatment. The review sought specifically to identify and categorise the range and type of outcome domains examined in the literature as well as the outcome measures and indicators used to measure these domains. The findings from the studies themselves were therefore not of direct relevance to this review.

## Review methods

### Search strategy

The search strategy aimed to identify studies from a range of sources. Reports were included regardless of publication status. Searches were conducted on 1 June 2015. The electronic databases searched were MEDLINE, PsycINFO, EMBASE, Allied and Complementary Medicine, Health Management Information Consortium, the British Nursing Index and the Cumulative Index to Nursing and Allied Health Literature from inception to May 2015. A broad search strategy was employed, with intellectual disability terms being combined with forensic terms. For terms specific to intellectual and developmental disabilities, search terms employed were based on those used for a previous Cochrane review.<sup>6</sup> Forensic and offender terms search terms were adapted from a large review for the Department of Health by Duggan *et al.*<sup>7</sup> The full search terms including 'explode' terms, keywords and text words are in Appendix 1.

In addition, the grey literature ([opengrey.eu](http://opengrey.eu)) was searched online on the same date using the same keywords. References of suitable studies were examined to identify additional relevant articles. Finally, expert members of the project steering group were consulted in order to identify any key references not retrieved by the search strategy or in press or unpublished articles and service evaluation reports.

### Inclusion and exclusion criteria

#### Scope

The search related to studies worldwide written in any language. When studies were written in languages other than English, translations were obtained. The search was limited to studies from 1980 onwards, as provision for FIDD patients was either sparse or non-existent prior to this date.

#### Types of studies

We included any study design, including those at the lower levels of the hierarchy of evidence. Owing to the likely paucity of randomised or controlled studies, the search strategy was designed to capture two primary types of quantitative study:

1. Cohort studies with follow-up. These are studies that report outcomes of intervention at the whole service level from one point in treatment to another (e.g. from admission to present; from admission to discharge) or post discharge, with any length of follow-up.

2. Cross-sectional studies. We also aimed to include cross-sectional studies that reported outcomes either at a single point or for a defined period of time during FIDD service intervention. While the primary goal of such studies is not necessarily to evaluate outcomes from services, studies were included provided they presented data on potential measures or indicators of outcomes. For example, the purpose of the study might be prediction of risk, but outcome data pertaining to 'incidents of aggression' in the service may be presented: this was considered to be a potential outcome domain/indicator. This type of study was included within the review for two reasons. First, the aim of the review was to identify outcome domains and outcome indicators appropriate for measuring the effectiveness of FIDD services; the cross-sectional studies provided important information in this regard. Second, FIDD services often provide long-term treatment and, therefore, what happens to patients during treatment and prior to discharge can also be considered an indicator of effectiveness.

### **Participants and settings**

The search strategy sought to capture studies that included data on adults (aged  $\geq 18$  years) with intellectual and/or developmental disabilities who had current or previous access to specialist FIDD services. Both male and female samples, with a range of offending histories, were included. High-, medium- and low secure inpatient forensic health services, forensic rehabilitation services (service categories 1 and 4 as defined by the Royal College of Psychiatrists, 2013<sup>2</sup>) and community FIDD services were all included. Studies of prison and youth offending services were not considered for this review, as services specifically for people with IDD tend not to exist in these settings. Studies of mixed FIDD and non-FIDD populations were included provided the FIDD data were identifiable.

### **Intervention**

The intervention of interest was at the whole service level, that is, the effect that being treated in the service as a whole has on patients' outcomes and how that is measured. Studies that evaluated the effects of specific interventions (e.g. sex offender treatment) were excluded. The outcome domains and indicators/measures of such domains were of primary interest, as opposed to the findings of the studies.

### **Outcomes**

There are as yet no agreed outcome measures for use in FIDD services, which was a primary driver for the review. Therefore, inclusive criteria regarding the types of outcomes of interest were adopted. Outcomes were nevertheless broadly conceptualised as falling into the following three overarching domains, reflecting the three key quality areas outlined by the Department of Health in the first NHS Outcomes Framework.<sup>8</sup>

### **Effectiveness**

This domain was conceptualised to include any factors that related to the impact of FIDD service-level treatment on the patient, in both the long and short term.

### **Patient safety**

In the current context, the patient safety domain was conceptualised to include outcomes related to avoidable harm such as the extent of restrictive practices in services, and patient injury or death.

### **Patient experience**

This domain was conceptualised to include any factors that related to the patient experience of care, such as patient quality of life, patient satisfaction, etc.

Inclusion and exclusion criteria are summarised in *Appendix 2*.

### **Study selection**

After removal of duplicates, titles and abstracts of articles were screened against the inclusion criteria. In order to avoid false negatives, all studies that could not be shown to be outside the inclusion criteria were initially included. The full texts of the remaining articles were screened against inclusion and exclusion

criteria in order to identify appropriate articles for the review. Two reviewers (CM and NG) independently rated each article using a screening tool developed for the purposes of the study (see *Appendix 3*). Any disagreements were resolved by a third reviewer (MF).

### Data extraction

The articles were subjected to data extraction using a structured form (see *Appendix 3*). Details regarding the sample, design, service type, methods, outcome domains and related measures were obtained, coded and reported. The information is presented in the form of data summary tables (see *Tables 1–6*).

### Hierarchy of evidence

On the advice of the systematic review consultant on the project, it was decided a priori that no structured quality assessment was to be undertaken. This decision was taken for a number of reasons. First, as noted above, the aim of the current review was to identify the range and type of outcome domains and related measures that have been used in FIDD services research. Its purpose was not to critique the methodology of the studies or to draw robust conclusions about the findings. Furthermore, it was recognised the studies were likely to be heterogeneous and there would be no single quality assessment tool that would be appropriate for included studies. Quality or risk-of-bias ratings would not have influenced the inclusion of studies as, arguably, a poor-quality study could nevertheless have presented outcome domains of interest for the review. We therefore decided simply to code study design using a hierarchy of evidence. The York Centre for Reviews and Dissemination hierarchy of evidence was considered, but it was found that included studies were difficult to classify using that hierarchy. Instead, study designs were coded with reference to the simpler hierarchy of evidence employed by Greenhalgh<sup>9</sup> as follows:

1. systematic reviews and meta-analyses
2. randomised controlled trials with definitive results
3. randomised controlled trials with non-definitive results
4. cohort studies (follow participants over time)
5. case-control studies (matched control group)
6. cross-sectional surveys
7. case reports or case series.

### Analysis

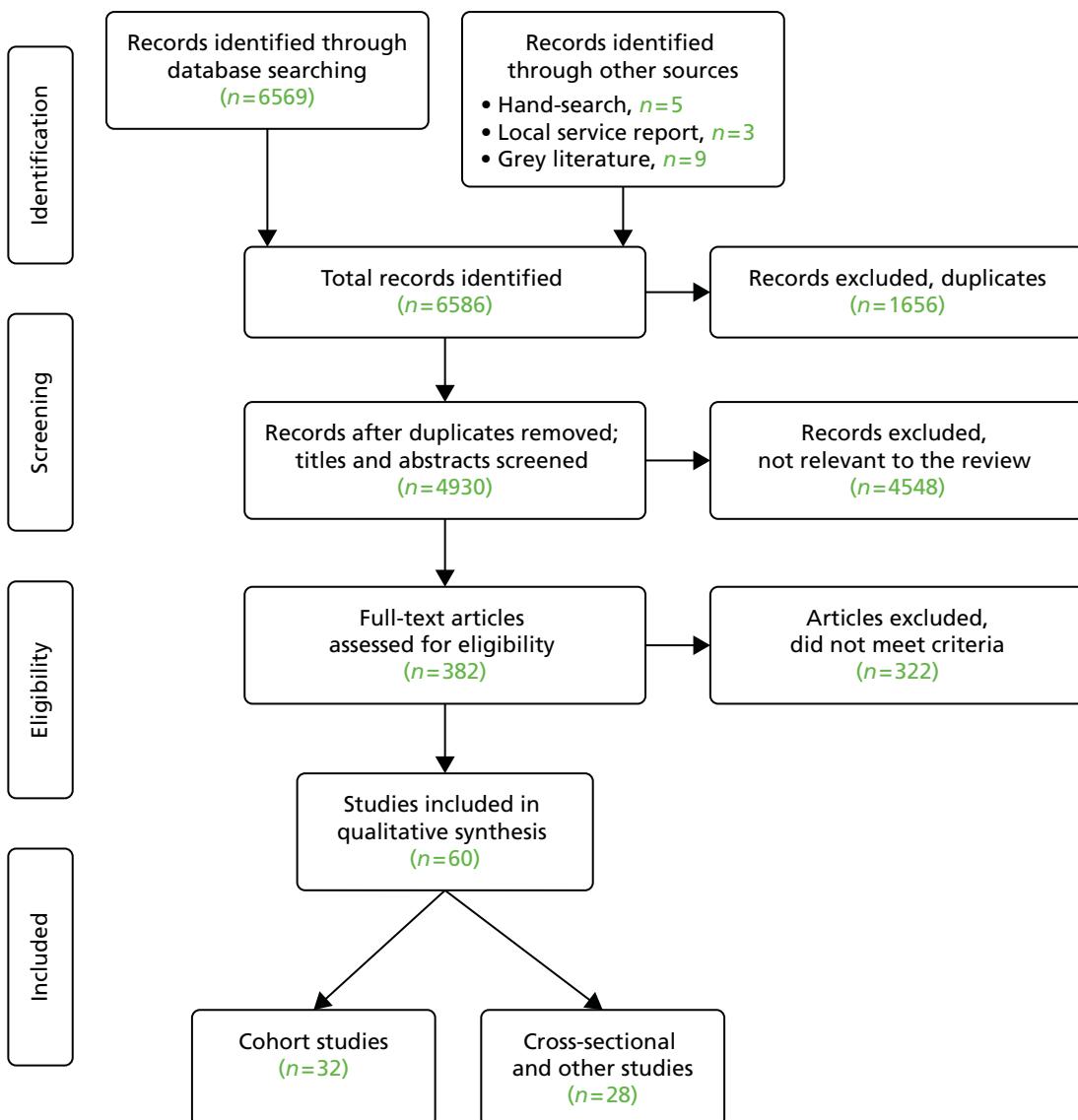
The broad inclusion criteria applied for the review meant that the included studies represented a wide variety of services, study designs, outcome domains and measures. A method of content analysis<sup>10</sup> was used to synthesise the outcome domain types and related measures and indicators. This approach involved an iterative process of identifying categories to capture the outcome measures reported in the studies. Using the aforementioned three core outcome domains (effectiveness, patient safety and patient experience) as an a priori superordinate framework, the outcome measures from all included studies were listed. A process of refining and grouping similar subdomains together was then undertaken. This led to the construction of a ‘framework’ to describe the outcome domains that have been studied in the literature. The number of studies falling into each final outcome domain was also quantified.

## Results of the review

*Figure 1* shows the flow chart of the study selection process and details number of studies identified at each stage. A list of the 322 excluded studies is available on request from the authors.

Sixty studies met the inclusion criteria; of these, 28 were cohort outcome studies (type 4) as described (with follow-up from 1 to 20 years) and a further 32 were other study designs. These were primarily cross-sectional studies (type 6) which reported service-level outcome data at one time point, with a small number of case-control and case series designs. Some of these included studies reported overlapping samples. Only two studies were from outside the UK. Most studies were of predominantly male or

## STAGE 1: SYSTEMATIC LITERATURE REVIEW



**FIGURE 1** Flow chart of study selection process.

male-only samples; only two studies reported exclusively on female FIDD samples. Of the 60 included studies, 83% were conducted in a variety of secure inpatient settings, and 17% in community settings. The numbers of participants ranged from 10 to 1891.

Tables 1–6 display the included studies. As the cohort studies are the more ‘prototypical’ studies of outcome, these are tabled separately. Thus, Tables 1–3 show the cohort studies and Tables 4–6 show cross-sectional and other studies in each of the three superordinate domains of effectiveness, safety and patient experience, respectively. Tables 1 and 2 cover the effectiveness studies, Tables 3 and 4 cover safety studies and Tables 5 and 6 cover patient experience studies. Studies can therefore appear in more than one table. The tables present data for each study: study setting; design and the hierarchy of evidence code (1–7; see p. 16); subdomains of outcomes examined in the study, and the indicators or measures used to measure these subdomains.

The content analysis of outcomes identified a number of subdomains within each superordinate outcome domain. The final framework of outcome domains is described in Table 7 along with the number of studies that reported outcomes in these domains.

**TABLE 1** Summary of studies presenting data on the effectiveness outcome domain (cohort studies)

Study and setting	Design (hierarchy of evidence code, p. 18)	n	Outcome subdomain	Measure/indicator
<b>Alexander et al. (2006)<sup>11</sup></b>	Retrospective cohort study (4)	64	Treatment response	Level of CPA support, MHA status and CGIS
Medium secure	Follow-up: up to 13 years		Discharge outcome/pathway	Level security/type of placement at discharge
			Readmissions	% of patients readmitted to the same unit
			Relapse in MH	% of patients who experienced a relapse in MH symptoms
			Reoffending	Number of patients formally reconvicted, cautioned or who had police contact
			Offender-like behaviour	Behaviour that could be classed as an offence but did not lead to police contact
<b>Alexander et al. (2010)<sup>12</sup></b>	Retrospective cohort study (4)	138	Length of stay	Mean and median number of days
Medium secure	Discharged patients		Discharge outcome	% of positive (move to a lower level of security) or negative (move to higher level of security) discharges
	Follow-up: 6 years		Discharge pathway	Level security/type of placement at discharge
<b>Alexander et al. (2011)<sup>13</sup></b>	Retrospective cohort study (4)	138	Length of stay	Mean and median number of days
Medium secure	Follow-up: 6 years		Discharge outcome	% discharged successfully (to a lower level of security) or not (to same/higher level of security)
<b>Alexander et al. (2015)<sup>14</sup></b>	Retrospective cohort study (4) (arson vs. no arson)	30	Length of stay	Discharged patients only; mean and median days
Medium secure	Follow-up: 6 years		Discharge pathway	% of discharged patients who moved to either a lower or same/higher level of security
<b>Alexander et al. (2012)<sup>15</sup></b>	Retrospective cohort study (4)	145	Length of stay	Median number of days and age on discharge
Medium secure	Discharged patient (personality disorder vs. intellectual disabilities)		Clinical symptoms	PCL-SV pre-treatment scores (clinician rated)
			Risk assessment	HCR-20 pre-treatment scores (clinician rated)
	Follow-up: up to 9 years		Reoffending	Reconvictions at 1-, 2- and 5-year follow-up. Categorised as serious/violent offending (as defined by Home Office)
			Time to reoffend	The difference between discharge date and reconviction date for subsequent offence (median)

continued

**TABLE 1** Summary of studies presenting data on the effectiveness outcome domain (cohort studies) (*continued*)

Study and setting	Design (hierarchy of evidence code, p. 18)	n	Outcome subdomain	Measure/indicator
<b>Ayres and Roy (2009)<sup>16</sup></b> <i>Community</i>	Case series (7)	26	Cost	Average cost saving per patient (based on hourly rate of support) and for the service over 3 years
	Follow-up: up to 3 years		Level of support	Hours per annum providing both direct/indirect support
<b>Barron et al. (2004)<sup>17</sup></b> <i>Community</i>	Cohort study (4)	61	Clinical symptoms	ABC and Mini PAS-ADD (clinician rated)
	Follow-up: 9.5 months average		Treatment response	Categorised treatment use and % with history of service use
			Reoffending	Number of patients who reoffended; mean number of offences per patient
			Offender-like behaviour	Telephone call with carers regarding police contact
<b>Benton and Roy (2008)<sup>18</sup></b> <i>Community</i>	Cohort study (4)	113	Reoffending	Number of patients arrested and reconvicted and cases dropped
	Follow-up: up to 3 years		Discharge pathway	Level security/type of placement at discharge
			Discharge outcome	% of referrals discharged
			Prevention of inpatient admissions	Number of patients whose inpatient admission was prevented by community treatment
<b>Butwell et al. (2000)<sup>19</sup></b> <i>High secure</i>	Cohort study (4)	Up to 278	Length of stay	Median and mean years, calculated per episode
	Follow-up: 10 years		Discharge pathway	Level security/type of placement at discharge
<b>Day (1988)<sup>20</sup></b> <i>Medium secure</i>	Cohort study (4)	20	Length of stay	Mean number of months
	Follow-up: 3 years		Treatment response	Categorised as either good (settled and co-operative), fair (continuing lesser problems) or poor (severe problems)
			Discharge pathway	% of patients discharged to rehabilitation villa, community or hostel
			Discharge outcome	Level of adjustment at follow-up, based on personal knowledge, hospital notes and liaison with involved agencies
			Readmission	% of patients readmitted to the same unit
			Reoffending	Number who reoffended or returned to prison
<b>Dickens et al. (2010)<sup>21</sup></b> <i>Medium and low secure</i>	Cohort study (4)	48	Length of stay	Mean number of days
	Follow-up: 15 months		Clinical symptoms	HoNOS: change between baseline and final rating. Quartile points used to allow for different lengths of stay (clinician rated)

**TABLE 1** Summary of studies presenting data on the effectiveness outcome domain (cohort studies) (*continued*)

Study and setting	Design (hierarchy of evidence code, p. 18)	n	Outcome subdomain	Measure/indicator
<b>Fitzgerald et al. (2011)<sup>22</sup></b>	Retrospective cohort study (4)	145	Reoffending	Home Office records; % of patients with general and violent offences
Medium secure	Follow-up: 2 years		Risk assessment	OGRS
<b>Gray et al. (2007)<sup>23</sup></b>	Retrospective cohort study (4)	145	Reoffending	Home Office records; % of patients with both general and violent offences
Medium secure	Follow-up: 2 years		Risk assessment	HCR-20/VRAG/PCL-SV scores (rated once)
<b>Halstead et al. (2001)<sup>24</sup></b>	Cohort study (4)	35	Length of stay	Mean and median months
Medium secure	Discharged patients		Treatment outcome	Rated as either good (risks reduced, safe for discharge), some (progress made in some areas, risk remains), none (no change) or poor (worse than admission)
	Follow-up: up to 13 years		Discharge outcome	% of patients discharged
			Discharge pathway	Level security/type of placement at discharge and follow-up
			Relapse in MH	Recurrence of symptoms of illness or challenging behaviour
			Readmissions	% of patients readmitted to hospital
			Offender-like behaviour	Behaviour that could be interpreted as an offence
			Reoffending	Number of patients reconvicted
<b>Lindsay et al. (2002)<sup>25</sup></b>	Cohort study (4)	62	Offender-like behaviour	% of patients suspected of reoffending
Community	Follow-up: 13 years		Reoffending	% of patients with clear evidence of reoffending
<b>Lindsay et al. (2004)<sup>26</sup></b>	Cohort study (4)	184	Reoffending	Number of patients with clear evidence of reoffending
Community	Follow-up: 7 years		Harm reduction	Decrease in the number of incidents 2 years before referral vs. incident data at follow-up
<b>Lindsay et al. (2004)<sup>27</sup></b>	Case series (7)	18	Reoffending	Number of patients with clear evidence of reoffending
Community	Follow-up: 3 years			
<i>Females only</i>				
<b>Lindsay et al. (2006)<sup>28</sup></b>	Cohort study (4)	247	Reoffending	Number of patients with clear evidence of reoffending
Community	Follow-up: 12 years		Harm reduction	Decrease in the number of incidents 2 years before referral vs. incident data at follow-up

continued

**TABLE 1** Summary of studies presenting data on the effectiveness outcome domain (cohort studies) (*continued*)

Study and setting	Design (hierarchy of evidence code, p. 18)	n	Outcome subdomain	Measure/indicator
<b>Lindsay et al. (2013)<sup>29</sup></b>	Cohort study (4)	309	Reoffending	Number of patients with clear evidence of reoffending
Community	Follow-up: up to 20 years		Harm reduction	Standardised service incident report data; number of offences committed in the 2 years before referral vs. follow-up reoffending data
<b>Lindsay et al. (2010)<sup>30</sup></b>	Cohort study (4)	197	Discharge pathway	Number of patients discharged and level security/type of placement at discharge at the 1-year and 2-year follow-ups
Mixed services	Follow-up: 2 years			
<b>Linhorst et al. (2003)<sup>31</sup></b>	Cohort study (4)	252	Reoffending	Local law agency data and arrests frequencies used
USA community service	Follow-up: 6 months		Treatment response/engagement	Number of patients who completed treatment
<b>Marks (E Marks, University of Birmingham, 2011, personal communication)</b>	Retrospective cohort study (4)	28	Reoffending	% of patients who reoffended (even if this did not lead to police contact), determined by interview with current care team
	Follow-up: 4 years		Length of stay	Mean and median number of years
			Discharge pathway	% of patients in high, medium, low and community services
<b>Morrissey and Taylor (2014)<sup>32</sup></b>	Prospective cohort study (4)	13	Clinical symptoms	YSQ (patient rated), IPDE Screen and PCL-SV (clinician rated): change in mean scores
High secure	Follow-up: 2 years		Discharge outcome	Number of patients remaining in treatment, discharged to a medium secure ward or transferred to another high secure ward
<b>Morrissey et al. (2014)<sup>33</sup></b>	Cohort study (4)	70	Risk assessment	HCR-20: change in mean scores over 5 years
High secure	Follow-up: 5 years			
<b>Morrissey et al. (2007)<sup>34</sup></b>	Prospective cohort study (4)	73	Discharge outcome	% of patients who made positive (move to a lower level of security) or negative (the same level of security) progress
High secure	Follow-up: 2 years		Risk assessment	HCR-20
			Clinical symptoms	PCL-R (clinician rated)
<b>Morrissey et al. (2015)<sup>35</sup></b>	Retrospective cohort study (4)	68	Length of stay	Median number of years
High secure	1. in-treatment cohort 2. admission cohort	24	Incidents	Frequency per year in the first 4 years of treatment using hospital incident records. Mean number of violent incidents per patient/year
	Follow-up: up to 6 years		Clinical symptoms	EPS-BRS (clinician rated) and EPS-SRS (patient rated)
			Discharge pathway	Level security/type of placement at discharge
			Discharge outcome	% of patients who moved to a lower level of security
			Readmission	Number of returns from trial leave

**TABLE 1** Summary of studies presenting data on the effectiveness outcome domain (cohort studies) (continued)

Study and setting	Design (hierarchy of evidence code, p. 18)	n	Outcome subdomain	Measure/indicator
<b>Palucka et al. (2012)<sup>36</sup></b>	Retrospective cohort study (4)	20	Length of stay	Median number of days
<i>Canadian inpatient unit</i>	Follow-up: up to 9 years		Discharge outcome	Number of patients discharged
			Discharge pathway	Level security/type of placement at discharge
			Reoffending	Any criminal justice involvement (even if charges were not pressed)
<b>Reed et al. (2004)<sup>37</sup></b>	Retrospective cohort study (4)	45	Length of stay	Mean number of weeks
<i>Low secure</i>	Follow-up: up to 14 years		Discharge pathway	Level security/type of placement at discharge
			Discharge outcome	Positive (discharged to a level of lower security) or negative (discharged to a level of higher security) outcome
			Incidents	Collected from hospital incident records. The number of incidents at baseline (weeks 6–10 of stay) was compared with the number at the end of stay (last 4 weeks of treatment). Frequency (total number of incidents per month) was adjusted for length of stay. Change in incidents calculated per person per week
<b>Xenitidis et al. (1999)<sup>38</sup></b>	Retrospective cohort study (4)	64	Length of stay	Mean months of hospital stay
<i>Low secure</i>	Follow-up: up to 11 years		Discharge pathway	Level security/type of placement at discharge
			Discharge outcome	Good (discharged to community) or bad (not placed in a community setting) outcome
			Incidents	Collected from hospital incident records. The number of incidents at baseline (weeks 6–10 of stay) was compared with the number at the end of stay (last 4 weeks of treatment). Frequency (total number of incidents per month) was adjusted for length of stay

ABC, Aberrant Behaviour Checklist; BRS, Behaviour Rating Scale; CGIS, Clinical Global Impressions Scale; CPA, Care Programme Approach; EPS-BRS, Emotional Problem Scale Behaviour Rating Scale, EPS-SRS, Emotional Problem Scale Self-Report Inventory; HCR-20, Historical, Clinical Risk 20; HoNOS, Health of the Nation Outcome Scales; IPDE, International Personality Disorder Examination; MH, mental health; MHA, Mental Health Act; Mini PAS-ADD, Mini Psychiatric Assessment Schedules for Adults with Developmental Disabilities; PCL-SV, Psychopathy Checklist Screening Version; OGRS, Offender Group Recoviction Scale; PCL-R, Psychopathy Checklist Revised; VRAG, Violence Risk Appraisal Guide; YSQ, Young Schema Questionnaire.

#### Note

The sample in Alexander et al.<sup>12,13</sup> and Esan<sup>39</sup> overlaps. The sample in Fitzgerald et al.<sup>22</sup> overlaps with that of Gray et al.<sup>23</sup> The sample in Lindsay et al.<sup>25</sup> overlaps with that of Lindsay et al.<sup>26,28,29</sup> The sample in Reed et al.<sup>37</sup> overlaps with that of Xenitidis et al.<sup>38</sup>

**TABLE 2** Summary of studies presenting data on the effectiveness outcome domain (cross-sectional studies)

Study and setting	Design	n	Outcome subdomain	Measure/indicator
<b>Ajmal (2008)<sup>40</sup></b> <i>High secure</i>	Cross-sectional (6)	79	Clinical symptoms	GSI and RSES (patient rated)
<b>Beer et al. (2005)<sup>41</sup></b> <i>Low secure</i>	Cross-sectional (6)	59	Placement appropriateness	% of patients requiring a less secure placement
<b>Beer et al. (2005)<sup>42</sup></b> <i>Low secure</i>	Cross-sectional (6)	68	Clinical symptoms	SBS (clinician rated)
<b>Chaplin et al. (2015)<sup>43</sup></b> <i>Low secure</i>	Cross-sectional (6)	22	Length of stay	Mean number of months
			Placement appropriateness	% of patients requiring less secure care
			Clinical symptoms	Main reason for delayed discharge
				HoNOS-secure (clinician rated)
<b>Chilvers and Thomas (2011)<sup>44</sup></b> <i>Medium secure</i>	Cross-sectional (6) (Males vs. females)	77	Risk assessment	HCR-20 median scores
<b>Crossland et al. (2005)<sup>45</sup></b> <i>High, medium and low secure</i>	Cross-sectional (6)	60	Incidents	Average per patient at 3-monthly intervals. Coded for severity using the MOAS
			Length of stay	Median number of incidents
				Median number of days
<b>Dickens et al. (2013)<sup>46</sup></b> <i>Medium and low secure</i>	Cross-sectional (6) 16-month period	68	Clinical symptoms	NAS-PI scores (patient rated)
			Length of stay	Median number of months
<b>Esan et al. (2015)<sup>39</sup></b> <i>Medium and low secure</i>	Cross-sectional (6) (Autism vs. non autism)	114	Incidents	Severity rated: near miss, minor, moderate, high or very high
			Length of stay	Incidents/total bed-days × 100.
				Average number of incidents per 100 occupied bed-days; violent/aggressive incidents and total incidents
<b>Fitzgerald et al. (2013)<sup>47</sup></b> <i>Medium and low secure</i>	Cross-sectional (6)	25	Discharge outcome	Mean and median months for both discharged and in-treatment patients
			Level of supervision/discharge pathway	Number of patients with a good (move to a lower level of security) or poor (move to a higher level of security) outcome
				Number of patients who were informal, under a MHA Section/guardianship or supervised discharge
			Risk assessment	HCR-20 and VRAG
			Incidents	Number of patients involved in an incident in 6 months

**TABLE 2** Summary of studies presenting data on the effectiveness outcome domain (cross-sectional studies) (*continued*)

Study and setting	Design	n	Outcome subdomain	Measure/indicator
<b>Hall et al. (2014)<sup>48</sup></b> <i>Medium and low secure</i>	Cross-sectional (6)	136	Treatment needs	Clinician ratings
			Security need	Reference group ratings of appropriate security level
			Delayed discharge	Number of patients no longer requiring current security level, main obstacle to progress
			Length of stay	Maximum and average years per level of security
			Incidents	Number of patients with incident in the past 6 months
<b>Hogue et al. (2007)<sup>49</sup></b> <i>High, medium, low and community</i>	Cross-sectional (6)	228	Clinical symptoms	EPS-BRS (clinician rated)
<b>Johnson (2012)<sup>50</sup></b> <i>Medium and low secure</i>	Cross-sectional (6)	44	Clinical symptoms	RSES and EBS (patient rated)
			Length of stay	Mean number of months
<b>Kellet et al. (2003)<sup>51</sup></b> <i>High secure</i>	Cross-sectional (6)	45	Clinical symptoms	BSI (clinical cases) (patient rated)
<b>Lindsay et al. (2004)<sup>52</sup></b> <i>Community</i>	Cross-sectional (6)	52	Offender-like behaviour	% of patients suspected of reoffending
			Reoffending	% of patients with 'clear evidence' of reoffending
<b>Lindsay et al. (2008)<sup>53</sup></b> <i>High, medium and low secure</i>	Cross-sectional (6)	212	Risk assessment	HCR-20, VRAG, Static-99, SDRS, RM-2000
			Clinical symptoms	EPS-BRS (clinician rated)
<b>Lindsay et al. (2010)<sup>54</sup></b> <i>High, medium, low and community</i>	Cross-sectional (6)	197	Risk assessment	VRAG and Static-99
<b>Lofthouse et al. (2014)<sup>55</sup></b> <i>Rehabilitation, acute admission and residential home</i>	Cross-sectional (6)	64	Length of stay	Mean number of years
			Risk assessment	CuRV
			Incidents	Aggression defined as acts of physical violence, aggression, force to hurt or damage staff, peers or environment. Included verbal abuse. Two researchers rated each incident as aggression present or aggression absent. Number of patients who were aggressive in month 1 vs. month 5

continued

**TABLE 2** Summary of studies presenting data on the effectiveness outcome domain (cross-sectional studies) (continued)

Study and setting	Design	n	Outcome subdomain	Measure/indicator
<b>Mansell et al. (2010)<sup>56</sup></b>	Cross-sectional (6)  Medium and low secure	1891  NHS vs. private provider units	Delayed discharge  Incidents	% of patients who had completed treatment but did not have any plans to leave the service in the next month  Average frequency with which another patient was hurt by a patient or staff member (per patient over a 6-month period)
<b>McMillan et al. (2004)<sup>57</sup></b>	Cross-sectional (6)  Medium secure	124  6-month period	Risk assessment  Incidents	MDT ratings per patient on risk of physical violence (scale of 0–8) and number of times patient had been violent in 6 months prior to risk assessment  Author coded each description of incident from computerised record, based on explicit criteria and guidelines
<b>Morrissey et al. (2007)<sup>58</sup></b>	Cross-sectional (6)  High secure	60  12-month period	Incidents  Risk assessment	Coded as either interpersonal physical aggression or verbal aggression/aggression to property. Rated as low, medium or high risk of harm  Number of patients involved in an aggressive incident
<b>O'Shea et al. (2015)<sup>59</sup></b>	Cross-sectional (6)  Medium, low and rehabilitation	109	Risk assessment  Incidents	HCR-20  PCL-R and EPS-BRS (clinician rated)  HCR-20  Hospital records in 3-month period following risk assessment for aggression and self-harm. Coded using Overt Aggression Scale. Rated on severity (1–4)  Number of patients involved in any incident
<b>Perera et al. (2009)<sup>60</sup></b>	Cross-sectional (6)  Medium and low secure	388	Length of stay  Delayed discharge	Median number of years and % of patients who had stayed longer than 5 years  % of patients assessed as requiring a less secure placement
<b>Thomas et al. (2004)<sup>61</sup></b>	Cross-sectional (6)  High secure	102	Length of stay  Delayed discharge	Mean and median years  Percentage of patients assessed as requiring a less secure placement and main reason for this
			Treatment needs	SDTN scale completed by key worker and RC  CANFOR-Short and CANDID-Short. Average number of needs and unmet needs

**TABLE 2** Summary of studies presenting data on the effectiveness outcome domain (cross-sectional studies) (continued)

Study and setting	Design	n	Outcome subdomain	Measure/indicator
<b>Uppal and McMurran (2009)<sup>62</sup></b>	Cross-sectional (6)  High secure	Up to 396  15-month period of incidents (IDD sample included)	Incidents	Hospital computerised reporting system. Coded as per the Department of Health:  <ul style="list-style-type: none"> <li>• Category A: major incidents (e.g. abscond, hostage taking)</li> <li>• Category B: serious incidents (e.g. serious assault involving a weapon, attempted suicide)</li> <li>• Category C: untoward incidents (e.g. attempted abscond, assault with weapon)</li> <li>• Category D: all other incidents (minor assault and verbal abuse)</li> </ul>
				Most frequent location and time of incident. Percentage of incidents which were violent and which were self-harm. Average monthly figure generated

BSI, Brief Symptom Inventory; CANDID, Camberwell assessment of need for adults; CANFOR, Camberwell assessment of need – forensic version; CuRV, Current Risk of Violence; EBS, Evaluative Beliefs Scale; EPS-BRS, Emotional Problem Scale Behaviour Rating Scale; GSI, Global Symptom Inventory; HCR-20, Historical, Clinical Risk 20; HoNOS, Health of the Nation Outcome Scales; MDT, multidisciplinary team; MHA, Mental Health Act; MOAS; Modified Overt Aggression Scale; NAS-PI, Novaco Anger Scale – Provocation Inventory; PCL-R, Psychopathy Checklist Revised; RM-2000, Risk Matrix 2000; RSES, Rosenberg Self-Esteem Scale; SBS, Social Behavioural Schedule; SDRS, Short Dynamic Risk Scale; SDTN, Security, Dependency and Treatment Needs Scale; VRAG, Violence Risk Appraisal Guide.

**TABLE 3** Summary of studies presenting data on the patient safety outcome domain (cohort studies)

Study and setting	Design	n	Outcome subdomain	Measure/indicator
<b>Alexander et al. (2015)<sup>14</sup></b>	Retrospective cohort study (4)  Medium and low secure	30  Follow-up: 6 years	Seclusion, restraint and intensive observations	Mean number of episodes per patient/month
<b>Alexander et al. (2010)<sup>12</sup></b>	Retrospective cohort study (4)  Medium secure	138  Follow-up: 6 years	Seclusion, restraint and intensive observations	Mean number of episodes per patient/month (adjusted for length of stay)
<b>Alexander et al. (2011)<sup>13</sup></b>	Retrospective cohort study (4)  Medium secure	138  Follow-up: 4 years	Seclusion, restraint and intensive observations	Mean and median episodes per patient/month
<b>Ayres and Roy (2009)<sup>16</sup></b>	Case series (7)  Community	26  Follow-up: up to 3 years	Medication	Case study: reduction in frequency of use of PRN medication
<b>Butwell et al. (2000)<sup>19</sup></b>	Cohort study (4)  High secure	Up to 278  Follow-up: 10 years  (IDD subsample)	Death	Frequency of episodes (number and % of all patients)

continued

**TABLE 3** Summary of studies presenting data on the patient safety outcome domain (cohort studies) (continued)

Study and setting	Design	n	Outcome subdomain	Measure/indicator
<b>Morrissey and Taylor (2014)<sup>32</sup></b>	Cohort study (4)	13	Seclusion	Hours per patient for every 6 months of treatment over 2 years
<i>High secure</i>	Follow-up: 2 years			
<b>Reed et al. (2004)<sup>37</sup></b>	Retrospective cohort study (4)	45	Seclusion, restraint and relocation	Episodes at baseline (weeks 6–10 of treatment) were compared with end of stay (last 4 weeks of treatment)
<i>Low secure</i>	Follow-up: up to 14 years			Mean monthly rates calculated to control for length of stay
<b>Xenitidis et al. (1999)<sup>38</sup></b>	Retrospective cohort study (4)	64	Seclusion	Episodes at baseline (week 6–10 of treatment) compared with end of stay (last 4 weeks of treatment)
<i>Low secure</i>	Follow-up: up to 11 years			
PRN, pro re nata.				

**TABLE 4** Summary of studies presenting data on the patient safety outcome domain (cross-sectional studies)

Study and setting	Design	n	Outcome subdomain	Measure/indicator
<b>Esan et al. (2015)<sup>39</sup></b>	Cross-sectional (6)	114	Medication	PRN usage: mean number of episodes (total frequency divided by total number of months of stay to provide an average monthly figure)
<i>Medium and low secure</i>	(ASD vs. non-ASD)		Restraint, seclusion and intensive observations	
<b>Mansell et al. (2010)<sup>56</sup></b>	Cross-sectional (6)	1891	Medication	PRN usage: average number of episodes
<i>Medium and low secure</i>	6-month period		Seclusion, restraint, locked areas	Average number of episodes
			Access to health care	% of units who reported a delay in patients accessing primary (nurse/dentist) health care
<b>Mason (1996)<sup>63</sup></b>	Cross-sectional (6)	36	Seclusion	Number of patients secluded; average number of seclusion episodes per patient/year; reason for seclusion and distress-related behaviours after seclusion
<i>High secure</i>	12-month period			
ASD, autistic spectrum disorder; PRN, pro re nata.				

**TABLE 5** Summary of studies presenting data on the patient experience outcome domain (cohort studies)

Study and setting	Design	n	Outcome subdomain	Measure/indicator
<b>Fish and Lobley (2001)<sup>64</sup></b>	Cohort study (4)	20	Quality of life	QoLS: change from pre to post move
<i>Community</i>	Follow-up: 1 year			
<b>Long et al. (2014)<sup>65</sup></b>	Cohort study (4)	10	Milieu	EssenCes change from pre to post move
<i>Low secure</i>	Follow-up: 3 months		Satisfaction	Inpatient satisfaction questionnaire: change from pre to post move
<i>Female only</i>				

**TABLE 5** Summary of studies presenting data on the patient experience outcome domain (cohort studies) (continued)

Study and setting	Design	n	Outcome subdomain	Measure/indicator
<b>Marks (E Marks personal communication)</b>	Retrospective cohort study (4)	28	Quality of life	QoLS scores during treatment
<i>Medium secure</i>	Follow-up: 4 years			
<b>Trout (S Trout, National High Secure Learning Disability Service, Rampton Hospital, 2011, personal communication)</b>	Cohort study (4)	44	Quality of life	PWI scores: change from pre to post move
<i>High secure</i>	Follow-up: up to 2 years		Satisfaction	Service specific evaluation questionnaire using a visual Likert scale via interview

EssenCES, Essen Climate Evaluation Scale; PWI, Personal Wellbeing Index; QoLS, Quality of Life Scale.

**TABLE 6** Summary of studies presenting data on the patient experience outcome domain (cross-sectional studies)

Study and setting	Design	n	Outcome subdomain	Measure/indicator
<b>Langdon et al. (2006)<sup>66</sup></b>	Cross-sectional (6)	18	Milieu	CIES read aloud to patients, scores during treatment
<i>Medium and low secure</i>				
<b>Mansell et al. (2010)<sup>56</sup></b>	Cross-sectional (6)	1189	Service satisfaction/complaints	Number of patient generated complaints per unit over 6-month period, recorded via standardised survey
<i>Medium and low secure</i>	6-month period		Involvement	Number of patients with an up-to-date and accessible copy of their own care plan and number of visitors for each patient per unit
<b>Steptoe et al. (2006)<sup>67</sup></b>	Cross-sectional (6)	28	Quality of life	SOS and LEC scores during treatment
<i>Community</i>				
<b>Willetts et al. (2014)<sup>68</sup></b>	Cross-sectional (6)	45	Milieu	EssenCES scores during treatment
<i>Medium and low secure</i>				

CIES, Correctional Institutions Environment Scale; EssenCes, Essen Climate Evaluation Scale; LEC, Life Experience Checklist; SOS, Significant Others Scale.

## Discussion: analysis of outcome domains and measures

### Domain 1: effectiveness

A total of 53 studies (29 of which were cohort studies) presented data on at least one outcome that measured the effectiveness of FIDD services. Twelve outcome subdomains were identified as a result of content analysis.

**TABLE 7** Framework of outcome domains and subdomains (stage 1)

<b>Effectiveness</b>	<b>Number of studies</b>
Discharge outcome/direction of care pathway	16
Delayed discharge/current placement appropriateness	6
Length of hospital stay	22
Readmission (i.e. readmitted to the same setting)	4
Clinical symptom severity/treatment needs (clinician rated)	16
Clinical symptom severity/treatment needs (patient rated)	6
Treatment response	5
Reoffending (i.e. charges/reconvictions)	18
'Offending-like' behaviour (which did not result in charges)	5
Risk assessment measures	12
Incidents (violence/self-harm)	14
Security need	3
Other	3
Total	130
<b>Patient safety</b>	
Restrictive practices (restraint/relocation/intensive observations)	12
Restrictive practices (seclusion/segregation)	9
Medication (i.e. PRN usage/exceeding BNF prescribing limits)	3
Physical health	1
Premature death/suicide	1
Total	26
<b>Patient experience</b>	
Quality of life	4
Therapeutic milieu	3
Patient experience: involvement	1
Patient experience: satisfaction/complaints	3
Total	11

BNF, British National Formulary; PRN, pro re nata.

Studies can be included in multiple domains.

### Length of stay

An indirect measure of effectiveness, length of hospital or service stay was one of the most commonly reported outcome domains (22 studies; see Tables 1 and 2). Length of stay was usually reported for discharged patients, although it is well known that this is not a comprehensive measure because of the failure to reflect those patients who have never been discharged. Length of stay can therefore also be described at a fixed point in time for a current hospital population, and this was reported in many of the cross-sectional studies (e.g. Beer *et al.*,<sup>42</sup> Crossland *et al.*,<sup>45</sup> Esan *et al.*,<sup>39</sup> Hall *et al.*,<sup>48</sup> Johnson *et al.*,<sup>50</sup> Lofthouse *et al.*,<sup>55</sup> Perera *et al.*<sup>60</sup> and Thomas *et al.*<sup>61</sup>). Inevitably, these data are less easy to interpret unless an admission cohort is used (as in Morrissey *et al.*<sup>35</sup>) and the numbers in that cohort who are still in treatment and who have exceeded the mean length of stay of discharged patients are reported. Length of stay was variously reported in days,<sup>12,13</sup> weeks,<sup>37</sup> months<sup>45</sup> or years.<sup>19,35</sup> This was calculated as either a mean or a median measure. Reported average lengths of hospital stay ranged from 9 years in high secure conditions<sup>35</sup> to 55 weeks in low secure conditions.<sup>38</sup>

Readmission to the same or another hospital setting was clearly recorded in only four cohort studies<sup>11,20,24,35</sup> in which there was follow-up. Only one study<sup>11</sup> provided more detail, with the mean number of bed-days for those readmissions being supplied. Studies usually described length of stay in the hospital under study rather than total hospital stay (including in other settings) since first admission.

### **Discharge outcome/direction of care pathway/delayed discharge**

A total of 16 cohort studies (see *Tables 1* and *2*) examined discharge outcome or direction of care pathway in terms of the level of security of the receiving service or type of community placement (e.g. independent living, supported living, residential accommodation). This was frequently coded as either a 'successful' (move to a lower level of security) or 'unsuccessful' (move within the same or to a higher level of security) discharge outcome.<sup>12,13,24,34,37,38</sup> Follow-up periods for post-discharge pathway outcome ranged from 2 years<sup>23</sup> to 13 years<sup>11</sup> for former inpatients and 20 years for a forensic community service.<sup>29</sup>

A further six studies reported on current placement appropriateness or delayed discharge. For example, this was reported in terms of the percentage of patients assessed as requiring a less secure placement.<sup>38,42,48,60,61</sup> Similarly, Mansell *et al.*,<sup>56</sup> in their large cross-sectional study of 1891 patients in medium and low secure units, reported more specifically on the percentage of patients who had 'completed treatment but did not have any plans to leave the service in the next month'. Reasons for delayed discharge were recorded in around half of these studies.

In summary, discharge outcome was generally reported in relation to a fixed point in time at either discharge from hospital or later follow-up. It is not unusual, however, for some patients to demonstrate initial progress on discharge followed by subsequent regression, placement moves and potential readmission. It was notable that few of the studies described these more complex pathways, which can be common in this population, although there was some attempt by Lindsay *et al.*,<sup>30</sup> in their study of pathways to secure care, to take this into account.

### **Clinical symptom or severity ratings/treatment needs**

Sixteen studies (see *Tables 1* and *2*) reported on potential outcome domains relating to clinical symptoms or treatment needs using clinician ratings [often known as clinician-rated outcome measures (CROMs)] and six studies used patient ratings of their symptoms/needs [often reported as patient-rated outcome measures (PROMs)] (see *Tables 1* and *2*). However, of these, only two cohort studies actually reported change over time in such symptoms during treatment in a service, through repeated measurement on the same patients (i.e. treated clinical symptom 'change' as an outcome measure). Thus, Dickens *et al.*<sup>21</sup> reported on change in 48 patients on the Health of the Nation Outcome Scales (HoNOS-secure) (security scales and clinical scales) during 15 months of treatment in medium- and low secure units, finding significant reduction in severity of symptoms over time. Morrissey *et al.*<sup>35</sup> reported on change over 2–3 years on the Emotional Problem Scales (EPS)<sup>69</sup> as a result of treatment of 68 men in a high secure setting. Both the EPS Behaviour Rating Scale (a CROM) and the EPS Self-Report Inventory, a patient-rated outcome measure (a PROM) designed for an intellectual disabilities population, were employed. It is notable that Morrissey *et al.* is the only included cohort study that has reported on patient-rated symptom change over time as a result of intervention at the service level.

Relatively few additional included studies reported on patient-rated clinical outcome measures at a fixed time point. Those studies that did so used a range of measures, which included the Young Schema Questionnaire,<sup>32</sup> Brief Symptoms Inventory,<sup>51</sup> Rosenberg Self-esteem Scale,<sup>40</sup> Novaco Anger Scale<sup>44</sup> and the Evaluative Beliefs Scale.<sup>50</sup> Of these, only the Novaco Anger Scale was reported to be appropriately adapted for IDD respondents.

Most studies reported CROMs at a fixed point in time. These measures included HoNOS-secure,<sup>21,42</sup> EPS,<sup>49,53,58</sup> Psychopathy Checklist Revised (PCL-R) and Psychopathy Checklist Screening Version (PCL-SV),<sup>23,32,34,53,58</sup> International Personality Disorder Evaluation Screen,<sup>32</sup> Clinical Global Impressions Scale,<sup>11</sup> Aberrant Behaviour Checklist,<sup>17</sup> Mini Psychiatric Assessment Schedules for Adults with Developmental Disabilities<sup>17</sup> and the Social

Behavioural Schedule.<sup>41</sup> Treatment needs were assessed in one study using the Camberwell Assessment of Needs-Forensic Short Version or the equivalent intellectual disability version, Camberwell Assessment of Needs for Adults with Developmental and Intellectual Disabilities, and a measure called the Security, Dependency and Treatment Needs Scale.<sup>61</sup>

### Treatment response

Only five studies (see *Tables 1* and *2*) reported on outcomes that were categorised as global 'treatment response'. Most of these used qualitative ratings. For example, Day<sup>20</sup> coded responses as 'good' (settled and co-operative), 'fair' (no serious difficulties but continuing lesser problems) or 'poor' (severe behaviour problems). Similarly, Halstead *et al.*<sup>24</sup> coded responses as 'good' (risks reduced, safe for discharge), 'some' (progress made in some areas, risk remains), 'none' (no change) or 'poor' (worse than admission). Only one study<sup>11</sup> used a psychometric measure to measure this outcome: the Clinical Global Impressions Scale. Finally, Barron *et al.*<sup>17</sup> recorded whether patients had 'current', 'previous' or 'no' access to particular treatments, such as psychological therapies using standardised definitions, although they did not report the extent to which patients had engaged in these interventions.

### Reoffending/'offending-like' behaviour/incidents

In total, 18 studies (see *Tables 1* and *2*) examined formal reoffending (i.e. formal charges and convictions) on follow-up; most commonly these were retrospective discharge cohort studies utilising official records such as police or Ministry of Justice conviction data. The most comprehensive of these reported the percentage of individuals with serious/violent convictions at 1-, 2- and 5-year follow-up and also examined time to reoffend.<sup>15</sup> Barron *et al.*<sup>17</sup> reported the number of offences committed as opposed to a dichotomy. Gray *et al.*<sup>23</sup> and Fitzgerald *et al.*<sup>22</sup> (using the same data set) reported on whether a conviction occurred within 2 years of discharge and was violent or non-violent. A community forensic service study provided more detailed data on the number of participants arrested or reconvicted or cases dropped.<sup>18</sup> One of the few non-UK studies reported 'any criminal justice involvement', which included arrest without charge following discharge from an Australian hospital unit, arrest data being likely to be a better reflection of offending behaviour than conviction.<sup>36</sup> Only one linked series of studies attempted to address change in offending behaviour as a result of treatment, comparing the number of formal incidents in the 2 years before referral to a community FIDDs service with those in a follow-up period.<sup>26,28,29</sup>

Five studies examined and attempted to measure 'offending-like' behaviour in the community that had not been officially recorded.<sup>11,13,24,25,31</sup> This is arguably an important outcome given the frequency with which people with IDD are not progressed through the criminal justice system.<sup>70</sup> These outcome data were generally based on carer report and were described with various definitions, including 'behaviour which could be interpreted as an offence' or 'suspected offending.' Alexander *et al.*<sup>11</sup> differentiated between quasi-offending behaviour that led to police contact (but may not have ended with charges) and that which did not. This study also attempted to identify seriousness and persistency of relapse, differentiating between 'regular, ongoing offending-like behaviour' and 'phasic' or 'occasional' relapse. Because of some reliance on carer report in this domain and the retrospective nature of follow-up, the information reported is likely to have poor reliability.

A proxy measure of maintenance of problem behaviour is the occurrence of violent incidents during inpatient treatment, reported in 14 studies. In general, this was recorded from electronic hospital records, and standardised for length of stay (e.g. reported as average incidents per 100 bed-days). Some studies coded severity or used a rating scale such as the Overt Aggression Scale.<sup>43,46</sup> Other reports differentiated between physical violence and verbal aggression/threats.<sup>58</sup> However, measures of change in incident frequency over the course of treatment in FIDD services were reported in only a small number of studies. Xenitidis *et al.*<sup>38</sup> and Reed *et al.*<sup>37</sup> calculated change between a 4-week period at baseline and a 4-week period at the end of stay. Morrissey *et al.*<sup>35</sup> calculated the number of violent incidents in the first year of high secure intervention for each patient and compared that with the number in each subsequent year in treatment. A series of community studies<sup>26,28,29</sup> compared the number of incidents 2 years before referral to the service with the number of incidents during intervention and follow-up. No studies reported change in the level of seriousness of incidents over time as an outcome measure.

Although not a type of offending, self-harm is a form of challenging behaviour that can lead to detention and, therefore, may be a target for behaviour change. Self-harm incidents as a service-level outcome indicator were reported in only two studies.<sup>59,62</sup> Neither of these studies reported change over time in self-harm as a result of intervention at the service level.

### Risk assessment

A further potential proxy measure of behaviour change as a result of service intervention is the reduction in scores on dynamic structured risk assessment ratings over time. Twelve included studies reported data from such measures gathered in FIDD services. Most commonly, services used the structured clinical judgement tool the Historical, Clinical Risk 20 (HCR-20).<sup>23,33,34,43,53,54,58,59</sup> Other studies reported on static risk assessment measures such as the Violence Risk Appraisal Guide (VRAG),<sup>23,53,54</sup> Risk Matrix 2000,<sup>53</sup> Offender Group Recoviction Scale<sup>22</sup> and Static-99,<sup>53</sup> although these would not have utility as outcome measures as they would not be expected to change. The vast majority of these studies reported only cross-sectional data and not within-patient change in such measures over time. Indeed, only one study reported change in scores over 5 years on the clinical risk items of the HCR-20 as an outcome indicator in a FIDD service,<sup>33</sup> despite the large number of services that are required to collect routine data on this measure.

In addition to risk assessment tools, patients were assessed for their specific security needs in three studies. This was examined as part of the security items in the HoNOS-secure ratings (e.g. Morrissey *et al.*<sup>32</sup> and Dickens *et al.*<sup>21</sup>) Thomas *et al.*<sup>61</sup> used the informant-rated Security, Dependency and Treatment Needs Scale which indicated the type of environment required in terms of level of security.

### Domain 2: patient safety

A total of 11 studies (see *Tables 3* and *4*) reported on some aspect of patient safety, which were classified into five subdomains. Two of these subdomains related to interventions that could be perceived as 'restrictive practices'<sup>71</sup>: the first included physical restraint or periods of increased intensive nursing observations, and the second included seclusion/segregation in response to risky or 'challenging' behaviour. These were reported either in hours or in terms of the number of episodes. In parallel with recording numbers of violent incidents, mean rates per patient/month or year of treatment were typically reported, in order to control for length of stay. These outcomes could arguably also be construed as an effectiveness indicator if change in rates over time in treatment is measured. Only two studies<sup>37,38</sup> reported on such change in seclusion rates in a cohort with follow-up. Only one study reported on the reason for seclusion, and on distress-related behaviours after seclusion, that is, the outcome measured had a specific emphasis on patient safety.<sup>63</sup>

Premature death was reported in only one study, which differentiated between natural causes and suicide.<sup>19</sup> Physical health outcomes or access to services was reported by one study only.<sup>56</sup> This is surprising given the higher incidence of premature death and physical health-care problems in forensic psychiatric populations.<sup>72</sup> Use of pro re nata (PRN) medication, which could also be perceived as a restrictive practice, was monitored as an outcome in three studies. The number of episodes of PRN use was recorded in two secure service studies<sup>39,56</sup> and via a case study demonstrating a reduction in use in a community patient.<sup>16</sup>

### Domain 3: patient experience

A total of 11 of the included studies reported on four patient experience-related subdomains (see *Tables 5* and *6*). Four studies addressed quality of life using a number of rating scales. These included the 10-item Personal Wellbeing Index,<sup>73</sup> the only measure specifically designed for people with intellectual disabilities (S Trout, personal communication). Other measures employed were the Quality of Life Questionnaire,<sup>74</sup> used among both a medium secure (E Marks, personal communication) and female community sample,<sup>64</sup> and the Life Experience Checklist<sup>67</sup> in a community sample. When change over time in reported quality of life was examined, this was in relation to a change of environment, that is, a service development. There were no community studies of quality-of-life maintenance over time in discharged FIDD patients.

Three studies addressed satisfaction with services. These related to a specific service development or move, in a community setting,<sup>64</sup> a low secure unit<sup>65</sup> and a high secure unit (S Trout, personal communication). A range of satisfaction instruments that were service specific and tailored for use with people with IDD were used. Only one study evaluated the number of patient complaints as a service outcome measure.<sup>56</sup>

A fourth subdomain of patient experience identified from the literature was the therapeutic environment, reported in three studies using either the Essen Climate Evaluation Scale<sup>75</sup> (EssenCES), which was rated by both patients and staff, or the Correctional Institutions Environment Scale.<sup>76</sup> There was no indication that these measures had been specifically adapted for IDD patients in any of the studies. These were typically cross-sectional studies<sup>66,68</sup> or evaluated a specific change in environment after 3 months.<sup>65</sup> No identified studies reported long-term change over time in milieu quality, although it is feasible that such measures could be used as a repeated cross-sectional service outcome indicator. Only one community study reported on the level of support that patients received.<sup>16</sup>

Finally, patient involvement as an outcome indicator was reported in only one study: Mansell *et al.*,<sup>56</sup> in their large study, reported the number of patients with an up-to-date and accessible copy of their care plan. This is one of the outcomes addressed by the current Transforming Care programme care and treatment reviews.<sup>3</sup>

## Conclusions

This systematic review identified 60 studies that either examined substantive outcomes or reported on potential outcome measures from generic treatment in forensic services for people with intellectual and developmental disabilities. Predictably there were no case-control studies that compared FIDD services with some other type of intervention. Around half of the included studies were cohort outcome studies that followed up patients either during or after a period of treatment in such services. The remainder were primarily cross-sectional studies that reported on potential outcome domains at a fixed point in time (although these studies did not necessarily have the explicit aim of evaluating outcomes). Few studies acknowledged the complex outcome pathways common in this clinical population and, interestingly, none mentioned prison as an outcome destination, although this is likely to have been the outcome for some patients.

A broad range of effectiveness outcome domains and measures was identified from the literature, although it is evident that such domains are measured in different ways, with few consistently applied measures other than in the realm of risk assessment. Even apparently categorical data relating to violent incidents or offending were measured differently across studies. Significantly, very few studies examined 'change' in patients over their time in treatment using repeated measures of effectiveness, for example change in incident frequency or rated risk, clinical symptoms or progression in achievement of treatment goals. This no doubt reflects the challenges in collecting and analysing longitudinal patient linked data, although it could also relate to the explicit exclusion of studies that evaluated specific treatment interventions as opposed to interventions at the service level. It was notable that that very few of the included service-level outcome studies describe details of the different components of the treatment that patients have received, an issue which needs to be addressed in future research. Finally, there was a relative paucity of reports on patient-rated outcome measures, particularly those relating to treatment progress, recovery and patient experience, and to the quality of community life following discharge from FIDD services.

It is acknowledged that the published research evidence is driven by a range of factors, including the availability of data in services, and does not necessarily reflect the outcomes domains of importance to clinicians, patients and carers. This is addressed in stages 2 and 3 of the project.

# Chapter 3 Stage 2: patient and carer consultation groups

## Aim

The purpose of consulting patients and carers was to incorporate their views into the framework of outcome domains appropriate for future research on outcomes from FIDD services. It was considered important to obtain perspectives from these different groups, as their views may differ to those of experts in relation to which outcomes are important and relevant.

## Consultation methodology

As the consultation related to future research it was construed as patient and carer involvement by the Nottinghamshire Healthcare Foundation Trust Research Governance Group and was therefore deemed not to require a further ethical opinion.

Three patient consultation groups were conducted in May 2015 in the context of routine patient meetings. Patients were provided with information sheets (see *Appendix 4*), gave written consent to participate and had the opportunity to withdraw at any point. Two groups were conducted in a high-security institution (a NHS service) and one in medium-/low-security institution (an independent sector service). These groups included three female patients, one transgender patient and 11 male patients. Seven were from low- and medium-security institutions and eight were from high-security institutions.

Carer consultation took place in June 2015. Four carers were recruited from one hospital's carer group and consulted as a group, and two carers were separately recruited and interviewed as a pair. The relatives of those consulted were in three different units at the time of consultation. Of these six carers, one was male and five were female. Carers were provided with an information sheet, and gave written consent to participate, and were provided with travel expenses and costs. Relatives of all carers were in low- or medium secure FIDD care, and one was in a bespoke service within a hospital (these carers expressed a willingness to be identifiable).

All consultation meetings were led by two members of the research team, including in all but one patient group the project lead. An independent advocate was included in the high secure meetings.

A semistructured topic guide was employed to facilitate discussion. This focused on the outcomes that patients and carers would consider important from a period in hospital in the short, medium and longer term (see *Appendix 5*). The discussion groups ranged in duration from 1 to 1.5 hours, and relative focus on each area depended on the response of the group. Detailed notes or full transcription of consultation meetings was undertaken depending on security restrictions. Interview data were broadly content analysed by the lead researcher according to the three main domains (effectiveness, safety and patient and carer experience), with the initial framework from the stage 1 systematic review used as a starting point (see *Table 7*). Although a formal qualitative data analysis approach was not undertaken, comments and discussion points were listed under the domain and subdomains already identified. Where appropriate, new subthemes were identified from the consultation data.

## Findings

This section of the report summarises the content from the consultation groups, under the three superordinate domain headings. Not all of the original subdomains were commented on in detail in the interviews, and subdomains are therefore combined in the discussion. However, a number of additional outcome subdomains which had not included in the initial framework were identified. *Box 1* therefore represents the framework from stage 1 amended to incorporate additional themes generated from patients and carers.

Quotations are included for illustrative purposes. Quotations are referenced only as patient or carer, as linking quotations can lead to potential identification of individuals. In some instances the gender reference in the quotation has been changed in order to preserve anonymity.

### **BOX 1 Framework of outcome domains following stage 2**

#### **Effectiveness**

- Discharge outcome/direction of care pathway.
- Delayed discharge/current placement appropriateness.
- Length of hospital stay.
- Readmission (i.e. readmitted to the same setting within a specified period).
- Clinical symptom severity/treatment needs: patient/carer rated.
- Clinical symptom severity/treatment needs: clinician rated.
- Treatment response/recovery measures: clinician rated.
- Treatment response/recovery measures: patient/care rated.*
- Reoffending (formal charges/convictions).
- 'Offending-like' behaviour (no formal charges).
- Incidents (violence/self-harm) in service.
- Risk assessment measures.
- Security need (i.e. physical/procedural/escort/leave).
- Adaptive functioning.*
- Engagement in treatment/services.*

**BOX 1 Framework of outcome domains following stage 2 (*continued*)****Patient safety**

Premature death/suicide.

Physical health.

Medication (i.e. PRN usage/exceeding BNF limits/side effects/patient experience).

Restrictive practices (restraint).

Restrictive practices (seclusion/segregation).

*Victimisation/safeguarding/feeling safe.*

**Patient and carer experience**

Patient experience: involvement.

Patient experience: satisfaction/complaints.

Quality of life: clinician rated.

Quality of life: patient rated.

Therapeutic climate.

Access to work/meaningful activity (when appropriate).

*Carer experience: communication.*

*Carer experience: involvement.*

*Closeness to 'home' area.*

*Level of support/involvement in community (when appropriate).*

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BNF, British National Formulary.

Italic = new subdomain following stage 2.

**Effectiveness domain****Length of hospital stay/readmission/pathways**

Length of stay in hospital was identified as an important outcome variable by patients, and a number were frustrated by what they saw as extended time in treatment. However, some of the carers we consulted did not believe a shorter length of stay was necessarily a positive outcome, with fear being expressed by several carer participants regarding premature discharge.

*It has to be the right length of stay for that person.*

*Carer*

*The fact that the service wasn't there in the community to start with will make his hospital stay longer. So we can't just look at the hospital stay – it has to be the overall picture.*

Carer

*Longer length of stay is not worse – I don't want him pushed out too soon before he is ready.*

Carer

*Just because they are out of hospital does not mean they are better.*

Carer

Patients in high secure hospital naturally saw a medium secure unit as an appropriate pathway and those in medium and low secure units were looking to community discharge as an indication of progress and positive outcome. Moving up levels of security or readmission to hospital were perceived by patients as negative (albeit sometimes necessary) outcomes. A number of carers noted that frequent changes in hospital or living environment were destabilising and, therefore, constituted a negative outcome.

#### Placement appropriateness/meeting clinical needs

Placement appropriateness was reported to be very important to carers and patients, with delayed discharge in a progressive direction being a particular concern (e.g. owing to appropriate unit or accommodation availability). Indeed, placement appropriateness in terms of meeting the relative's specific needs was considered more important to many carers than distance from home:

*I would much rather he be further away for 8/9 months [and get the right treatment] than be nearer for 18 months.*

Carer

*It is very important for people to go to a place where they are happy. Not just because it is closer to family.*

Patient

Carers and patients reported that it was important that specific clinical needs were met by appropriate care and treatment in order that progress could be achieved. This included both the model of care (e.g. whether or not it was appropriate for a patient with autism), psychological treatment (e.g. specific treatment programmes) and appropriate levels of meaningful activity being available.

*You have to be able to do your offending treatment. I need an arson group and there isn't one starting.*

Patient

*[I need] Psychology . . . the Moving On group . . . they make you a pack so you know what to do.*

Patient

*Other hospitals let patients get real jobs. I want this to happen in this hospital.*

Patient

*It's boring here there isn't enough to do.*

Patient

Carers were very clear that their priority for their relatives was an appropriate individualised pathway through hospital care, as opposed to rigid programmes which had to be adhered to regardless of the individual's needs:

*I know from meetings there seemed to be a lot 'he needed to do this this and this' – we can't do this before we do this' . . . almost setting him up to fail. This is how it works whether you engage or not, whether it's relevant or not and therefore if it's not relevant and they're not going to engage it's a fail before they've started.*

Carer

*It has got to be individually led.*

Carer

*He needed an individualised package of support which was right for him.*

Carer

Finally, when it came to moving into the community from hospital, carers in particular were concerned that an 'appropriate' placement constituted adequate levels of support to keep people safe:

*Coming home with me or if he was left in a little flat, he wouldn't take his medication – he'd go on the drugs and then he would kill somebody or somebody else would kill him.*

Carer

*I worry about the fact that the service wasn't there in the community . . . there's so little support in the community.*

Carer

### Clinical symptomology/behaviour change

Participants were asked what changes would indicate an improvement in their own or their relatives' health. Both patients and carers recognised that there would be indicators of clinical improvement which would be reflective of therapeutic change and progress. These included a reduction in the frequency of incidents of violence and self-harm, as well as perhaps less tangible clinical change.

*A reduction in incidents. Reduction in restraints, using diversion more frequently, pre-empting incidents.*

Carer

*[I will know there is change when] he joined in to the real world again because at the moment he is living in . . . his world.*

Carer

Clinical progress was typically described by patients as 'communicating better' or 'getting angry less often':

*Before I wouldn't engage in conversation and now I've learnt different strategies so I don't kick off so often.*

Patient

*A better attitude towards staff and not taking your bad day out on a staff member.*

Patient

Patients also seemed to recognise the difficulty of identifying and measuring progress, often identifying more qualitative changes:

*I know what it feels like when I am better . . . I don't put my head in my hands as much anymore.*

Patient

*Some people 'toe the line' and pretend they're more agreeable but they aren't really on the inside.*

Patient

There was a feeling expressed by some carers that patients do not really understand what they have to achieve to make progress and that there was too much emphasis on 'incidents' in determining progress:

*Every time he does something [the goal] gets further ahead. And [name] goes why the hell am I doing this; what's the point of doing it if I am always going to get failed.*

Carer

Furthermore, some carers felt that they were often in a better position than staff to identify nuanced changes in their relative's functioning, and that this should be included in assessments of change.

*[they should get] feedback from families . . . because the families know the person . . . we know our family members best and if the family members flag up a concern or alternatively they say they can see an improvement that should be as critical as the professional.*

Carer

A number of patients emphasised that an increase in positive behaviour should be as reflective of change as a decrease in negative behaviour. For example, using low-stimulation areas as opposed to being nursed in seclusion should be seen as positive progress even if incidents were ongoing.

Finally, one carer made the important point that an increase in violent incidents per se need not necessarily be construed as a bad outcome:

*It's important to recognise that even if someone has a bad patch that isn't a bad outcome – the outcome is how it's managed. If the staff can see them through the bad patch it's not necessarily a bad outcome if the service manages it appropriately.*

Carer

Similarly, a higher level of observation/staffing was not necessarily seen as negative, if that was necessary for an individual:

*I wouldn't want a reduction [in staffing] because it keeps him happy and safe.*

Carer

Finally, a number of participants felt that a concentration on the number of incidents was simplistic and that there should instead be an emphasis on a more nuanced analysis of them:

*There is too much focus on incidents and not on understanding them . . . taking it back to the beginning of the process as opposed to just dealing with what the consequences are.*

Carer

*I get fed up with hearing about the same thing . . . you should just take it off the record and put it somewhere.*

Patient

Finally, both patients and carers also spontaneously mentioned engagement with services and therapies as an important positive indicator of clinical progress:

*I know when I am doing well. I talk to staff more . . . I'm doing my groups.*

Patient

*Talking to staff having a good relationship with others. I'm a peer facilitator now.*

Patient

*. . . at the moment he doesn't engage in any therapies . . . if it doesn't meet his criteria he's not going to bother to engage.*

Carer

### **Reoffending on discharge**

Both patients and carers mentioned staying 'safe' on discharge as being a positive outcome. Although they talked little about reoffending specifically as an outcome domain which required measurement, a number

of the carers considered themselves at potential risk as victims and their own safety was evidently important to them:

*If they did say take him home now I'd be too scared.*

Carer

Reduction in risk assessment ratings was not mentioned spontaneously, perhaps because patients and carers are less aware of these methodologies than practitioners. Nonetheless, both patients and carers clearly understood the concept of risk reduction and saw it as important.

### Adaptive functioning

Patients were very enthusiastic about hospital treatment aimed at improving their life skills such as budgeting and work skills, but some were also fearful that hospital had caused them to lose skills they had previously had:

*Since we've been locked up here we don't get a chance to do that sort of thing [budget] so you don't know what to do when you get it [money].*

Patient

*I haven't been given skills like cooking and cleaning ...*

Patient

*Other hospitals let patients get real jobs. I want this to happen in this hospital.*

Patient

A carer also mentioned loss of adaptive skills as a negative outcome of hospital care:

*He used to be able to do those things. He's lost those skills since he's been here.*

Carer

### Patient safety domain

#### Restrictive practices: seclusion/restraint

The patients we consulted, particularly those in high security, mentioned a reduction in incidents of seclusion as being a relevant outcome indicator. One pair of parents also mentioned reduction in staff assaults and restraint as a pertinent outcome domain for their son.

Once again some interviewees resisted the focus on negative events and considered that positive examples of behaviour, and seclusion avoidance in previously high-risk situations, should be monitored.

#### Restrictive practices: medication

Although some carers identified medication as having led to improvements, medication reduction was seen to be a relevant goal for some patients and some parents:

*A reduction in PRN and other medication [is a goal].*

Carer

*If he could come off olanzapine, that would be progress.*

Carer

It seemed to be important to patients and carers that patients' experiences of medication were considered, which was an area that had not been considered in the literature. Indeed, a number of patients and carers

expressed concerns about perceived overmedication and concurrent side effects and viewed this as a restrictive practice:

*He's never been on this amount of medication . . . he's so heavily dosed up . . . If he's been medicated to manage his behaviour he's not learned how to manage his behaviour.*

Carer

*Can you be careful about medication and patients being overdosed?*

Patient

### **Victimisation**

Patients evidently had a need to feel 'safe' in hospital. A number of patients spontaneously mentioned victimisation by other patients as something they had experienced in hospital and, therefore, a reduction in such incidents was considered desirable as a service-level outcome goal.

### **Patient (and carer) experience domain**

#### **Quality of life**

Both patients and their carers reported that in hospital and beyond discharge from hospital the quality of life they would achieve was of vital importance to them. In summary, their hopes and priorities were much the same as most people: a home, jobs, relationships and community involvement, but with an emphasis on quality support.

#### **Appropriate accommodation and level of support in the long term**

The carers we consulted emphasised that discharge from hospital 'is not the end of the story' for them and, therefore, monitoring of long-term outcomes post discharge is important:

*[T]here's a whole long chapter after that . . . and it has to be looked at in the context of that and not well we've been discharged from hospital so somebody else – some other authority – can take them over so we've got rid of them and that is that file closed.*

Carer

In terms of appropriate homes post discharge from hospital, carers expressed a preference for high-quality accommodation that meets their relative's individual needs in terms of support. They were also clear that inadequate support would lead to increased risk:

*He would be in accommodation that was specifically designed for people with autism, but he had sufficient support with people who actually understood his condition and were able to spot the warning signs so I didn't have to keep flagging them up. And that they would possibly move him into independent living . . . [with] ongoing regular support and checking up which is the low level preventative support [which] stops things happening; you haven't got a measured outcome of what you stopped because you've only got somebody's idea of what could have happened.*

Carer

*He needs an individual planned package with sufficient staff with appropriate training. They need to put a tender out for staff who want to work with him.*

Carer

*[Name] will need 24-hour support for the rest of his life.*

For carers in particular, confidence in the long-term nature and consistency of the support received by their relative was vital:

*[S]he went from being escorted everywhere to be put in a flat, see you later. That went . . . rapid downhill in less than a year.*

Carer

*I hope it's for life.*

Carer

*We don't want the care to be changing, we want to know that in future years the care will be the same . . . we need to know he's going to be cared for the rest of his life.*

Carer

*I just don't have much faith in if I wasn't around I don't think he's be very well looked after.*

Carer

It was also clear that for some carers back-up of an inpatient service in times of crisis was also important:

*[In crisis] for him to go back in a secure unit because he's a danger when he does deteriorate.*

Carer

The patients we consulted typically mentioned wanting 'supported living'-type arrangements, although some also wanted to live independently, with professional help they could call on should they have the need:

*[S]omewhere with staff to help you if you need it.*

Patient

*I would like to see a doctor when I need to – I don't want a long wait as things could escalate.*

Patient

### Meaningful activity

For patients, having paid employment was identified very strongly as an important 'quality-of-life' factor in the community. Similarly, hospital patients described wanting more meaningful activity and to experience less boredom:

*Best thing was my kitchen cleaner job in my other hospital.*

Patient

*Having a job keeps you out of trouble.*

Patient

*I want to do paid work not voluntary.*

Patient

*A job to keep you busy . . . I had a job in Waitrose before in the shop helping people get their shopping.*

Patient

*I want to work as a tree surgeon.*

Patient

*I used to work outside in a charity shop. That was very good.*

Patient

Carers naturally also wanted their relatives to be able to achieve goals within their abilities:

*We want him achieving something we are proud of like any parent.*

Carer

### **Relationships and community involvement**

Relationships with others, including family, friends and pets, and the development of intimate relationships were considered important, particularly by the patients themselves:

*I'd like a girlfriend. I need to do more confidence work in psychology.*

Patient

*I want to have a pet for a companion, to look after it. When you come home from work and the dog is at the door waiting for you.*

Patient

Community involvement and the development of social networks on discharge were spontaneously mentioned as important outcomes by both patient and carer groups. Examples given in addition to paid work were church groups, educational programmes and using community facilities.

### **Carer satisfaction: communication and involvement**

The carers we consulted generally had clear views on whether or not they were satisfied with the service their relative was in, and this level of satisfaction evidently was an important outcome for them. Satisfaction clearly led to carers experiencing less worry and concern in relation to their relatives' well-being:

*The hospital are fantastic, the staff are fantastic and at long last somebody is realising the amount of problems he has got and that is one of the problems I had before.*

Carer

*It is a dream come true. The place where he is now, it's lovely . . . it's a dream for places like that to be about.*

Carer

*They have got the service he needs right now. It's as good as it gets for me right now.*

Carer

The ultimate goal for carers was to feel secure in the knowledge that their relative would be cared for appropriately:

*Not having to be worried about him, if we died tomorrow services would be there for him and do what was best for him without thinking of the cost.*

Carer

Although some carers were happy with their involvement in the care, others felt that they had had to fight for the right services in the past, and others felt less involved than they should have been in their relative's current care:

*There was nothing much we could say which would be taken on board . . . it was very much 'no, this is what we think'.*

Carer

*I was asking for help in the community for years before my son was admitted to hospital.*

Carer

Communication with carers was raised as an important issue, with some carers feeling that communication from services was excellent and others feeling that it could have been much better:

*We can ring up or turn up at any time.*

Carer

*I am part of the team there, I go to ward rounds and I feel we all have valid points of view and bring different strengths to the team.*

Carer

*The staff is supposed to phone me every 6 weeks if there's been an update but they don't . . . it's the only thing I can fault.*

Carer

*[T]he messages I am leaving . . . there's no return call and then its days and days and I am sort of banging my head against a wall. And then your relationship with the people dealing with the relative are breaking down because there is a lack of trust, there's a lack of communication, you are not included in decisions or discussions so the whole thing is really not working is it basically.*

Carer

Finally, a need for support for carers was identified, which was not always in place:

*The situation, the hospital, impacts on families. How they are getting on impacts on how we feel outside.*

Carer

*I've never been in touch with anybody . . . if I'm ever struggling with anything or having questions I feel are unanswered, if there's any groups within the hospital for getting to get in touch with, I've not been given any information [about them].*

Carer

## Conclusions

Although necessarily limited in its scope, the consultation with parents and carers validated the importance of some of the outcome domains that have been studied in the literature and that were described in Chapter 2. However, it was clear from the consultation that the original overarching domain of 'patient experience' needs to be expanded to include the experience of carers, an area that had not been reflected in the FIDD literature. In addition, the consultation identified a number of further subdomains of outcomes from services that had not been identified in the systematic review of research studies.

These additional subdomains (or areas within subdomains) are summarised as follows:

Effectiveness domain:

- treatment response/recovery (patient or carer ratings as opposed to clinician ratings)
- acquiring adaptive functioning skills
- evidence of engagement with therapies and services.

Patient safety domain:

- safeguarding/victimisation of patients and patients' experience of safety
- overuse of medication (specifically in term of patient perceived overmedication/misuse/side effects).

Patient and carer experience domain:

- carer experience (including satisfaction, involvement and communication with services)
- closeness to home area
- access to work/meaningful activity (in hospital/in community)
- level of support in the community
- involvement in the community.

These areas are incorporated into the outcome framework developed at stage 1 in *Box 1*.

# Chapter 4 Stage 3: Delphi survey of professionals

## Aims

The aims of stage 3 of the project were to:

1. Gain consensus on expert/senior clinician views on the most important outcome domains for use in future evaluation of FIDD services, based on the domains identified from stages 1 and 2. This included both patient-related outcomes and aspects of the quality of care in services.
2. Identify preferred outcome measures/indicators and their important domains and those being used in services at the time of the study.

## Method

The Delphi technique is particularly useful for inquiry into opinion regarding priorities and future areas for research.<sup>77,78</sup> Using an iterative, multistage process, this method seeks to gain a group consensus on a significant issue when agreement is required.

An adapted Delphi method comprising two rounds was conducted online in August 2015. The survey was distributed via a mechanised survey tool (Bristol Online Survey). Within the three overarching outcome domains of 'effectiveness', 'patient safety' and 'patient experience', a list of 31 subdomains/indicators was created from those that had been identified at stages 1 and 2. The Delphi asked participants for their views on the most important/highest priority outcome subdomains using quantitative rating methods. The survey is in *Appendix 6*.

## Participants

Members of the Clinical Research Group in FIDD services were invited to participate in the Delphi exercise. In addition, senior clinicians and commissioners in the field (identified by the Project Steering Group) were contacted. An intended sample size of 15–20 experts was sought in line with Delphi recommendations.<sup>79</sup> Participants were eligible to participate if they had clinical, academic, managerial or commissioning experience of working in FIDD services. No specific exclusion criteria were applied given the purposive sampling method. Individuals were asked to highlight their professional background, current area of work (i.e. clinical/academic/commissioning/managerial), type of FIDD service(s) by level of security in which they were currently working and number of years of experience working within such services.

## Procedure

Participants were contacted by e-mail to explain the study and to seek participation. For round 1, 76 individuals were invited to take part. The invitation e-mail provided the rationale and intended aims of the Delphi exercise. The web link, closing date and a contact for further questions were also provided. On opening the link, participants were provided with the information sheet (see *Appendix 6*) and instructions for completing the survey.

If respondents consented to continue, they were asked to provide brief professional background information as described above. Next, participants rated how important each of the 31 outcome subdomains was for the evaluation of (FIDD) services, within the three superordinate domains of effectiveness (15 subdomains presented), patient safety (six subdomains) and patient experience (10 subdomains). A Likert scale anchored 1 (not at all important) to 5 (extremely important) was used to rate each item, with each score having operationalised definitions. For each subdomain participants were able to supply their preferred measures or indicators in a free-text box. Participants were then asked to specify any additional outcome subdomains or indicators which they considered as important from their expert knowledge. Following this, participants were asked to select up to five subdomains which they considered to be the most important/highest priority.

This included subdomains already identified as well as any additional items. Finally, in order to fulfil the study's second aim, all participants indicated the outcome measures used routinely to collect data on all patients in their own service(s). Respondents had 2 weeks to complete the first round. A reminder e-mail was sent 5 days before the closing date to those who had not responded.

Those who completed the first round were invited to take part in the second round (see *Appendix 7*). The e-mail was sent on an individual basis with the web link, closing date and the participant's individual round 1 ratings in a portable document format (PDF) attachment. On continuing to the survey web page, further instructions were provided. It was outlined that the second round was an opportunity to reappraise ratings in the light of the average group response, which was provided adjacent to each subdomain. First, participants were asked to rate the importance of each subdomain using the same Likert scale. Second, participants were asked to select up to five subdomains that they perceived to be the most important/highest priority. Participants were reminded that they did not have to change their answer from their original response if they did not wish to do so. Round 2 was available to complete over a 2-week period, with a reminder e-mail sent at the halfway point.

### **Analysis**

Descriptive methods were used to report findings. Frequency data were generated to describe the professional backgrounds of participants. Percentages and average figures were calculated to describe the ratings made in rounds 1 and 2. The consensus level for items rated using the Likert scale was set at an average rating of 4.0 or above (i.e. items rate as either 'moderately' or 'extremely' important). The percentage of participants who ranked each subdomain in their top five was calculated. Free-text answers were analysed using content analysis.

### **Ethical and governance considerations**

The Delphi study was reviewed by the Nottinghamshire Healthcare NHS Foundation Trust Research and Development Department. As only professionals took part, ethics approval was not deemed to be required and consent was implied by participation. The results were downloaded in an anonymous format onto an encrypted computer. A participant identifying number generated by the Bristol Online Survey was known only to the research assistant. Responses were kept strictly confidential. Direct quotations from free-text answers were anonymised so as not to be traceable back to individuals. Data were stored for the duration of the research project only and then deleted.

## **Results**

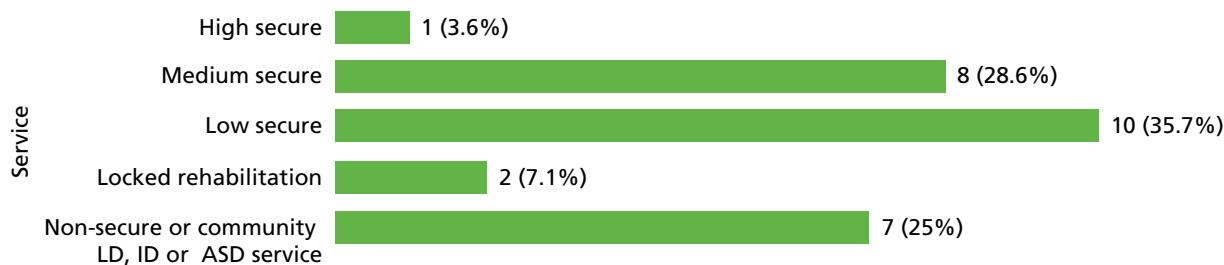
### **Characteristics of participants**

A total of 17 respondents completed round 1 (22% response rate). The majority of participants were psychologists and psychiatrists who worked in a clinical role at the time of participation (*Figures 2 and 3*). Respondents had on average 12.5 years' experience of working in FIDD services (range 1–25 years). Fifteen of these respondents participated in the second round (88% response rate).

Although all security levels of FIDD services were represented by respondents, the majority were working in medium and low secure care as shown in *Figure 4*. Seven respondents were working across either two or three different levels of security. Both the NHS and independent sectors were represented.



**FIGURE 2** Area of work.

**FIGURE 3** Type of role.**FIGURE 4** Type of service currently working in. ASD, autism spectrum disorder; ID, intellectual disability; LD, learning disability.

### Ratings

In round 1 respondents were asked to rate how important they thought each outcome subdomain was for the evaluation of FIDD services. The subdomains with an average group score from round 1 of 4.0 and above (the consensus threshold level) were presented in round 2. Participants rated each item. The mean scores were then calculated for each subdomain and are presented in *Table 8*.

None of the items was rated as 'not at all important' or 'slightly important.' There were five items which did not reach the consensus level at round 1 (length of stay, security needs, adaptive functioning, clinician-rated quality of life and closeness to home area). A decision was made to retain one item (length of stay) as, paradoxically, this item was highly ranked in the 'top five' domains section. At round 2, two items (length of stay and physical health) did not reach consensus level.

The subdomains that gained the highest ratings at the end of round 2 were discharge outcome, treatment response/engagement, reoffending (effectiveness domain), premature death (patient safety domain), therapeutic milieu and access to meaningful activity (patient experience domain).

### Top five outcomes

Participants selected up to five subdomains that they believed were the most important/highest priority for the evaluation of FIDD services. The percentages of respondents who endorsed each subdomain as one of their most important outcomes were calculated for both rounds and are presented in *Table 9*.

### Suggested measures/indicators

Professionals were asked to suggest an ideal or preferred measure/indicator for each subdomain using a free-text response.

## Discussion

A total of 15 experts completed both rounds of the survey; they had an average of 12.5 years of experience and represented a wide range of FIDD services. Although the total number of respondents was relatively small, this is common in Delphi studies. As the primary aim is to identify the level of consensus

**STAGE 3: DELPHI SURVEY OF PROFESSIONALS**

**TABLE 8** Average ratings for each subdomain

<b>Effectiveness</b>	<b>R1</b>	<b>R2</b>	<b>Change</b>
Discharge outcome/direction of care pathway	4.53	4.80	+0.27
Treatment response/engagement	4.65	4.73	+0.08
Reoffending (charges/reconvictions)	4.59	4.60	+0.01
'Offending-like' behaviour (i.e. behaviour that did not result in charges)	4.47	4.53	+0.06
Recovery measures/progress on treatment goals (clinician rated)	4.47	4.47	0.00
Risk assessment measures	4.35	4.47	+0.12
Recovery measures/progress on treatment goals (patient rated)	4.53	4.40	-0.13
Clinical symptom severity/treatment needs (clinician rated)	4.41	4.40	-0.01
Clinical symptom severity/treatment needs (patient rated)	4.24	4.40	+0.16
Readmission (i.e. the patient is readmitted within a specified time period)	4.00	4.27	+0.27
Incidents (violence/self-harm)	4.29	4.20	-0.09
Delayed discharge/current placement appropriateness	4.24	4.07	-0.17
Length of hospital stay	3.65	3.40	-0.25
Security need (i.e. physical/procedural/escort/leave)	3.94	N/A	N/A
Adaptive functioning	3.82	N/A	N/A
<b>Patient safety</b>			
Premature death and suicide	4.59	4.73	+0.14
Victimisation/safeguarding	4.53	4.47	-0.06
Restrictive practices (i.e. seclusion/segregation)	4.29	4.40	+0.11
Restrictive practices (i.e. restraint)	4.29	4.33	+0.04
Medication (i.e. PRN/exceeding BNF prescribing limits)	4.24	4.07	-0.17
Physical health	4.12	3.87	-0.25
<b>Patient/carer experience</b>			
Access to work/meaningful activity	4.65	4.60	-0.05
Therapeutic milieu	4.41	4.60	+0.19
Support/involvement in community	4.35	4.47	+0.12
Quality of life (patient rated)	4.59	4.40	-0.19
Patient experience: involvement	4.41	4.33	-0.08
Carer experience: communication	4.18	4.20	+0.02
Patient experience: satisfaction/complaints	4.29	4.07	-0.22
Carer experience: involvement	4.06	4.07	+0.01
Quality of life (clinician rated)	3.94	N/A	N/A
Closeness to 'home' area	3.59	N/A	N/A

BNF, *British National Formulary*; N/A, not applicable; R1, round 1; R2, round 2.  
Dark shading = average score of  $\geq 4.5$ ; light shading = average score of  $\leq 4.0$ .

**TABLE 9** Frequency of participants who rated each subdomain as the top five most important (%)

<b>Effectiveness</b>	<b>R1</b>	<b>R2</b>
Clinical symptom severity/treatment needs	70	80
Reoffending/offending-like behaviour	59	80
Treatment response/engagement/insight	47	73
Risk assessment measures	41	67
Recovery measures/progress on treatment goals	41	67
Discharge outcome/direction of care pathway	41	53
Length of hospital stay	24	13
Adaptive functioning	24	13
Delayed discharge/current placement appropriateness	18	13
Readmission	18	13
Incidents (violence/self-harm)	18	0
Security need (i.e. physical/procedural/escort/leave)	12	0
<b>Patient safety</b>		
Restrictive practices (i.e. seclusion/segregation/restraint)	12	7
Premature death and suicide	12	0
Medication (i.e. PRN/exceeding BNF prescribing limits)	12	0
Physical health	6	0
Patient safety in general	6	0
Victimisation/safeguarding	3	0
<b>Patient/carer experience</b>		
Access to work/meaningful activity (when/where appropriate)	24	13
Patient experience	24	0
Quality of life	12	0
Therapeutic milieu	6	0
Carer experience	0	0
Closeness to home area	0	0
Support/involvement in community (when/where appropriate)	0	0

BNF, British National Formulary; R1, round 1; R2, round 2.

Shading = domains in which consensus is achieved.

among experts, rather than generalising to a larger population, obtaining a sufficient degree of expertise and a representative panel can be considered more important than obtaining a large sample.

### **What are the most important/highest priority outcomes?**

There were six subdomains which were clearly rated as greatest importance by respondents (shaded in Table 9). Clinical symptom severity, treatment response and reoffending were most frequently endorsed as being within the top five most important subdomains. In addition, recovery/progress on treatment goals and risk assessment measures and discharge outcome were also most commonly ranked as being the most important outcome domains. This broadly concurred with the Likert scale ratings. By the end of the second

round, respondents favoured items under the superordinate domain of effectiveness only, with only a few respondents including items from patient safety or patient experience in their top five.

Although in round 1 there appeared to be little difference between the ratings of most domains, if the Likert rating and the top five are combined, the second round identified clear consensus for the nine most highly rated outcome subdomains, as shown in *Box 2*.

It is worth noting that in round 1, reoffending (formal convictions) and offender-like behaviour (activity that could be construed as an offence but for which no formal convictions or criminal justice system involvement followed) were similarly rated. One participant emphasised that the latter was 'as important as formal convictions' to measure. Another respondent highlighted 'offender-like' behaviour was of particular importance 'to capture in an LD [learning disability] population'. In round 2, these two outcomes were therefore presented as one subdomain to reflect this.

### **Additional subdomains**

Only one participant suggested an additional subdomain, degree of patient insight, which did not appear in the original list of items presented in round 1. This was combined with the 'engagement' item at round 2, as it was considered to be similar in theme.

### **Current use of outcome measures**

In round 1, participants were asked to indicate any outcome measures used to collect routine data on all patients in the service(s) in which they worked. *Table 10* provides a summary of responses. Services routinely measured levels of risk using structured clinical judgement methods (most commonly with the HCR-20). Change on risk measures (such as the HCR 20 and Short-Term Assessment of Risk and

#### **BOX 2 Highest priority subdomains (rating and 'top five' method combined)**

##### **Effectiveness**

- Discharge outcome/direction of care pathway.
- Recovery measures/progress on treatment goals.
- Global treatment response/engagement/insight.
- Clinical symptom severity.
- Reoffending (charges/reconvictions) and offender-like behaviour.
- Risk assessment.

##### **Patient safety**

- Premature death and suicide.

##### **Patient experience**

- Therapeutic milieu.
- Access to work/meaningful activity.

**TABLE 10** Percentage of respondents who reported using each measure/indicator routinely in their service(s) (round 1: n = 17)

Effectiveness	%
<b><i>Risk assessment measures including</i></b>	
HCR-20	47.1
Short-term Assessment of Risk and Treatability	23.5
Dynamic Risk Assessment and Management System	5.9
Short Dynamic Risk Scale	5.9
St Andrew's Sexual Behaviour Assessment Scale	5.9
Sexual Violence Risk-20	5.9
HoNOS-secure	23.5
HoNOS-LD	5.9
HoNOS (unspecified)	11.8
Incident data	41.2
Length of stay	41.2
Delayed discharge	17.6
Discharge outcome/direction of care pathway	17.6
Recovery star (and versions)	17.6
<b><i>Clinical symptom severity measures including</i></b>	
Clinical Outcomes Routine Evaluation – LD	17.6
Brief Psychiatric Rating Scale	5.9
EPSS	5.9
Schedules for Clinical Assessment in Neuropsychiatry	5.9
Attitudinal, motivational and skills assessments (used pre, during and post psychological interventions)	5.9
Modified Overt Aggression Scale	5.9
Number of patients in psychological treatment	5.9
Brooklands Outcome Scale Secure	5.9
Security need (e.g. physical/procedural/escort/leave)	11.8
<b><i>Patient safety</i></b>	
Restrictive practices	47.1
Medication	17.6
Death/suicide	17.6
Physical health	11.8
Victimisation/safeguarding	17.6
<b><i>Patient/carer experience</i></b>	
Unspecified patient-experience measures	17.6
Carer Satisfaction Survey	11.8
EssenCES	11.8
Patient Satisfaction Survey	11.8
25 hours of meaningful activity	5.9
Friends and Family Test	5.9
Involvement in community and access to work/meaningful activity	5.9
Main Identified Problem Scale	5.9
My Shared Pathway	5.9
Where general subdomains are indicated, no specific measure/indicator was suggested.	

Treatability) was clearly considered important, despite the fact that the literature review indicated that there are very few studies that examine change over time in risk measures as a result of treatment. Those that do exist suggest that the measures are quite insensitive to change. It should also be noted that the authors of the HCR-20 caution against ‘totalling up’ of scores, which is the only way of measuring change in rated risk, unless only the summary risk rating (high, medium, low) is used. Totalling of scores is also complicated by the new ‘relevance’ ratings in the HCR-20 latest Version 3, which is now in use. The rated importance of risk measures as an outcome variable by professionals fails to acknowledge such problems and may be driven more by their availability owing to mandated use as part of Commissioning for Quality and Innovation targets.

There was not a clearly preferred measure of clinical change or treatment progress. Clinical symptoms were most commonly rated using HoNOS-secure or other versions of HoNOS. Patients’ views on their own progress were not routinely collected, despite their rated importance, although a small number of participants mentioned trust-led patient satisfaction surveys or patient self-risk ratings.

Incident data and associated restrictive practices were routinely monitored, but there was no evidence of a standardised coding system across services, which would be necessary for benchmarking purposes. This may reflect the multiplicity of service providers in this sector.

### ***Additional issues raised***

Respondents were given the opportunity to provide additional free-text responses in both rounds. The key themes are as follows:

- Barriers to measuring outcomes: participants reflected on the difficulties of measuring outcomes in FIDD services in general. One participant summarised the issue as ‘a lack of clear objective measures and outcomes for forensic intellectual disabilities services’ suggesting an absence of current guidance and paucity of appropriate outcome measures for the population. Another respondent indicated that ‘there is a huge reliance on clinical judgement and this can be flawed and biased’. As the literature review found, it is notable that the majority of collected data reflect professional opinion and there is a relative dearth of outcomes from the patient perspective.
- Additional subdomains: participants were given the opportunity to suggest any subdomains which were not presented in round 1. The limited number of extra subdomains suggested that the original list of subdomains was comprehensive. It therefore appeared that the relevant and important items were captured by the framework developed from stages 1 and 2.
- Discord around direction of ‘positive’ outcomes: with regard to length of stay, the comments of some participants highlighted ambivalence as to the desired direction of this outcome indicator. For example, although having a shorter length of stay may initially appear to be a positive outcome, it was noted that it is ‘important to pick up inappropriate early discharges due to bed pressures’ among inpatient services. It was also noted that, for some forensic patients, an extended length of stay may be clinically appropriate and, therefore, not a ‘negative’ outcome, a theme echoed in the carer interviews. This ambivalence about length of stay as an outcome indicator may be reflected in its relatively low importance rating (indeed, it fell below the consensus threshold in both rounds).
- Ambivalence regarding closeness to home area: although it is emphasised as being desirable in a range of policy papers, interestingly, closeness to home area was not considered a priority by professionals. One respondent commented that ‘our regional and supra regional Gatekeeper role sometimes experiences the benefit of some “geographical distance”’. This implies that for some patients living near to their family or local authority area may not necessarily be a constructive outcome.
- Patient-rated outcomes: several respondents recommended using patients’ self-reported data to capture outcomes including patients’ assessment of how safe they perceive they are – often relates to ability to engage in therapeutic change and achieve treatment goals/reduce risk. Professionals also outlined ways that this could be achieved, for example ‘co-production of such [patient satisfaction] measures from within our patient advisors’. It is notable that ‘My Shared Pathway’<sup>80</sup> was intended by

the Department of Health to be an outcomes monitoring system; it was mandated for use as a CQUINN (Commissioning for Quality and Innovation) target for secure services in 2013 and includes patient ratings of progress on treatment goals. The almost total lack of mention of this tool by clinicians (one respondent) suggests that it is not being used consistently as an outcome measure or indicator by IDD services.

Finally, it is noteworthy that all subdomains were generally rated towards the upper end of the scale, indicating that respondents believed that all items had a degree of importance. Nevertheless, clear consensus around key priorities emerged.

## Conclusions

The aim of the Delphi exercise was to obtain an expert group consensus on the most important/highest priority outcomes to be measured in the evaluation of FIDD services in the future. We were therefore interested in service-level outcomes, as opposed to outcomes that clinicians might assess at individual patient level in the consideration of progress and discharge, although these may overlap. A total of 15 experts completed both rounds of the survey. The participants had an average of 12.5 years of experience and represented a wide range of FIDD services.

In summary, the majority of the most highly rated items came under the superordinate domain relating to effectiveness, with items from patient safety and patient experience domains rated less frequently as a priority. Indeed, consensus was clearer as defined by the top five rating: the domains rated in the 'top five' were all in the effectiveness domain with none in the other two domains. Perhaps unsurprisingly, clinician respondents therefore particularly prioritised items that relate to how successful services are in helping patients to reduce their clinical symptoms and progress their treatment goals while they are receiving care, as opposed to items reflecting service quality. These clinical effectiveness outcome domains were found not to be well represented in the literature in stage 1, but were found to be important to the patients and carers, particularly in terms of their own rating, in stage 2. It appears that a variety of measures and indicators could be used to index these outcomes meaningfully (including those developed in the Department of Health-led 'My Shared Pathway'<sup>80</sup>), but it seems there are no consistently used outcome measures across the services represented in the survey. It may be concluded that further work needs to be conducted to develop clinical symptom and treatment progress indicators which are both acceptable to clinicians and patients with intellectual disabilities and are valid and reliable.

The majority of the measures that professionals reported were collected routinely in their services were risk assessment measures (such as the HCR-20), and data on incidents and restrictive practices such as seclusion and restraint, which are required by the Department of Health. Length of stay was also routinely collected. Many services collected data on the same outcome subdomain, although the exact measure/indicator will differ (e.g. one way that incidents are coded in each setting differs widely).

The findings suggest that implementing a minimum data set among FIDD services is feasible, at least for some core measures. However, it was apparent that services, while they may collect some similar information, do not necessarily record it systematically on databases and are even less likely to analyse group data on a longitudinal basis, in order to identify change over time in their patients. This was also evident from the paucity of longitudinal studies in the systematic review. This finding may well be because services do not generally have resources to collect and analyse data systematically unless they have research departments (which only applies to some of the larger service providers). It would therefore require a specific research study or direction to services from commissioners to address the issue of developing a core common data set.



# Chapter 5 Synthesis of findings and conclusions for future research

## Overview

This development project comprised three stages: a systematic review of outcome domains, measures and indicators used in the literature; a series of consultation groups with patients and carers; and a Delphi survey of clinicians and experts. Although they are studies with findings of independent interest, together these allow some conclusions to be drawn about the most important domains and associated measures/indicators for examination in outcome evaluation and research in the forensic intellectual disability field. A key finding is that there appears to be a paucity of widely used, reliable and valid measures and indicators in some of the important domains.

As intended, the project also allowed a group of researchers and an expert by experience in the field to reflect together, through two day-long meetings, on what the future research needs are in relation to outcomes from intellectual disability services.

## Final framework of outcome domains

The first output is the final outcome framework which synthesises the evolving framework of outcome domains developed alongside the three studies. For the purposes of this final framework, no domain which had been added at any of the three stages was removed, although a small number were collapsed. For example, 'closeness to home area' was subsumed under 'patient satisfaction', and 'treatment response/engagement/insight' was subsumed under 'recovery/engagement/progress on treatment goals', as these were similarly rated by clinicians and were considered to overlap. *Table 11* describes this framework and the source of the inclusion of the subdomain. It should be noted that only new domains generated from stage 2 were added to those generated at stage 1 (systematic review). In the event, no new subdomains were added from stage 3.

These domains are therefore those that we recommend be considered for the purposes of developing benchmarking measurement of outcomes from all FIDD services, and for comprehensive outcome research into such services.

## Long list of indicators

The second output is a 'long list' of domains alongside suggested measures or indicators of the domains identified in the framework. The stage 1 systematic review identified a range of indicators and measures (see *Tables 1–6*), which have been used to index the outcome subdomains in the FIDD literature. Similarly, the stage 3 Delphi study gave a consensus on the domains of most importance, and also allowed identification of those measures preferred by clinicians and those that are collected routinely in services. Stage 2 naturally did not include consideration of specific measures, as patients and carers would not necessarily be familiar with these.

Accordingly, information gained from the study as a whole was synthesised to produce a provisional outcome measure or set of indicators for each subdomain. This 'long list' was based on a combination of robustness of research findings, clinician preference according to the Delphi exercise and ease of collection and accessibility in services.

**TABLE 11** Final framework of outcome domains

<b>Effectiveness</b>	<b>Source</b>
Discharge outcome/direction of care pathway	1
Delayed discharge/current placement appropriateness	1
Readmission (i.e. readmitted to hospital or prison)	1
Length of hospital stay	1
Adaptive functioning	2
Clinical symptom severity/treatment needs (patient rated)	1
Clinical symptom severity/treatment needs (clinician rated)	1
Recovery/engagement/progress on treatment goals (clinician rated)	1
Recovery/engagement/progress on treatment goals (patient/carer rated)	2
Reoffending (i.e. charges/convictions) on discharge	1
Offending-like behaviour (no CJS involvement) on discharge	1
Incidents (violence/self-harm) (in care setting)	1
Risk assessment measures	1
Security need (i.e. physical/procedural/escort/leave)	1
<b>Patient safety</b>	
Premature death/suicide	1
Physical health	1
Medication (i.e. PRN usage/exceeding BNF limits/side effects patient rating)	1/2
Restrictive practices (restraint)	1
Restrictive practices (seclusion/segregation)	1
Victimisation/safeguarding	2
<b>Patient/carer experience</b>	
Patient experience: involvement in care	2
Patient experience: satisfaction/complaints	1
Quality of life (patient rated)	1
Therapeutic climate	1
Access to work/meaningful activity (when appropriate)	2
Level of support/involvement in community/social network (post discharge)	2
Carer experience: communication with services/involvement in care	2

BNF, British National Formulary; CJS, Criminal Justice System.

Source of domain: stage 1 = systematic review; stage 2 = patient/carer involvement.

The long list is presented in *Appendix 8* and will serve as a draft set of important variables for a future minimum data set and longitudinal research study (see below). Importantly, it identifies both the measures to be collected during hospital care and those to be collected post discharge on follow-up in the community. Those areas identified as less important by clinicians but flagged by patients and carers as important have currently been left in the long list. In some areas we recognise that consistency with the relevant NHS Outcomes Framework indicators and Adult Social Care Outcomes Framework should be achieved.

Clearly, further work needs to be undertaken on the precise source of the outcome data in many subdomains and on the exact measurement to be employed. Given the evidence of lack of comparable outcome measures across FIDD services currently, this is a priority task which is all the more important given the current policy context.

## Current policy context

During the course of this project NHS England published *Building the Right Support*,<sup>80</sup> along with a National Service Model for people with intellectual and developmental disabilities.<sup>81</sup> These publications are in further response to the abuse that occurred at Winterbourne View<sup>3</sup> and focus on transforming services in order to increase community-based services and reduce the use of inpatient beds for people with developmental disabilities, including those with forensic needs. The National Service Model is based around nine clear principles with the person and their family at the centre. Specialist mental health care services, including forensic services, should be offered within community-based settings in order to circumvent admission. However, principle 9 recognises that hospital admission may be required for some individuals, but that change and improvement within services is needed. For example, all hospital-based services need to be integrated into community-based teams, while admissions need to be more clearly justified and associated with active, clear and robust discharge planning to prevent unnecessary hospital stays. Admissions also have to be within the context of a clear care-pathway and subject to a pre-admission Care and Treatment Review.

The findings from our current project outline some of the key indicators that are likely to index treatment outcome as a result of stay in a secure hospital. These effectiveness indicators could be used to routinely measure outcome during and following a hospital stay, and have implications for refining the care pathway for individual service users. In the patient experience domain we also have identified some important indicators for monitoring long-term outcomes for community care for these patients post discharge, which are strikingly consistent with several of the nine principles in the new National Service Model. Accurate collection of such data could support implementation of the model and the vision outlined within *Building the Right Support*,<sup>80</sup> as this framework will allow service providers, NHS England, Clinical Commissioning Groups and those undertaking care and treatment reviews to objectively measure change and progress (or otherwise) in people with IDD who have been in forensic care.

## Recommendations for future research

Moving forward from the current preliminary study, our final objective was to inform and underpin a large-scale longitudinal research project on outcomes from FIDD services. We are therefore in the process of developing an outline protocol for further research. As an output of the preliminary studies we have produced a list of key outcome domains (along with preliminary suggestions for measures/indicators with which to index these domains) and we propose to investigate their reliability and validity across a further series of studies. Our overarching goal is to create a standardised index of outcome for application across all IDD secure hospitals in England and to develop a national minimum data set of patients with IDD within secure hospitals which tracks them through their hospital treatment and discharge. Although key effectiveness variables would be the focus, this data set would ideally also include the patient safety and patient experience domain variables which cover some of the overarching principles in the new service framework. This information could potentially be used by NHS England both to monitor patient outcomes objectively and to provide benchmarking across services. It would also enable prediction of those patients who make most progress and the reasons for this, including effective treatments. It should also help to support appropriate care pathways within secure hospitals, and could highlight difficulties that need to be addressed, such as any lack of appropriate treatment provision, which could in turn lead to a reduction in length of stay.

It is proposed that the first workstream would involve an initial refinement of the domains, and the specific indicators of the domains and how they are to be measured. Our current long list, while comprehensive, may have disadvantages with respect to the time and cost of large-scale regular data collection on all variables, some of which may not prove valid or reliable indicators of change. We have already obtained consensus on a smaller subset of priority areas for clinicians, but would propose to undertake a further 1-day face-to-face consensus rating exercise with experts and other stakeholders (e.g. NHS England, patients and carers) with an aim of finalising a shortlist of core outcome measures/indicators for piloting.

Our second workstream would involve piloting our key indicators in several regions within England. We expect that this would be done collaboratively with NHS England and other key stakeholders (e.g. the Care Quality Commission and the Health and Social Care Information Centre). This workstream would allow us to investigate the feasibility of data collection by services and to establish the reliability and validity of our indicators over time. A secondary aim of this workstream would be to reduce the number of indicators further using item response theory methodology.

Within our third workstream, having refined our effectiveness indicators, and developed a reliable, valid and robust set, we would envisage continuing to work collaboratively with NHS England and other partners to create a longitudinal data set of all patients with IDD in secure hospitals. We would collect and refine these data, using a variety of methods, over a minimum period of 5 years. In summary, we therefore envisage the creation of a national FIDD minimum data set, which follows patients longitudinally through secure care to discharge and subsequent long-term follow-up. Patient safety and patient experience would also be monitored at a service level. Although a number of data sources exist (e.g. NHS England's Transforming Care tracker; NHS Outcomes Framework; Mental Health Minimum Dataset) these do not easily allow identification of FIDD patients, measure treatment outcome (particularly in terms of patients' progress over time), or adequately track care pathways from secure hospital into the community or to other outcome destinations such as prison. These areas of measurement are necessary if the Department of Health is to achieve its vision as outlined within *Building the Right Support*<sup>80</sup> for forensic patients. It is believed that a robust future research programme will help to support genuine and lasting change within secure IDD services consistent with that vision. The programme should be associated with an improvement in the key indicators for all people with IDD and forensic needs by helping to ensure that they are not admitted to hospital unnecessarily, and, for those who are admitted, that they remain in hospital for no longer than is absolutely necessary.

To summarise, the research priorities are therefore:

1. refining the priority domains and the measures and indicators with which to represent the domains
2. creating a longitudinal minimum data set on all patients in secure services, including follow-up at discharge for a predetermined period.

## Limitations

The preliminary research reported in this report was intended only to inform development of future substantive research and there are therefore some limitations. The systematic review was intentionally broadly focused and comprehensive for its primary purpose of identifying how outcomes have been studied in FIDD services, but a synthesis of the findings of the 60 included studies themselves was beyond the scope of the study. Such a synthesis may nevertheless have been of interest, in which case the addition of quality ratings may have identified the studies on which to put most weight, but the reasons for not conducting quality ratings have been clearly outlined. The Delphi survey tapped into the views of only a small pool of 15 experts, and a more comprehensive survey with a larger sample from a more diverse range of professional groups, including more nurses, might have identified more detail and accuracy about data available from services. Furthermore, although carers were represented from three settings, a more

structured and representative survey of carer 'experts by experience' may have added to the overall picture, but would have been more methodologically complex and time-consuming.

The consultation with patients was limited in a number of ways, particularly in relation to the generalisability of the views of the small number of patients consulted. First, the patients we consulted were detained in two secure settings; we recognise that it was difficult for people with intellectual disabilities in such settings to reflect on a subject (i.e. discharge) of which they have limited choices or control. Furthermore, those willing and able to be consulted were by definition those most able and engaged in services; the voices of those who were the least able or in seclusion or segregation were not heard. In addition, those who had been discharged from services were not consulted in the study, although those former service patients would have had an important perspective on outcomes.

## Final remarks

This project comprised preliminary scoping work. While FIDD services serve a unique group of patients, we recognise that the framework we have produced may need to be considered in the context of other frameworks, including the recently proposed Intellectual Disability Outcomes Framework for improving the quality of community services for people with intellectual disability was published while the current work was ongoing.<sup>82</sup> The five domains outlined in that framework (which directly reflect those in the NHS Outcomes Framework<sup>83</sup>) are nevertheless covered by our three overarching domains of effectiveness, patient safety and patient experience, but it will be important that specific indicators used are common across frameworks when this is meaningful. Finally, we recognise that this preliminary research has not yet identified a 'definitive' list of outcome measures/indicators for use in services or future research; this is in large part a result of our finding of a lack of consensus for the use of, or even existence of, measures in some of the domains and reinforces the need for more refinement of measures as a first phase of any future project.

## Dissemination strategy

The findings of this report will primarily feed into the design of future substantive research. Findings will be accessible to professional groups and policy-makers through published papers in peer-reviewed journals, and presentation at professional conferences. Patients and carer groups received feedback in the form of the summary in Appendix 9.



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## Contributions of authors

The systematic review study selection, data extraction, synthesis and initial write-up of the report were carried out by **Catrin Morrissey** (Senior Research Fellow, Forensic Intellectual Disability) and **Nicole Geach** (Research Assistant).

The consultation groups and the Delphi survey were conducted and synthesised by **Catrin Morrissey**, **Nicole Geach** and **Verity Chester** (Research Associate).

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## Data sharing statement

All available data can be obtained from the corresponding author. All data will be shared in a way that safeguards the confidentiality and anonymity of respondents.



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# Appendix 1 Search strategy

## PsycINFO

Date range searched: 1806 to May week 4 2015.

Date searched: 1 June 2015.

### Search strategy

1. exp intellectual development disorder/ (39,999)
2. Learning disorders/ (2170)
3. Developmental Disabilities/ (10,651)
4. ((intellectual\$ or learning\$ or development\$) adj3 (impair\$ or disab\$ or disorder\$ or difficult\$ or subnormal\$ or sub-normal\$)).tw. (66,491)
5. ((mental\$ or development\$) adj3 (retard\$ or disab\$ or defici\$ or handicap\$ or impairment\$ or subnormal\$ or sub-normal\$)).tw. (58,870)
6. (feeble-minded\$ or moron\$ or imbecil\$ or cretin\$).tw. (2851)
7. de lange\$.tw. (112)
8. Cri-du-chat.tw. (87)
9. (WAGR adj3 syndrome).tw. (2)
10. (down\$ adj3 syndrome\$).tw. (6387)
11. (Rubinstein adj3 Taybi).tw. (39)
12. (prader adj3 willi).tw. (637)
13. (williams adj3 syndrome).tw. (1038)
14. fragile X.tw. (1897)
15. ((Martin Bell or FRAXE or FRAXA) adj3 syndrome\$).tw. (19)
16. (les?h adj3 nyhan\$).tw. (184)
17. Adrenoleukodystrophy.tw. (151)
18. (Coffin adj Lowry).tw. (32)
19. Menkes.tw. (60)
20. Glycogen Storage Disease.tw. (43)
21. Mucopolysaccharidosis.tw. (90)
22. Rett\$.tw. (1073)
23. Pyruvate Dehydrogenase.tw. (80)
24. or/1-23 (118,478)
25. forensic.tw. (14,524)
26. (secure adj (unit\$ or hospital\$ or service\$)).tw. (676)
27. Criminals/ (11,153)
28. offen\$.tw. (36,629)
29. or/25-28 (51,835)
30. 24 and 29 (2011)

## MEDLINE(R) (via Ovid)

Date range searched: 1946 to May week 4 2015.

Date searched: 1 June 2015.

***Search strategy***

1. exp Intellectual Disability/ (82,875)
2. Mentally Disabled Persons/ (2227)
3. Learning disorders/ (12,856)
4. Developmental Disabilities/ (15,682)
5. ((intellectual\$ or learning\$ or development\$) adj3 (impair\$ or disab\$ or disorder\$ or difficult\$ or subnormal\$ or sub-normal\$)).tw. (48,293)
6. ((mental\$ or development\$) adj3 (retard\$ or disab\$ or defici\$ or handicap\$ or impairment\$ or subnormal\$ or sub-normal\$)).tw. (51,852)
7. (feeble-minded\$ or moron\$ or imbecil\$ or cretin\$).tw. (1645)
8. de lange\$.tw. (793)
9. Cri-du-chat.tw. (368)
10. (WAGR adj3 syndrome).tw. (133)
11. (down\$ adj3 syndrome\$).tw. (17,498)
12. (Rubinstein adj3 Taybi).tw. (519)
13. (prader adj3 willi).tw. (2673)
14. (williams adj3 syndrome).tw. (1673)
15. fragile X.tw. (4927)
16. ((Martin Bell or FRAXE or FRAXA) adj3 syndrome\$).tw. (202)
17. (les?h adj3 nyhan\$).tw. (969)
18. Adrenoleukodystrophy.tw. (1653)
19. (Coffin adj Lowry).tw. (187)
20. Menkes.tw. (1086)
21. Glycogen Storage Disease.tw. (2005)
22. Mucopolysaccharidosis.tw. (2613)
23. Rett\$.tw. (3054)
24. Pyruvate Dehydrogenase.tw. (5100)
25. or/1-24 (17,7158)
26. forensic.tw. (25,673)
27. (secure adj (unit\$ or hospital\$ or service\$)).tw. (315)
28. Criminals/ (1347)
29. offen\$.tw. (15,415)
30. or/26-29 (40,461)
31. 25 and 30 (718)

**EMBASE**

Date range searched: 1974 to 2015 week 22.

Date searched: 1 June 2015.

***Search strategy***

1. exp mental deficiency/ (124,913)
2. intellectual impairment/ (12,230)
3. developmental disorder/ (27,419)
4. Learning disorders/ (21,725)
5. Developmental Disabilities/ (24,896)
6. ((intellectual\$ or learning\$ or development\$) adj3 (impair\$ or disab\$ or disorder\$ or difficult\$ or subnormal\$ or sub-normal\$)).tw. (69,880)

7. ((mental\$ or development\$) adj3 (retard\$ or disab\$ or defici\$ or handicap\$ or impairment\$ or subnormal\$ or sub-normal\$)).tw. (69,505)
8. (feeble-minded\$ or moron\$ or imbecil\$ or cretin\$).tw. (2271)
9. de lange\$.tw. (1017)
10. Cri-du-chat.tw. (483)
11. (WAGR adj3 syndrome).tw. (157)
12. (down\$ adj3 syndrome\$).tw. (22,586)
13. (Rubinstein adj3 Taybi).tw. (652)
14. (prader adj3 willi).tw. (3535)
15. (williams adj3 syndrome).tw. (2497)
16. fragile X.tw. (6134)
17. ((Martin Bell or FRAXE or FRAXA) adj3 syndrome\$).tw. (226)
18. (les?h adj3 nyhan\$).tw. (1152)
19. Adrenoleukodystrophy.tw. (2064)
20. (Coffin adj Lowry).tw. (219)
21. Menkes.tw. (1331)
22. Glycogen Storage Disease.tw. (2559)
23. Mucopolysaccharidosis.tw. (3866)
24. Rett\$.tw. (4102)
25. Pyruvate Dehydrogenase.tw. (6090)
26. or/1-25 (257,407)
27. forensic.tw. (40,822)
28. (secure adj (unit\$ or hospital\$ or service\$)).tw. (577)
29. exp offender/.(8941)
30. offen\$.tw. (23,256)
31. or/27-30 (65,604)
32. 26 and 31 (1413)

## Allied and Complementary Medicine

Date range searched: 1985 to May 2015.

Date searched: 1 June 2015.

### Search strategy

1. exp learning disability/ (3019)
2. exp mental retardation/ (2432)
3. exp Developmental disabilities/ (849)
4. ((intellectual\$ or learning\$ or development\$) adj3 (impair\$ or disab\$ or disorder\$ or difficult\$ or subnormal\$ or sub-normal\$)).tw. (7938)
5. ((mental\$ or development\$) adj3 (retard\$ or disab\$ or defici\$ or handicap\$ or impairment\$ or subnormal\$ or sub-normal\$)).tw. (4951)
6. (feeble-minded\$ or moron\$ or imbecil\$ or cretin\$).tw. (9)
7. de lange\$.tw. (15)
8. Cri-du-chat.tw. (8)
9. (WAGR adj3 syndrome).tw. (0)
10. (down\$ adj3 syndrome\$).tw. (825)
11. (Rubinstein adj3 Taybi).tw. (5)
12. (prader adj3 willi).tw. (78)
13. (williams adj3 syndrome).tw. (74)
14. fragile X.tw. (81)

15. ((Martin Bell or FRAXE or FRAXA) adj3 syndrome\$).tw. (1)
16. (les?h adj3 nyhan\$).tw. (4)
17. Adrenoleukodystrophy.tw. (4)
18. (Coffin adj Lowry).tw. (0)
19. Menkes.tw. (0)
20. Glycogen Storage Disease.tw. (8)
21. Mucopolysaccharidosis.tw. (4)
22. Rett\$.tw. (71)
23. Pyruvate Dehydrogenase.tw. (7)
24. or/1-23 (11,351)
25. forensic.tw. (226)
26. (secure adj (unit\$ or hospital\$ or service\$)).tw. (22)
27. exp crime/ (312)
28. offen\$.tw. (339)
29. or/25-28 (698)
30. 24 and 29 (193)

## **Health Management Information Consortium**

Date range searched: 1979 to March 2015.

Date searched: 1 June 2015.

### ***Search strategy***

1. exp learning disabilities/ (6239)
2. ((intellectual\$ or learning\$ or development\$) adj3 (impair\$ or disab\$ or disorder\$ or difficult\$ or subnormal\$ or sub-normal\$)).tw. (4440)
3. ((mental\$ or development\$) adj3 (retard\$ or disab\$ or defici\$ or handicap\$ or impairment\$ or subnormal\$ or sub-normal\$)).tw. (3030)
4. (feeble-minded\$ or moron\$ or imbecil\$ or cretin\$).tw. (7)
5. de lange\$.tw. (0)
6. Cri-du-chat.tw. (0)
7. (WAGR adj3 syndrome).tw. (0)
8. (down\$ adj3 syndrome\$).tw. (254)
9. (Rubinstein adj3 Taybi).tw. (0)
10. (prader adj3 willi).tw. (3)
11. (williams adj3 syndrome).tw. (0)
12. fragile X.tw. (12)
13. ((Martin Bell or FRAXE or FRAXA) adj3 syndrome\$).tw. (0)
14. (les?h adj3 nyhan\$).tw. (0)
15. Adrenoleukodystrophy.tw. (0)
16. (Coffin adj Lowry).tw. (2)
17. Menkes.tw. (0)
18. Glycogen Storage Disease.tw. (0)
19. Mucopolysaccharidosis.tw. (3)
20. Rett\$.tw. (6)
21. Pyruvate Dehydrogenase.tw. (0)
22. or/1-21 (8443)
23. forensic.tw. (427)

24. exp secure mental health services/ (195)
25. exp psychiatric secure units/ (133)
26. (secure adj (unit\$ or hospital\$ or service\$)).tw. (553)
27. offenders/ (1921)
28. offen\$.tw. (1971)
29. or/23-28 (3691)
30. 22 and 29 (189)

## **British Nursing Index Healthcare Databases Advanced Search platform**

Date range searched: 1994 to May 2015.

Date searched: 1 June 2015.

### **Search strategy**

1. BNI; (exp AND MENTAL AND RETARDATION).ti,ab (0)
2. BNI; ((mental\* OR development\*) adj3 (retard\* OR disab\* OR defici\* OR handicap\* OR impairment\* OR subnormal\* OR sub-normal\*).af (1904)
3. BNI; ((intellectual\* OR learning\* OR development\*) adj3 (impair\* OR disab\* OR disorder\* OR difficult\* OR subnormal\* OR sub-normal\*).af (7333)
4. BNI; (feeble-minded\* OR moron\* OR imbecil\* OR cretin\*).af (8)
5. BNI; Cri-du-chat.af (5)
6. BNI; (WAGR adj3 syndrome).af (0)
7. BNI; (down\* adj3 syndrome\*).af (453)
8. BNI; (Rubinstein adj3 Taybi).af (1)
9. BNI; (prader adj3 willi).af (27)
10. BNI; (williams adj3 syndrome).af (16)
11. BNI; "fragile X".af (49)
12. BNI; ((Martin Bell OR FRAXE OR FRAXA)).af (2)
13. BNI; ((les?h adj3 nyhan\*).af (1)
14. BNI; Adrenoleukodystrophy.af (0)
15. BNI; (Coffin ADJ Lowry).af (0)
16. BNI; Menkes.af (3)
17. BNI; "Glycogen Storage Disease".af (3)
18. BNI; Mucopolysaccharidosis.af (2)
19. BNI; Rett\*.af (26)
20. BNI; "Pyruvate Dehydrogenase".af (0)
21. BNI; "de lange\*".af (20)
22. BNI; 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 (7790)
23. BNI; forensic.af (904) results.
24. BNI; exp SECURE PSYCHIATRIC HOSPITALS/ OR exp MENTALLY DISORDERED OFFENDERS/ (770)
25. BNI; (secure ADJ (unit\* OR hospital\* OR service\*)).af (527)
26. BNI; offen\*.af (1270)
27. BNI; 27 OR 28 OR 29 OR 30 (2057)
28. BNI; 26 AND 31 (364)

## Cumulative Index to Nursing and Allied Health Literature (via EBSCOhost)

Date range searched: 1806 to May week 4 2015.

Date searched: 1 June 2015.

### **Search strategy**

1. S1. (MH "Intellectual Disability+") (14,423)
2. S2. (MH "Mentally Disabled Persons") (2211)
3. S3. (MH "Developmental Disabilities") (4374)
4. S4. TX ((mental\* OR development\*) N3 (retard\* OR disab\* OR defici\* OR handicap\* OR impairment\* OR subnormal\* OR sub-normal\*)) (40,779)
5. S5. TX ((intellectual\* OR learning\* OR development\*) N3 (impair\* OR disab\* OR disorder\* OR difficult\* OR subnormal\* OR sub-normal\*)) (61,814)
6. S6. TX (feeble-minded\* OR moron\* OR imbecil\* OR cretin\*) (1735)
7. S7. TX Cri-du-chat (159)
8. S8. TX (WAGR N3 syndrome) (23)
9. S9. TX (down\* N3 syndrome\*) (8682)
10. S10. TX (Rubinstein N3 Taybi) (58)
11. S11. TX (prader N3 willi) (806)
12. S12. TX (williams N3 syndrome) (796)
13. S13. TX "fragile X" (1781)
14. S14. TX ((Martin Bell OR FRAXE OR FRAXA) N3 syndrome\*) (25)
15. S15. TX (les?h N3 nyhan\*) (150)
16. S16. TX Adrenoleukodystrophy (161)
17. S17. TX (Coffin N1 Lowry) (25)
18. S18. TX Menkes (277)
19. S19. TX "Glycogen Storage Disease" (220)
20. S20. TX Mucopolysaccharidosis (186)
21. S21. TX Rett\* (3568)
22. S22. TX "Pyruvate Dehydrogenase" (196)
23. S23. TX "de lange\*" (805)
24. S24. S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 (83,897)
25. S25. TI forensic or AB forensic (2740)
26. S26. TX (secure N1 (unit\* OR hospital\* OR service\*)) (1797)
27. S27. (MH "Mentally Ill Offenders") (1376)
28. S28. TI offen\* or AB offen\* (3951)
29. S29. S25 OR S26 OR S27 OR S28 (8721)
30. S30. S24 AND S29 (1195)

## Appendix 2 Inclusion and exclusion criteria

### Type of study

- Any study design

AND

- Presents quantitative data post 1980

AND is one of the following:

- in press, in preparation or published in a book or scientific, peer-reviewed journal
- unpublished service evaluation report
- grey literature.

Exclude: qualitative data only.

### Type of service/participant

**All** of the following apply:

Study includes data relating to:

- service includes forensic mental health service(s)
- IDD- or LD-specific service(s)
- adult services ( $\geq 18$  years).

If service is mixed the IDD data are identifiable as a separate group.

Exclude: child or adolescent services.

One or more of the following apply:

- high, medium or low secure service
- locked rehabilitation service
- community forensic service.

Non-UK equivalent of any of the above.

Exclude: prison studies; probation.

### Intervention

- Study evaluates/considers outcomes arising from the service as a whole.
- Study presents data on measures of effectiveness, quality or patient experience.

Exclude: studies that evaluate a specific/singular intervention (e.g. anger management).



# Appendix 3 Screening tool and data extraction form

## Screening tool

Reviewer 1	2	3	Study ID:
Title:			
Year:			Language or Place of study:
Authors:			

<b>1. Type of Study</b>		
<ul style="list-style-type: none"> <li>• Any study design</li> </ul> <p><b>AND</b></p> <ul style="list-style-type: none"> <li>• Presents quantitative data</li> </ul> <p><b>AND</b> is one of the following:-</p> <ul style="list-style-type: none"> <li>• In-press, in-preparation or published in a book or scientific, peer reviewed journal</li> <li>• Unpublished service evaluation report</li> <li>• Grey literature</li> </ul>	<p>Yes</p> <p>No: Exclude*</p> <p>Unsure</p>	Comments:
<b>2. Sample and Setting</b>		
<p>All of the following apply:-</p> <ul style="list-style-type: none"> <li>• Forensic/Offender service(s)</li> <li>• IDD or LD specific service(s)</li> <li>• Adult service(s) (18 years+)</li> </ul>	<p>Yes</p> <p>No: Exclude*</p> <p>Unsure</p>	Comments:
<p><b>One or more</b> of the following apply:-</p> <ul style="list-style-type: none"> <li>• High, Medium or Low secure service</li> <li>• Locked Rehabilitation service</li> <li>• Community forensic service</li> <li>• Non-UK equivalent of any of the above</li> </ul>	<p>Yes</p> <p>No: Exclude*</p> <p>Unsure</p>	Comments:
<b>3. Intervention</b>		
<ul style="list-style-type: none"> <li>• Study evaluates/considers outcomes arising from the service as a whole</li> </ul> <p><b>AND</b></p> <ul style="list-style-type: none"> <li>• Does not evaluate a specific/singular intervention (e.g. anger management)</li> </ul>	<p>Yes</p> <p>No: Exclude*</p> <p>Unsure</p>	Comments:
<b>4. Outcomes</b>		
<p>Study measures patient-related outcomes</p> <p><b>OR</b></p> <p>Study presents potential indicators of effectiveness</p>	<p>Yes</p> <p>No: Exclude*</p> <p>Unsure</p>	Comments:

**Decision: Is it appropriate for inclusion?**

Yes, Include)

\*No: Exclusion Reason:

Unsure. Discussed on \_\_\_\_/\_\_\_\_/2015

Outcome:

Yes, Include

\*No: Exclusion Reason:

## Data extraction tool for included studies

<b>Reference</b>		
Aim/Research Question		
Inclusion/Exclusion criteria		
Sample Information	<p>N: % Male: Mean Age: Additional Info:</p> <p>Category 1: High secure Category 1: Medium secure Category 1: Low secure Category 4 (Rehabilitation) Community Forensic Service Non-UK equivalent</p> <p>Single Site              Multi-Site</p>	
Study Design		
Details:		
Type A <ul style="list-style-type: none"> <li>• Cohort with follow up of any length</li> <li>• Measures data at two time points (e.g. shows potential change over time)</li> </ul>	<p>Type B</p> <ul style="list-style-type: none"> <li>• Cross-sectional study design</li> <li>• Measures data at one time point</li> </ul>	
Method		
Detailed description of a) outcomes examined and b) how measured/indexed:		
Outcome Domains		
Patient related clinical effectiveness Patient related safety or risk measures Patient/carer experience Other	<p>During service intervention Discharge Follow-up:</p>	

**Outcome Measures/Tools**

Specific outcome measure/tool used: Yes No

- 

**Relevant Findings**

-

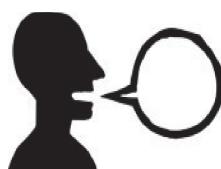
# Appendix 4 Patient and carer information for consultation groups

## Information for taking part in Discussion Group

- Next year we will be doing research to find out what happens to people after their stay in secure care. Before we do this we want to find out what patients' views are
- We are inviting you to take part in a **discussion group** about what is important to you in your treatment here and in your life after secure hospital4
- This will help us plan our research
- The lead for the study is Dr Catrin Morrissey. It is paid for by the NHS



Sometimes we need to see how well services are doing at helping people to get better - this is called an 'outcome'. We will be doing some research on outcomes from secure care. Before we do that research we want to know what kinds of outcomes are important to you.



We would like to hear your opinions about the ways you think you and other people change after treatment. We also want to know about things you think are important for your future.



What you say will be **confidential**. The things you say will not go in your notes but we may write down some of your ideas, because your opinions are important to us. We will not write down your name, so no one else will know who has said what. The things that you tell us today will not affect your care or treatment.



We are doing this discussion group so that we can include the things that are important to you, when we do our study in the future.

Are you happy to take part in the discussion? You can change your mind



Yes, I am happy to take part



No, I would not like to take part

Name: \_\_\_\_\_ Date: \_\_\_\_\_

St John's House,Lion  
Road,  
Palgrave,  
Diss,  
Norfolk  
IP22 1BA

Address  
Address  
Address  
Postcode

Dear [name]

We are writing to you to as a carer of a patient at St. John's Hospital, Partnerships in Care. We would like to invite you to take part in a discussion group.

- We are doing research to find out what happens to people during and after their stay in secure care.
- We want to find out what carers/relatives views are
- The discussion group is about what you think is important in the treatment of the person you care for both here and in future places.
- A payment of £120 will be given for your time
- Plus, travel expenses will be provided (at 45p per mile)

Please take time to read the **Information Sheet** enclosed with this letter carefully. This provides details about the discussion group.

If after reading the Information Sheet you would like to take part in the discussion group, please fill in the **Consent Form** enclosed with this letter and bring this along with you on the day.

We would appreciate your attendance at the discussion group. This will help professionals to gain a better understanding of the things that are important to consider from the point of view of carers and relatives. The details of the discussion group are as follows:

If you have any further questions please do not hesitate to contact me.  
Kind Regards,

Verity Chester  
Research Assistant, Partnerships in Care

## Information Sheet

### **NIHR Health Services and Delivery Research Programme. Project 13/114/37: Outcomes from forensic services for people with intellectual and developmental disabilities: evidence synthesis and expert and patient consultation**

We are writing to you to invite you to take part in a discussion group. This discussion group is part of the above named research project which is funded by the National Institute for Health Research. Please take time to read the following information carefully.

#### **What is the discussion about?**

The discussion group will be a group of 6-8 carers, relatives or friends of people who are currently using forensic learning/intellectual disability services at St. John's House.

#### **Why is the discussion group taking place?**

Although there has been some research into how well these types of services in hospitals are doing at helping people, the views of families/carers has not been widely considered in this research. We are interested in holding a discussion group so that we can gain the opinions of carer's/families.

#### **What is the aim of the discussion?**

The purpose of the discussion is to explore the outcomes that are important and relevant from the point of view of people who are family, friends, relatives or carers for the people using the learning/intellectual disability service at St. John's House.

#### **What is an Outcome?**

An outcome is a change that happens to someone as a result of them staying in hospital for treatment.

#### **What will I have to do?**

We would like to talk to you about the future of the people you care for who are using the service. We want to know what you want to happen for them after being in the current service and after secure care. Whilst we will ask you a few questions, the group will be an open discussion as we are interested in your thoughts and opinions on the topic.

#### **What happens on the day?**

You will be invited to come to St. John's House on Friday 29<sup>th</sup> May 2015. The group will last for approximately one hour. The project leader and a research assistant will ask you some questions to gather your opinions. They may write down the ideas that you say.

#### **What are the benefits of attending?**

We are able to provide payment of £120 per person for those who are able attend. Travel expenses will also be provided at 45 pence per mile.

Listening to the views of relatives and carers can also be important so that professionals are able to include these views in future research. It is also hoped that this will help to improve the way that services measure changes (outcomes) for patients.

#### **What will happen to the information?**

Your name will not be written down so that the discussion remains confidential. The discussion will be typed up. The transcript will only be read and used by the project lead and research assistant.

#### **How will the information be used?**

We are planning a future research project on finding out what happens to people after secure care. We want to hear both from patients themselves and carers or family members too. What you say will help us with this research.

**Who do I contact for more information?**

Please contact Verity Chester, Research Assistant at St. John's House.

Telephone:

Address:

Email:

**What Next?**

If you would like to take part please read through the attached consent form. If you are happy to do so, please sign and date the form.

# Appendix 5 Topic guides for consultation groups

**NIHR CRG-FIDD Project HSDR 13114/37**  
**Outcomes from Forensic Services for People with Intellectual and Developmental Disabilities:**  
**Evidence Synthesis and Expert and Patient Consultation**

**Stage 2: Patient Involvement/Consultation: Patient group topic guide**

**Preamble**

We are going to talk to you about your future. We want to know what you want to happen after secure care. This might be quite difficult to think about. There are no right or wrong answers. We are interested in your thoughts and feelings.

We are talking to patients about this because we are doing research on finding out what happens to people after secure care. What you say will help us with this research.

If you would like to take part please read through the consent form. If you are happy, please sign the consent form and write today's date on it.

---

I have a list of the sort of things that doctors, psychologists and researchers tend to look at when we think about treatment outcomes. I will start us off, but please contribute with any of your thoughts or suggestions.

**Priorities and Expectations**

- How do you want to change while you are in treatment in this hospital?
- What are the most important or the main changes your team should look for?

**Change**

- How have you changed from when you arrived at the hospital?
- What things are different now? (how you feel, how you talk to people, therapy you do)
- Is there anything you do more of?
- Is there anything you do less of?
- What has helped you to make changes?

**Progress**

- What things help you to feel better?
- What things help you move forward?
- How do you know when you are doing better?
- What should the team look at to see if you are getting better?
- How do you know when you are doing well?

**Goals**

- What are your goals?
- Where would you like to be in 1 year?
- Where would you like to be in 5 years?

**Relationships**

- What do your families want for you in the future?
- What do your family see is a sign that you are getting better?
- Would you like to have a partner (or children)?

### Employment

- Is it important to get a job? What kind of work would you like to do?
- Would you like to go to college? What training would you like to have?

### Living/Support/ Community

- Where would you like to live after you leave secure care?
- Who would you like to live with? (Family, friends, on your own, partner, staffed /unstaffed?) Why?
- What do you need support or help with?
- What type of support would you like in the future?
- How do you know when you are independent and doing things for yourself?
- Do you think it is important to have less support from people as you get better?

### Mental Health

- How do you know when your mental health is better?
- Has the way you talk about your feelings changed? Is this important to you?
- Is medication important?
- Has the way you speak to people changed?
- Has the way you act around people changed?
- What about self-harm? Is this something you can talk about? How has this changed?

### Adaptive Skills

- How much support will you need when living in the community? (prompt: 24 hour, few hours a day)
- Is it important to be in charge of your own money?
- Is it important to be able to look after yourself (cooking, washing, shopping)?
- How important is not using drugs and alcohol?

### Safety

- Do you feel safe? What about things that happen to you here that you don't like?
- What things would you want to happen to you less often? (P) Seclusion, restraint things like that? Would you like to be secluded less? What about being restrained? What should people do instead?
- Are you happy with your medication? Would you like to have more or less medication or PRN? If you were using that less often would it mean you were getting better?
- Bullying by other patients/or assault by other patients?
- Does that happen - would you like it to happen less?
- PRN or medication - would you like to have more or less medication? If you were using that less often would it mean you were getting better?
- What would help you to keep out of trouble when you are in the community?

### Final Question:

Of all the outcomes from treatment in hospital we have discussed what is the most important for you? (Ask each person)

Is there anything else you would like to say about your life after secure care?

Is there anything else that should be researched about what happens to people in secure care?

**Close**

Talking about these issues can be difficult. If talking about you and your future has made you feel unhappy please speak to staff. Talking to you has been really helpful. Thank you for taking part.

**NIHR CRG-FIDD Project HSDR 13114/37**  
**Outcomes from Forensic Services for People with Intellectual and Developmental Disabilities:**  
**Evidence Synthesis and Expert and Patient Consultation**

## **Stage 2: Patient/Carer Involvement /Consultation**

### **Carer Group: Topic guide**

#### **Preamble**

We are going to talk to you about the future of the people you care for who are using the service. We want to know what you want to happen for them after being in the current service and after secure care. This might be quite difficult to think about. There are no right or wrong answers. We are interested in your thoughts and opinions.

The questions are about outcomes. An outcome is a change that happens to someone as a result of being in the hospital and receiving support.

We are planning a research project on finding out what happens to people after secure care. We want to hear both from patients themselves and carers or family members too. What you say will help us with this research.

If you would like to take part please read through the consent form. If you are happy to do so, please sign the consent form and write today's date on it.

---

#### Priorities and Expectations

- What are your expectations for the person you care for?
- What are the priorities (important or main changes) for looking at outcomes for the person you care for?

#### Change

- How has the person you care for changed from when they first arrived at the hospital?
- What things are different now?
- Is there anything they do more of?
- Is there anything they do less of?
- What do you think has helped them to make changes?

#### Progress

- What things have helped them to feel better?
- What things have helped them to move forward?
- How do you know when the person you care for is doing better?
- From your point of view, what should the team look at to see if the person you care for is getting better?

#### Needs

- What are the outcomes (positive changes) that you think should be looked at for the person you care for?
- What about outcomes for yourself?

**Goals**

- Where would you like the person you care for to be in 1 year?
- Where would you like the person you care for to be in 5 years?
- Do you have any other goals for this person?

**Employment**

- Would you like them to have a job? What kind of work?
- Would you like them to go to college?
- What kind of training would you like them to have?

**Living/Support**

- Where would you like them to live after secure care?
- Who would you like them to live with?
- What type of support would you like them to have in the future?
- What might they need support or help with?
- Do you think it is important that the person you care for has less support from people as they get better or will they always need support?

**Mental Health**

- How do you know when their mental health has improved?
- Has the way they talk about their feelings changed? Is this important?
- Has the way they speak to people changed? Is this important?
- Is medication important?

**Adaptive Skills**

- How much support do you think they will need in the future? (e.g. 24 hour, few hours a day)
- Is it important for them to be in charge of their own money?
- Is it important that they are able to look after themselves (cooking, washing, shopping)?
- How important is not using drugs and alcohol for the person you care for?

Is there anything else you would like to say about their life after secure care?

Is there any other outcome as a result of secure care that should be researched?

---

**Close**

Talking about these issues can be difficult. If talking about the person you care for and their future has made you feel unhappy please contact one of the research team. Talking to you has been really helpful. Thank you for taking part.



# Appendix 6 Delphi information sheet and round 1 questionnaire

## Outcome domains for services for people with intellectual and developmental disabilities

NIHR Health Services and Delivery Research Project 13/114/37

### Information Sheet

As a clinical or commissioning expert in the field of Forensic Intellectual and Developmental Disability (FIDD) we would like to invite you to take part in a Delphi consensus study. Before you decide whether or not you would like to take part, it is important to consider why the research is being done and what it will involve. Please read this information sheet carefully.

#### What is the purpose of the study?

Relatively little is known about outcomes from forensic intellectual developmental and disability (FIDD) services, other than from a small number of single site studies. This study is part of the scoping phase of a future longitudinal research project on outcomes from FIDD services, which would include secure and less secure services and specialist community forensic ID services for people with ID and ASD. This study aims to develop an expert consensus on which are the most appropriate outcome domains and indicators for use in future evaluation of such services. This would include outcomes which relate both to what happens to patients as a result of their care in such services, and aspects of the quality of care in services. We are interested in your views on the important domains and on how these are best measured.

#### What is a Delphi study?

The Delphi technique seeks to generate a level of agreement on a particular topic based on the opinions of experts. This is an iterative process designed to combine opinion into group consensus.

For the purposes of this study this will be a two-stage process. In round one, you will be asked to provide responses and ratings to a series of questions. The responses are collated, summarised and fed back in round two. During the second round you will have the opportunity to respond to the questions again. It is important that you complete both rounds.

All responses received in the study will be strictly confidential. Direct quotes from free-text answers may be used as part of the study report or later Delphi iterations, but these will be anonymised and therefore not traceable back to you.

Findings will inform the future wider project and will also be disseminated to FIDD services, commissioners, researchers, and patients to inform current clinical practice.

#### Who is organising and funding the research?

This research is part of a National Institute for Health Research (NIHR) funded research project examining outcomes for FIDD services. The Delphi study will be led by Dr. Catrin Morrissey, Principal Investigator. The research advisory team include Dr Regi Alexander, Dr Jayne McCarthy, Dr John Devapriam, Dr Peter Langdon, Prof. Conon Duggan, Prof. Bill Lindsay & Dr Dawn-Marie Walker

#### Confidentiality

No personal information will be collected and survey responses will be collated anonymously. All responses received in the study will be strictly confidential, and your identity will not be divulged. Direct quotes to free-text answers may be used as part of the study report or later Delphi iterations, but these will be anonymised and therefore not

**Data protection**

Survey responses will be collected online. Results will be downloaded to an encrypted Nottinghamshire Healthcare NHS Foundation Trust computer to allow analysis by the research team, using a participant identifying number known only to the research assistant. Data will be stored for the duration of the research project only and then deleted. You have the right to access submitted information according to UK data protection laws.

**Governance**

The proposed study has been reviewed by the Nottinghamshire Healthcare NHS Foundation Trust Research and Development Department.

**What do I do now?**

Thank you for reading this information sheet and for considering taking part in this research. If you are happy to proceed, read the instructions and proceed to complete the survey. If you have any questions or concerns please do not hesitate to contact the project lead via email ([Catrin.Morrissey@nottingham.ac.uk](mailto:Catrin.Morrissey@nottingham.ac.uk)).

## Instructions

- This survey is part of the scoping phase of a project relating to outcomes from forensic intellectual and developmental disability (FIDD) services. These services include those for people with ASD with or without intellectual disabilities.
- We are aiming to identify which outcome domains and indicators should be a priority for FIDD service evaluation. This relates to evaluating both the progress of patients treated in such services (both in the short and longer term i.e. during treatment in hospital and post discharge) and for evaluating the quality of care in such services as a whole.
- We are therefore consulting experts for their views on the areas of greatest importance and highest priority. The aim is to develop a consensus on which indicators should be included in a future longitudinal study of such services, and could potentially be utilised as common outcome indicators across such services. The three overarching domains of interest are those identified in the NHS Outcomes Framework - Effectiveness, Patient Safety and Patient Experience. However there are many potential sub-domains within these three areas. We are interested both in your views on the most important domains and on how these are best measured.
- The domains, sub-domains and indicators listed below have been identified from a systematic review of the literature in this area in June 2015 and from consultations with patients and carers conducted in June 2015.
- There are five parts to this questionnaire; please complete all five sections. It should take no longer than 10-15 minutes

**Part One: Background Information**

Discipline/background	Psychiatry Psychology Nursing AHP Other .....
Area of Work (tick all that apply)	Academic/Research Clinical Commissioning Other .....
Number of years working in /researching/commissioning Forensic Intellectual Disability Services	___ years
Type of service currently working in (tick all that apply)	High Secure Medium Secure Low Secure Community Locked Rehabilitation Non-Secure LD, ID or ASD service

## Part Two: Effectiveness

Please rate how **important** you think the following outcome domains/indicators are for evaluation of forensic intellectual and developmental disability (FIDD) services. A key is provided below; ratings are made from 1 to 5.

IMPORTANCE/PRIORITY				
1	2	3	4	5
Not at all important	Slightly Important	Neither Important or Unimportant	Moderately Important	Extremely Important
<ul style="list-style-type: none"> <li>• Not important or appropriate outcome domain for FIDD services</li> <li>• Not a priority</li> </ul>	<ul style="list-style-type: none"> <li>• Slightly important and appropriate outcome domain for FIDD services</li> <li>• A low priority</li> </ul>	Neutral as to whether it is important or appropriate for FIDD services	<ul style="list-style-type: none"> <li>• Important and appropriate outcome domain for FIDD services</li> <li>• A priority</li> </ul>	<ul style="list-style-type: none"> <li>• Highly important and appropriate outcome domain for FIDD services</li> <li>• High priority</li> </ul>

Effectiveness		
	IMPORTANCE (1 to 5)	Preferred Measures/Indicators
Length of hospital stay		
Delayed discharge/ Current placement appropriateness		
Discharge outcome/ direction of care pathway (i.e. did the patient move to a lower level of therapeutic security/non hospital setting )		
Re-admission (i.e. was the patient readmitted within a specified time period?)		
Treatment response/engagement		
Clinical symptom severity /treatment needs – patient rated		
Clinical symptom severity – clinician rated		
Adaptive functioning		
Incidents (violence/self-harm)		

Re-offending (charges/reconvictions)		
'Offending-like' behaviour (i.e. behaviour which did not result in charges)		
Security need (e.g. physical/procedural/escort/leave)		
Risk assessment measures		
Recovery measures/progress on treatment goals – patient rated		
Recovery measures/progress on treatment goals – clinician rated		

**Please specify any additional outcome domains or indicators which you consider important from your expert knowledge / experience, which were not listed above.**

### Part Three: Patient Safety

Please rate how **important** you think the following outcome domains/indicators are for the evaluation of forensic intellectual disability services. A key is provided below, ratings are made from 1 to 5.

IMPORTANCE				
1	2	3	4	5
Not at all important	Slightly Important	Neither Important or Unimportant	Moderately Important	Extremely Important
<ul style="list-style-type: none"> <li>• Not important or appropriate for FIDD services</li> <li>• Not a priority</li> </ul>	<ul style="list-style-type: none"> <li>• Slightly Important and appropriate for FIDD services</li> <li>• Low priority</li> </ul>	Neutral as to whether it is important or appropriate for FIDD services	<ul style="list-style-type: none"> <li>• Important and appropriate for FIDD services</li> <li>• A priority</li> </ul>	<ul style="list-style-type: none"> <li>• Highly appropriate and important for FIDD services</li> <li>• High priority</li> </ul>

Patient Safety	IMPORTANCE (1 to 5)	PREFERRED INDICATOR
Restrictive practices: seclusion/segregation		
Restrictive practices: restraint		
Death/Suicide		
Victimisation/safeguarding		
Medication (e.g PRN/ exceeding BNF)		
Physical health		

**Please specify any additional outcome domains or indicators which you consider important from your expert knowledge / experience, which were not listed above.**

### Part Four: Patient Experience

Please rate how **important** you think the following outcome domains/indicators are for the evaluation of forensic intellectual disability services. A key is provided below, ratings are made from 1 to 5.

IMPORTANCE/PRIORITY				
1	2	3	4	5
<b>Not at all important</b>	<b>Slightly Important</b>	<b>Neither Important or Unimportant</b>	<b>Moderately Important</b>	<b>Extremely Important</b>
<ul style="list-style-type: none"> <li>• Not important or appropriate outcome domain for FIDD services</li> <li>• Not a priority</li> </ul>	<ul style="list-style-type: none"> <li>• Slightly important and appropriate outcome domain for FIDD services</li> <li>• A low priority</li> </ul>	Neutral as to whether it is important or appropriate for FIDD services	<ul style="list-style-type: none"> <li>• Important and appropriate outcome domain for FIDD services</li> <li>• A priority</li> </ul>	<ul style="list-style-type: none"> <li>• Highly important and appropriate outcome domain for FIDD services</li> <li>• High priority</li> </ul>

Patient Experience		
	IMPORTANCE (1 to 5)	Preferred Measures
Quality of Life (patient rated)		
Quality of Life (clinician rated)		
Patient experience: satisfaction/complaints		
Patient experience: involvement in care		
Carer experience: communication		
Carer experience: involvement		
Therapeutic Milieu		

**Please specify any additional outcome domains or indicators which you consider important from your expert knowledge / experience, which were not listed above.**

**Part Five: Top Outcome Domains**

Please select **up to five** outcome domains which, in your opinion, are the most important/highest priority for the routine evaluation of forensic intellectual disability services. I.e. if services had to collect only five outcome indicators which would they be?

You may include domains already identified in the lists above OR additional domains you identify as important.

1.
2.
3.
4.
5.

**Additional Comments**

**Thank you for completing the Delphi Exercise. The second stage will be e-mailed to you in 2 weeks time.**

# Appendix 7 Delphi round 2 questionnaire

## Round Two

**Thank you for taking part in the first round of this Delphi exercise. This is the second and final round. Please read these instructions carefully:**

We are interested in your views on the most important/highest priority outcome domains. The aim of this Delphi is to develop a consensus on which sub-set of indicators should be included in a future longitudinal study of such services, and could potentially be utilised as common outcome indicators across such services.

- There are two parts to this questionnaire. Firstly, please review and rate the importance of each sub-domain using the scale provided. There are 31 items to rate.
- Secondly, please select up to five sub-domains which you perceive to be the most important/highest priority.
- You will see two columns next to each subdomain in both sections. The middle column shows the group response and the right-hand column is blank and is provided for you to reconsider your original response in the context of the group response from the previous round.
- Your ratings from Round One are supplied as a PDF attachment to email invitation. You do not have to change your answer if you do not wish to do so.
- Please complete both sections. It should take no longer than 10 minutes.

## Section Two: Rating of Outcome Domains

Please rate how **important** the following outcome domains are for evaluation of forensic intellectual and developmental disability (FIDD) services.

- Please provide a new rating in the right-hand column Ratings are made from 1 (not important) to 5 (extremely important).
- Your original ratings are attached to your email invitation (Sections 3, 4 and 5).
- The average group score from Round One is presented in the middle column.
- You do not have to change your response from your original answer if you do not wish to.

<b>1 Not at all important</b>	<b>2 Slightly Important</b>	<b>3 Neither Important or Unimportant</b>	<b>4 Moderately Important</b>	<b>5 Extremely Important</b>
<ul style="list-style-type: none"> <li>• Not an important or appropriate outcome domain for FIDD services.</li> </ul> <p>Not a priority</p>	<ul style="list-style-type: none"> <li>• A slightly important and appropriate outcome domain for FIDD services.</li> </ul> <p>A low priority</p>	<p>Neutral as to whether it is an important or appropriate outcome domain for FIDD services.</p>	<ul style="list-style-type: none"> <li>• An important and appropriate outcome domain for FIDD services.</li> </ul> <p>A priority</p>	<ul style="list-style-type: none"> <li>• Highly important and appropriate outcome domain for FIDD services.</li> </ul> <p>A high priority</p>

<b>Effectiveness</b>	<b>Average Rating</b>	<b>Your Rating</b>
Length of hospital stay	3.65	
Delayed discharge/current placement appropriateness	4.24	
Discharge outcome/direction of care pathway (i.e. the patient moves to a lower level of therapeutic security/non hospital setting)	4.53	
Re-admission (i.e. the patient is readmitted within a specified time period)	4.00	
Treatment response/engagement	4.65	
Clinical symptom severity /treatment needs – patient rated	4.24	
Clinical symptom severity/treatment needs – clinician rated	4.41	
Adaptive functioning	3.82	
Incidents (violence/self-harm)	4.29	
Re-offending (charges/reconvictions)	4.59	
‘Offending-like’ behaviour (i.e. behaviour which did not result in charges)	4.47	
Security need (i.e. physical/procedural/escort/leave)	3.94	
Risk assessment measures	4.35	
Recovery measures/progress on treatment goals – patient rated	4.53	
Recovery measures/progress on treatment goals – clinician rated	4.47	
<b>Patient Safety</b>		
Restrictive practices (i.e. seclusion/segregation)	4.29	
Restrictive practices (i.e. restraint)	4.29	
Premature death and suicide	4.59	
Victimisation/safeguarding	4.53	
Medication (i.e. PRN/ exceeding BNF prescribing limits)	4.24	
Physical health	4.12	
<b>Patient/Carer Experience</b>		
Quality of Life - patient rated	4.59	
Quality of Life - clinician rated	3.94	
Patient experience: satisfaction/complaints	4.29	

Patient experience: involvement	4.41
Carer experience: communication	4.18
Carer experience: involvement	4.06
Therapeutic Milieu	4.41
Closeness to 'home' area	3.59
Involvement in community (where appropriate)	4.35
Access to work/meaningful activity (where appropriate)	4.65

## Section Two: Top Five Outcome Domains

In Round One, you selected up to 5 outcome domains which were the most important/highest priority for the evaluation of forensic intellectual disability services.

In the right-hand column, use the checkbox provided to select up to 5 sub-domains which are, in your opinion, the most important and of the highest priority.

The items you originally endorsed as being the most important ('top 5') are attached (question 6).

The percentage of respondents who endorsed each sub-domain as one of their top five most important outcomes is presented in the middle column.

You do not have to change your response from your original answer if you do not wish to.

Effectiveness	%	
Length of hospital stay	24	<input type="checkbox"/>
Delayed discharge/current placement appropriateness	18	<input type="checkbox"/>
Discharge outcome/direction of care pathway	41	<input checked="" type="checkbox"/>
Re-admission (i.e. the patient is readmitted within a specified time period)	18	<input type="checkbox"/>
Treatment response/engagement	47	<input checked="" type="checkbox"/>
Clinical symptom severity/treatment needs	70	<input checked="" type="checkbox"/>
Adaptive functioning	24	<input type="checkbox"/>
Incidents (violence/self-harm)	18	<input type="checkbox"/>
Re-offending (charges/reconvictions)/ 'Offending-like' behaviour	59	<input checked="" type="checkbox"/>
Security need (i.e. physical/procedural/escort/leave)	12	<input checked="" type="checkbox"/>
Risk assessment measures	41	<input type="checkbox"/>
Recovery measures/progress on treatment goals	41	<input type="checkbox"/>
Patient Safety		
Restrictive practices (i.e. seclusion/segregation/restraint)	12	<input type="checkbox"/>
Premature death and suicide	12	<input type="checkbox"/>
Victimisation/safeguarding	1	<input type="checkbox"/>
Medication (i.e. PRN/ exceeding BNF prescribing limits)	12	<input type="checkbox"/>
Physical health	1	<input type="checkbox"/>
Patient Safety in general	12	<input type="checkbox"/>

<b>Patient/Carer Experience</b>		
Quality of Life	12	<input type="checkbox"/>
Patient experience	24	<input type="checkbox"/>
Carer experience	0	<input type="checkbox"/>
Therapeutic Milieu	6	<input type="checkbox"/>
Closeness to 'home' area	0	<input type="checkbox"/>
Involvement in community (where appropriate)	0	<input type="checkbox"/>
Access to work/meaningful activity (where appropriate)	24	<input type="checkbox"/>

Please use this space to provide any other comments.

## Appendix 8 Provisional 'long list' of measures/indicators

Effectiveness domain	Measure/indicator (individual-/patient-level data)
Direction of care pathway (compared with 12 months ago)	% of patients who (compared with 12 months ago) are <ul style="list-style-type: none"><li>● in higher level of security hospital/prison</li><li>● in same level of security hospital</li><li>● in lower level of security hospital</li><li>● discharged to community</li><li>● in prison</li></ul> For those discharged, community status: <ul style="list-style-type: none"><li>● CTO</li><li>● conditional discharge</li><li>● guardianship</li><li>● no restrictions/framework</li></ul> Living arrangement and level of support
Readmitted (community)	For those discharged to community: <ul style="list-style-type: none"><li>● ever readmitted: yes/no</li><li>● number of bed-days in past 12 months</li><li>● number of prison-days in past 12 months</li></ul>
Length of hospital stay	Date of hospital admission – current date. If discharged, length of stay on discharge date
Clinical symptoms (patient rated)	Clinical Outcomes Routine Evaluation – LD (total score) (12-item outcome measure validated on intellectual disabilities)
Clinical symptoms (clinician rated)	HoNOS-secure clinical scale items (total score); Clinical Global Impression Scale
Recovery/engagement/progress on treatment goals (clinician rated)	Team rating, for example: <ul style="list-style-type: none"><li>● good (making good progress on treatment goals and well engaged)</li><li>● fair (mixed progress or static)</li><li>● poor (regression; disengagement or negative progress in relation to treatment goals)</li></ul> Or <ul style="list-style-type: none"><li>● HCR-20-V3 item C5</li><li>● treatment responsiveness measure (to be designed)</li><li>● Camberwell Assessment of Needs for Adults with Developmental and Intellectual Disabilities measure (need)</li></ul> Specific treatment goal measure (My Shared Pathway or similar)
Recovery/engagement/progress on treatment goals: (patient/carer rated)	Parallel ratings to be developed
Adaptive functioning	HoNOS-secure rating (item 10)
Risk assessment	HCR-20-V3 summary rating: <ul style="list-style-type: none"><li>● high</li><li>● medium</li><li>● low</li></ul> HCR-20-V3 clinical items total HoNOS-secure rating A (risk of harm)

<b>Effectiveness domain</b>	<b>Measure/indicator (individual-/patient-level data)</b>
Incidents	<p>Mean number contact violent/sexual incidents per month of inpatient stay (past 12 months) (<i>agreed definition required</i>)</p> <p>Mean severity of incidents (past 12 months)</p> <p>Each incident coded, for example:</p> <ol style="list-style-type: none"> <li>1. high risk of harm to others</li> <li>2. medium risk of harm to others</li> <li>3. low risk of harm to others</li> </ol> <p>Mean self-harm incidents per month (past 12 months) (<i>agreed definition required</i>)</p> <p>Mean severity of incidents (past 12 months)</p> <p>Each incident coded:</p> <ol style="list-style-type: none"> <li>1. high risk of harm to self</li> <li>2. medium risk of harm to self</li> <li>3. low risk of harm to self</li> </ol>
Level of security appropriate to current needs	<p>HoNOS-secure item C (compared with actual level)</p> <p>OR</p> <p>Security, Dependency and Treatment Needs scale</p>
Reoffending (community)	<p>In past 12 months:</p> <ul style="list-style-type: none"> <li>• number of arrests (police records)</li> <li>• number of charges (police records)</li> <li>• number of convictions (criminal records)</li> </ul>
Offence-like behaviour (community)	<p>In past 12 months:</p> <p>Number of incidents using same definition of 'incident' as for inpatient (service or carer records using structured format)</p>
<b>Patient safety domain</b>	<b>Measure/indicator (service-level data)</b>
Premature death/suicide	<p>Number of premature/unexpected deaths (past 12 months) (as NHS Outcomes Framework)</p> <p>Reason code</p>
Physical health	<p>HoNOS-secure item B (mean for service)</p> <p>HoNOS-LD (if community)</p>
Self-harm	Self-harm incidents (12 months)
Medication	<p>Number of patients exceeding BNF limit (past 12 months)</p> <p>Number of PRN episodes (past 12 months)</p>
Medication (patient rating)	<p>Patient survey rating with pictorial rating, for example:</p> <ul style="list-style-type: none"> <li>• my medication makes me feel worse</li> <li>• my medication does not make me feel better or worse</li> <li>• my medication makes me feel better</li> </ul> <p>Or LUNERS measure</p>
Seclusion	<p>Mean number of seclusion episodes per inpatient month (past 12 months)</p> <p>Or</p> <p>Number of episodes per month per 10 inpatient beds (see NHS benchmarking)</p>

Effectiveness domain	Measure/indicator (service-level data)
Restraint	Mean number of restraints per inpatient month (past 12 months)
	Or
	Number of restraints per month per 10 inpatient beds (see NHS benchmarking)
Victimisation/SG	Number of patient on patient assaults recorded (past 12 months)
	HoNOS-secure scales item F
	Patient survey rating, for example:
	% of patients who endorse 'I feel safe and secure in this service'
Patient/carer experience domain	Measure/indicator (all rated once in a 12-month period) (service-level data)
Patient complaints	Mean number of patient generated complaints per inpatient month
Patient involvement	Patient survey rating with pictorial rating, for example:
	<ul style="list-style-type: none"> <li>● I feel my team involve me a lot in my own care</li> <li>● I feel my team involve me a bit in my own care but I would like to be more involved</li> <li>● I feel my team do not involve me in my care</li> </ul> <p>(Or CTR rating achieved?)</p>
Quality of life	MANS-LD or European Quality of Life-5 Dimensions
Stability: number of home moves in past 12 months (community)	Number of home moves
Access to work and meaningful engagement	Mean number of hours meaningful activity per patient per week
	% in paid work (community) (see <i>NHS Outcomes Framework</i> <sup>83</sup> )
Carer experience	
Involvement	Carer survey rating, for example (% rating 'enough' involvement):
	<ul style="list-style-type: none"> <li>● I feel my team involve me enough in my relative's care</li> <li>● I feel my team involve me in my relative's care but I would like to be more involved</li> <li>● I feel my team do not involve me in my relative's care</li> </ul>
Communication	Carer survey rating, for example (% carers rating good communication):
	<ul style="list-style-type: none"> <li>● I feel there is good communication between the carer and the care team</li> <li>● I feel there is adequate communication between the carer and the care team</li> <li>● I feel there is poor communication between the carer and the care team</li> </ul>
Therapeutic climate	Friends and Family Test (% who would recommend service)
	At least 50% sample staff EssenCES within 12-month period
	At least 50% sample patient EssenCES (intellectual disabilities adapted) within 12-month period
	Mean total score on three EssenCES subscales
Level of support (patient-rating)	Patient/service user survey rating, for example (% rating good support):
	<ul style="list-style-type: none"> <li>● I feel I have good support</li> <li>● I feel I would like a bit more support</li> <li>● I feel I would like a lot more support</li> </ul>

Effectiveness domain	Measure/indicator (service-level data)
Level of support (carer-rating)	(% rating good support)
	<ul style="list-style-type: none"> <li>● I feel I/my relative has good support</li> <li>● I feel I/my relative would like a bit more support</li> <li>● I feel I/my relative would like a lot more support</li> </ul>
Social network (community)	Social Network Guide (Tizard Centre 2006, personal communication)

BNF, *British National Formulary*; CTO, Community Treatment Order; CTR, Care and Treatment Review; HCR-20-V3, Historical, Clinical Risk 20 version 3; LUNERS, Liverpool University Side Effects Rating Scale; MANS-LD, Maslow Assessment of Needs Scales - Learning Disabilities; SG, safeguarding.

**Notes**

Clinical background variables to be coded, for example: diagnoses; Wechsler Adult Intelligence Scale – IV; criminal history; MHA section; initial level of security, etc.

For most effectiveness variables change on the variable is to be measured, so the final indicator will need to be a summary rating of within-patient change. For example, (in past 12 months):

- % patients who increased score on item (got worse)
- % patients who reduced score on item (improved)
- % patients with unchanged score (no change).

It will be important to consider parallel indicator items from the NHS Outcomes Framework, Adult Social Care Outcomes Framework and Mental Health and Learning Disability minimum data set when appropriate.

# Appendix 9 Summary of research for public and patient involvement dissemination

## Health Services and Delivery Research Programme research project 13/114/37

What happens to people who are in secure services for people with intellectual and developmental disabilities?

Looking at the previous research and consulting with patients in hospital, their carers and their clinicians.

### **What we wanted to do**

- We are a group of researchers who work in different secure services.
- This is a report on some work we did in 2015.
- We want to know what happens when patients with IDD are in secure hospital and after hospital. We call this 'outcomes'.
- We want to know things like: how do they change, where do they end up and what support do they get later on?
- This small piece of work was part of planning our next big research project, which will take 5 years.
- Because it will be a big project we want to do it properly.
- So we want to know what questions to ask, what things are important to measure and how to measure them.
- To help to decide this we looked at work by other researchers, and we talked to secure patients and carers, and their doctors, nurses and psychologists.
- We wanted to find out to find out what these people thought we should look at when we are doing our big research project.
- The work was paid for by the NIHR.

### **What we did**

- We looked carefully at 60 studies from around the world.
- We talked to 11 patients and six carers and 15 clinicians.
- We put all this information together.

### **What we decided**

The main three areas we decided we should look at in future research were:

1. Does secure hospital treatment make people better?
2. How safe are patients in hospital?
3. What is hospital like for patients and their carers? And what is their experience on discharge from hospital?

We will talk about each of these.

#### **1. Does secure hospital treatment make people better?**

The conclusions were that in our next research the most important things to measure are:

- i. How peoples' mental health symptoms change and how patients see that change.
- ii. Whether people are reaching their goals for treatment and how patients see their progress.

- iii. How peoples' behaviour changes (e.g. do they harm others or themselves any less often?).
- iv. Whether people do actually commit offences or harm others when they come out of hospital.
- v. How people move through the hospital system and how fast do they do that?

**2. How safe are patients in hospital?**

The conclusions were that in our next piece of research we should look at:

- i. How often people are secluded or restrained?
- ii. How many people feel they are on too much medication?
- iii. How many people died or took their own life?
- iv. How often other patients are harmed by other patients?

**3. What is hospital like for patients and their carers and what happens on discharge?**

The conclusions were that in our next research project we should look at:

- i. How satisfied patients are with their care?
- ii. How satisfied carers are with their care?
- iii. How involved patients and carers feel in the care – do they have a say?

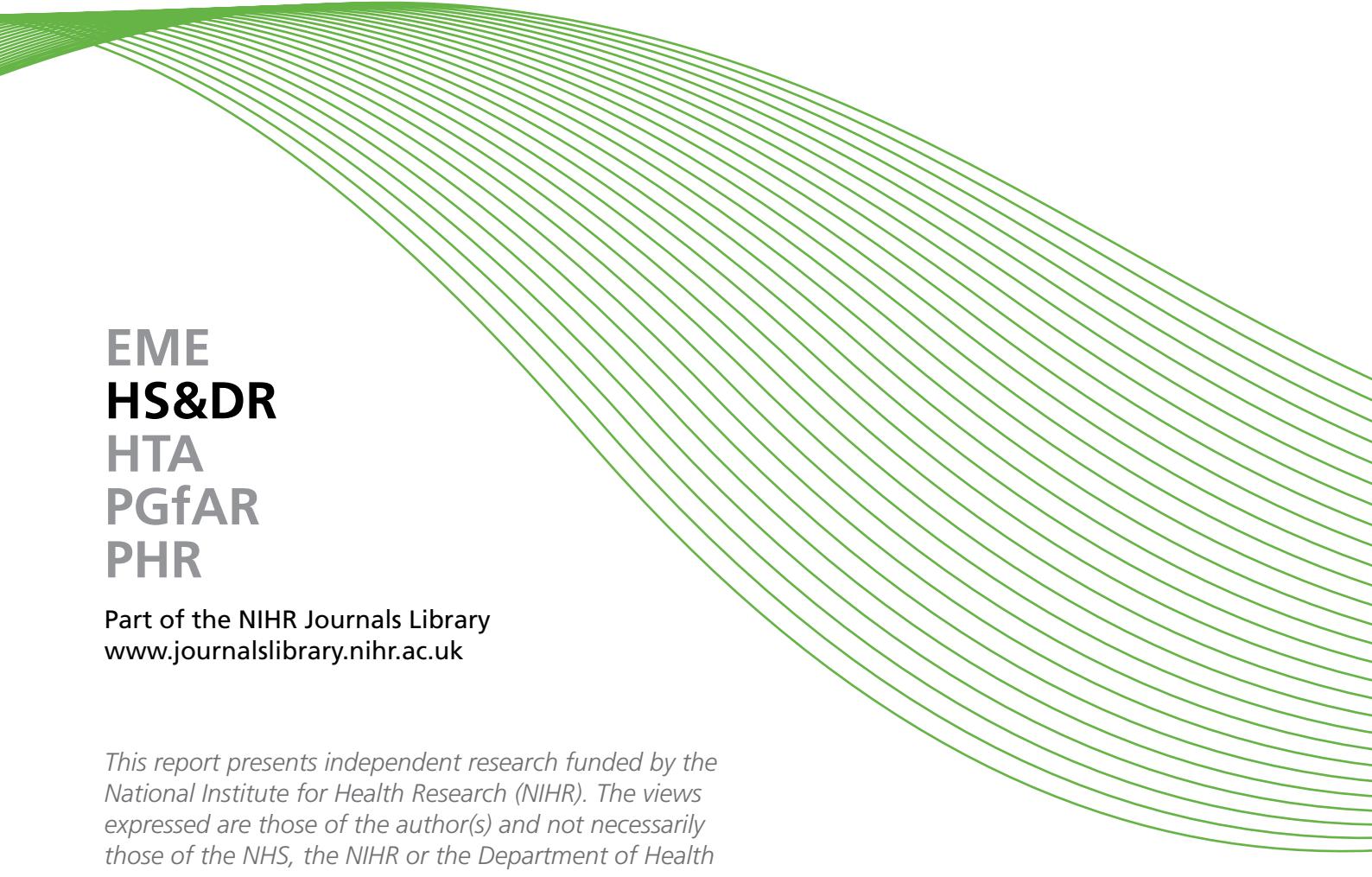
When they leave hospital:

- i. Where do people go?
- ii. How much support do people get when they leave hospital?
- iii. How involved they are in the community?
- iv. Whether patients have enough to do in hospital and after hospital.
- v. Do they go back to hospital or prison?

We have suggested ways to measure all these things.

We plan to apply for funding from NIHR to collect information on ALL people with LDs and autism who go through secure hospitals. We want to describe their characteristics in detail and to see what happens to them over 5 years. We want to know what happens both while they are in hospital and after hospital.





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