

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.

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.