

# CaFI Service Users Focus Group: Topic Guide

## Part 1: Introduction

Thank you so much for taking part in our interview today. We are really interested in hearing your views about talking therapies for African Caribbean people with schizophrenia and their families. It is important that we learn from your experience and that of others so that we can work together to create a treatment that meets the needs of African Caribbean people.

I'm Dawn Edge. I developed the research with input from service users, people in the community and other University researchers. This is Amy Degnan. Amy is the Project Manager for this research. We'll be working together. We will ask you questions and seek your views about information that we will share with you on flip charts.

### Technicalities

We will be using an electronic recorder to record the interview. This is because note-taking can be unreliable. If you want to have a closer look at it or try it out for yourself that's absolutely fine. Are you ok with me using the recorder? Ok. To help us remember points that we might want to come back to later or to record things that are especially important, we will take brief notes while we're speaking. If you want to check what we're writing just ask.

### Confidentiality

The recording is confidential. No-one, apart from specific members of this research team, will ever hear the recording. We will transfer what has been recorded onto a secure computer and erase the recording of our interview from the recorder. We will then transcribe (type out) our interview. When we type up the interview, we will remove any details that could identify you, anyone you mention by name, and any other details that could be used to identify you (such as names of schools, towns, hospitals, etc) from the transcript. This is to make sure ALL the information we collect is anonymised and that your identity is protected (*explain anonymisation if necessary*). Do you have any questions about any of that?

### Risk

As we've mentioned before, everything you tell us is confidential. We also ask that you respect the confidentiality of people in the group. However, if you tell me or Amy that you or someone else is at risk of being harmed, then we will need to break our confidentiality by telling the relevant people, for example, by speaking to one of the keyworkers here. I wouldn't usually do this without your knowledge, and would usually discuss this with you first. Before we begin the interview, it's important that we agree some ground rules. Tell us what you think they should be and we'll write them up on flipchart to remind everyone what we agree.

Before we start asking you questions, this is how we think **today's session will look** (*session outline*). What do you think?

## **Part 2: Perceptions of Need for 'talking therapy' & CaFI**

***Before we switch on the recorder, does anyone have any questions?***

We'd like to begin by finding out what you think about the idea of developing a 'talking therapy' **specifically for African Caribbean service users and their families.**

*[Explanation 'talking therapy': currently in NHS we have medical treatments and talking treatment which generally involve talking to people about their mental well being and helping them to think about changes in their lives that they could make to improve well being]*

**There are a number of family therapies available – including 'Family Intervention'.**

***[Explanation of FI: type of talking treatment that involves all the family and looks at finding other ways of coping with mental health issues that are causing problems for service users and/or their family members]***

**Q1. Does anyone here have experience of FI?**

*[Prompt: If so, can you tell us a bit about it?]*

**Q2. What do think about family therapy for African Caribbean people?**

- *Benefits*
- *Challenges*

**Q3. What do you think family therapy for African Caribbean people with schizophrenia should look like?**

Thanks for that. We're now going to look at the family therapy that Manchester Mental Health Services use. We would like your views about what, if anything would need to change to make it more appropriate for African Caribbean people. **The therapy is divided into 5 main parts** (*slide*). We will deal with each one in turn to make it easier for us to focus on specific issues. *[Brainstorm]*

## **Part 3: Current FI & Cultural-adaptation**

### **Interview Questions**

**Brief rationale for general aim of assessment:**

FI is a series of meetings with service users and families. The FI starts by assessing how the illness affects service users and their families. This helps service users and family members to tell the therapist what they want out of therapy. This is usually done in interviews before the therapy starts. So we'll start by looking at **'Service User Assessment'**

## Section A: Service User Assessment

The purpose of 'Service User Assessment' is to help the therapist to identify service user's problems, needs and strengths from their personal viewpoint.

**In the current therapy, this covers 4 key areas. For each area, please give us examples that are relevant for African Caribbean people (*flipchart*)**

### 1. Current and past episodes of illness

- Main symptoms/experiences like *hearing voices that others cannot hear, delusions, lack of motivation, low mood, not wanting to socialise*
- Treatment and other ways of managing symptoms/illness
  - *What worked?*
  - *What didn't?*

### 2. Level of functioning

- How the illness affects your ability to function (day –to-day living) – from your own experiences, what should this cover?

*Prompts:*

- *being with other people*
- *taking part in social activities*
- *work*
- *going into situations with lots of people like shops*
- *your ability to plan ahead*
- *ability to plan activities*
- *ability to think about the future*
- *ability to motivate yourself to do things like exercise, training and prepare food etc..*

### 3. Strengths

- *Interests*
- *Abilities*
- *Ability to cope/manage everyday life and problems*

### 4. Relationships (the therapist might ask.....)

- How important are your relationships with your family and other people to you?
- How does your illness affect your relationship with your family and other people who are important you?
- *Prompt: If so, how: give examples:*
  - *less likely to see family members*
  - *less likely to be trusted e.g. being left alone with young kids*
  - *less likely to be included in family events etc..*

### What do you think about these examples?

*Prompts: (give examples)*

- *feeling criticised (e.g. he is lazy and never gets out of bed)*
- *Warmth – feeling that people care and want the best for you*
- *Stigma- fear of being judges, feeling that you can't tell people about your thoughts and feelings*

- *Shame – feeling a failure, like you've let your family, friends and yourself down*
- *Feeling people trying to control you/tell you what to do*
- *Being blamed for your problems*
- *Caring for me*
- *Making me laugh/Helps me forget my problems*

**Please tell us whether you think any of these areas needs to be added or removed to meet the needs of African Caribbean people.**

**Next, we'd like you to tell us which of these areas is MOST IMPORTANT to you.** Using the post-it notes, put number 1 in the box under the thing you think is most important e.g.....

### **Section B: Family Assessment**

The family assessment helps the therapist understand how the family understands the illness and how the illness affects family members. It is important to get an understanding of how they cope with the problems associated with the illness, their concerns and any difficulties in the home situation.

In the current therapy, this assessment covers a number of key areas. **Please tell us how important these are for African Caribbean carers and family members?** (*slide*)

1. The relative's **beliefs and attitudes about the illness**, the symptoms, medication, and so on.
2. **Distress in relatives and situations**, including thoughts that trigger distress.
3. **Dealing with service user's experiences and difficulties** [*give examples: hearing voices, feeling down, not wanting to be around people*], and how these affect the service user and family members.
4. The **impact of the illness on the relative**, including any restrictions (*e.g. social life, occupation*), hardships and difficulties (*e.g. financial*).
5. The **relative's relationship with the service user** – how they get on together [*prompts: do they enjoy each other's company? Any dissatisfaction as direct result of the illness*]
6. Areas of **strength and effective coping** strategies (*e.g. social supports, positive relationship with the service user*).

**Now, tell us if anything needs to be changed or added to meet the needs of African Caribbean families.**

### **Section C: Psycho-education**

This part of the therapy aims to work with families to gain a greater understanding about schizophrenia. What do you think should be included?

These are some of the areas covered in the current psych-education sessions. They focus on the service user's symptoms and problems, beliefs and attitudes. **Please tell us what you think about them.** (*flipchart*)

- Beliefs about the illness – ‘helpful’ and ‘unhelpful’ e.g. ‘he’s lazy – he won’t get out of bed’
- Hearing voices
- Delusions
- Lacking motivation
- Low mood and concentration
- Controllability and responsibility – extent to which service users can control symptoms

**Do you think anything needs to be removed, changed or added to make it more acceptable and appropriate for African Caribbean families?**

*Prompts:*

- *Drugs - illicit and medication*
- *Spirituality*
- *How mental health systems work*
  - *‘Sectioning’*
  - *Different parts of the service (e.g. primary vs secondary care)*
  - *Roles of key professionals (people you may come into contact with who may be involved in your relative’s care)*
  - *Language – explaining medical terms and ‘jargon’*

Finally, in this section, please tell us what you think about the term ‘psycho-education’.

- *Can you think of any alternatives that might be more acceptable?*

## **Section D: Stress Management and Coping Responses**

Living with schizophrenia is hard for both the individual and close family, whether or not they live together. People diagnosed with schizophrenia may be unusually sensitive to stress, which can make their symptoms worse. It is common for relatives to feel anxious or upset at times – especially as a lot of the day-to-day care and support is carried out by family members. So, it’s important that they get help to manage their own stress and coping so that they can help the service user.

These are the areas covered in the current therapy. **Please tell us what you think about them.** (*flipchart*)

- Current stress in the family
  - Service-user focused situations that are difficult to cope with (*e.g. aggressive behaviour and suicide risk*)
- Stress management
  - Current helpful/unhelpful ways of coping with stress
  - Resources and strengths for helping to manage stress (*e.g. Social support, leisure interests, relaxation training*)
- Self-monitoring
  - Monitoring daily stressors, stressful situations and ways of coping (*e.g. diary*)
- Changing unhelpful ways of dealing with stress
  - Relatives’ unhelpful beliefs about behaviours and unrealistic expectations (*e.g. trying to change delusional beliefs/voice hearing through arguments or threats*)

**Do you think anything needs to be changed or added to make it more appropriate for African Caribbean people?**

## **Section E: Problem-solving and planning for positive change**

This part of the therapy is about helping families know better how to solve problems in positive and helpful ways by **seeing problems as needs that can be changed**. Problem solving is a way of helping people to manage current difficulties by helping them to feel more in control of their problems. To do this, it is important to identify what strengths the service user and their families have. The therapist then works **together** with the service user and family to identify problems and how to change things for the better. These are the 10 steps that the service user, therapist and the family work through to achieve the goals they agree (*slide*) and works through them using this cycle (*slide*)

*[Examples: problem: service user always short of money so borrows from family and friends; becomes when doesn't receive. Need: better budgeting. Strengths/resources: support from family, debt advice, support worker/care coordinator. Goal: encourage service users to budget better so don't ask family for money all the time and be aggressive when needs aren't met. Plan: weekly budget, written agreements, saving for rainy day, set amount each day. Review: increase independence with money. Commence new goal]*

- **Please tell us what you think of this process**
- **Is there anything that needs to change to make it more appropriate for African Caribbean people?**

Thank you very much for telling us what you think the therapy should look like. We now want to ask you about some other things that we think might be important.

## **Part 4: Delivery of CAFI**

### **Outcome measures**

When we have developed the new family therapy, we need to be able to show whether or not it makes a difference to service users and their families.

If you were to take part in this kind of therapy:

- **What would be most important changes or benefits you'd like to see? (*Flipchart*)**
  - *Prompts: symptoms, relapse, hospital admission, relative criticism, family environment/atmosphere, stigma, better coping/management*

[You could write on two bits of flipchart: Benefits for families and Benefits for service users, with 2 columns on each, titled "Change" and "Measure". And then ask people to shout out all the possible changes, then work together to think about the corresponding change.

***Perhaps use sticky dots so people can choose which of the Changes are most important to them personally, so you can measure strength of opinion.***]

- **Are there any bad outcomes that you would like to avoid?**
- **How could we measure these?**
  - *Prompts: interviews, short questionnaires, observations*
  - *Prompts: monitor every session, at the start and end of therapy*
- We're thinking of using a questionnaire that will help us measure family members'/relatives' knowledge about schizophrenia before and after the therapy (**show KASI**). **What do you think about this?**
- Have you filled out questionnaires like this before? If so, what was it like?

### **Delivery (working in groups - paper)**

- **How many sessions do you think would be best?**
  - *Prompt: the current therapy is about 10 sessions because that's what NICE recommend. What do you think?*
  - *Can you think of something else in your lives you have committed to – how long did they sustain that? What made you stick with it?*
- **How long do you think each session should last?**
  - *Prompts: the current therapy is 1-2 hours?*
- **How long should the therapy last?** The current therapy takes place over around 9 months. Initially, weekly sessions and then reducing to fortnightly and monthly when appropriate. **What do you think about this – is this too long or too short?**
- **Do you think families and service users should be seen together or separately?**
  - *Prompt: often people find it useful to do both*
- **Where should the therapy take place?**
  - *Prompts: family home, mental health services, community centres, university*
- **What do you think about having African Caribbean therapists versus therapists from different ethnic or cultural backgrounds?**
- **Are there any materials that you think might be beneficial for families to have during sessions?**
  - *Prompts: information sheets about discussions in the therapy, summaries of therapy sessions*
  - *What information would you want to know before you come?*

If you were to sign up for the therapy:

- **What would keep you coming back to the sessions?**
- **What might put you off?**
- **Can you think of anything in particular that might stop you completing the all the sessions?**

### **Proxy Families**

We're thinking of asking people from the community and former service users to sign up to be **'proxy families'** that service users who've lost touch with their families can get the therapy

*[service users will be able to nominate people but if they don't have anybody, we could recommend people who have volunteered e.g. church/youth workers].*

- **What do you think of this idea?**
- **What qualities do you think these people should have?**
- **What do you think are the pros and cons of having African Caribbean people versus other ethnic groups?**
- **We are going to provide training, what should we include?**

## Language

The therapists' use of language is likely to be very important. Often people find some medical terminology stigmatising and certain words to describe the service user's problems and treatment might mean different things for different people.

- **Is there anything around communication or language that you think the therapist needs to consider when delivering the therapy to African Caribbean people?**
  - *Prompts: medical jargon, slow pace for service users that are unwell, not too much information*
- **Please tell us what you think of the following terms:**
  - 'Intervention' and 'therapy'
    - Which do you think is the most appropriate?
  - 'Schizophrenia' and 'psychosis'
    - Which do you think is the most appropriate?
  - Proxy families
    - Can you think of any alternatives?

## Engagement & Uptake

- **Can you think of anything that might put you off taking part in the therapy?**
- **What might make it difficult for you to take part?**
- **What would make you want to get involved in this therapy?**

## Closing out

That's it! We've reached the end of the interview. But, before we finish:

- Is there anything else you feel that is important to tell us?
- Is there anything else you expected us to talk about that you'd like to discuss?
- Do you have any questions for us?
- Please tell us how you've found today.

Thank you very much for taking the time to share your thoughts and experiences with us. Your views are really important. They will play a big part in developing the new talking therapy for African Caribbean people. The research will take 3 years to complete. When it's finished, we'd be happy to let you have a copy of the findings. In the meantime, you can follow our progress on.... I think we're all finished so I'm going to turn off the recorder now.

[End Recording]