

# **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**

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

## 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
<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>

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
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>

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.**

A large, empty rectangular box with a thin black border, intended for the user to provide additional information or specify outcome domains and indicators 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.**