MIXED Focus Group: Topic Guide

Part 1: Introduction

Thank you so much for agreeing to take part in this session today to:
- Review the information we've collected from the 3 Focus Groups that you've taken part in (Service Users, Carers and Advocates, Health Professions).
- Comment on the what we think are the most important things you've told us
- whether you think there is anything we've misunderstood, missed out, not thought about

We will ask you questions and seek your views. It's really important that we have people's honest opinions, so please be as frank as possible. We'll be using PowerPoint and flip charts to help us share and capture information. Please take a look at the session outline that we've prepared. We're now going to go through some important information before we begin.

Technicalities

We will be recording the session to help us remember points that we might want to come back to later or to record things that are especially important. As before, Amy and I will be working together. Amy will take notes and might prompt if I forget anything.

Confidentiality

As previously, all information shared in the focus group and 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 job title, hospitals, teams 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 us that you or someone else is at risk of being harmed, then we will need to break our confidentiality. We would usually discuss this with you first. Before we begin the interview, here's a reminder of the ground rules you've previously suggested. Do we need to add anything else? *(Flipchart 1 - Ground rules)*

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

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

In previous Focus Groups, we asked people what they thought about the idea of **developing a 'talking therapy' specifically for African Caribbean service users and their families.**

Key Finding:
Pretty much everyone said they thought this was a good idea and long overdue.

In terms of what family therapy for African Caribbean people with schizophrenia should look like:

Key Findings:
People thought the current therapy/family intervention was generally ok but there were some things that would need to change/be emphasised to make it more appropriate for African Caribbean people.

To look at these, we're going to go through what you and other people said about each part of the current therapy – focussing particularly on what they thought needed to change. Does that sound ok?

Part 3: Current FI & Cultural-adaptation

Interview Questions

Section A: Service User Assessment

If you remember, the 1st part of the current family intervention/therapy is *'Service User Assessment'* – where the therapist helps the service user and their family wok out what they want out of therapy.
This assessment also helps to identify the service user's **problems**, **needs** and **strengths** from **their personal viewpoint**.

In the **4 key areas of the current therapy**, these are the things that people said would make the therapy more relevant for African Caribbean people *(Slide 1)*

1. Current and past episodes of illness. Therapist should ask explicitly about:
   ➢ Problems at school
   ➢ Bullying, harassment
   ➢ Racism (as trigger for illness): AC living in white society
   ➢ Service Users' coping strategies – helpful and unhelpful
   ➢ Spirituality and belief systems
   ➢ Impact of symptoms and what makes them better/worse
   ➢ Fear
   ➢ Body image - weight loss and gain
   ➢ Mood swings
   ➢ Wellness and wellbeing
   ➢ Previous experiences of services – helpful & unhelpful

- ➢ Previous treatment and interventions – what worked/didn't
- ➢ Medication – side effects

2. Level of functioning (How the illness affects service user's ability to function (day-to-day living))
   - ➢ Ability to do everyday things like:
     - o Getting out of the house/flat
     - o Being around people
     - o Shopping, cleaning
     - o Personal hygiene
     - o Managing money
     - o Decision making
     - o Make plans

   - ➢ How spend time – meaningful activity, work, volunteering
   - ➢ Vision and purpose – hope for the future
   - ➢ Sleep pattern disturbed
   - ➢ Diet and exercise
   - ➢ Social functioning – isolation/loneliness/withdrawal

3. Strengths
- ➢ Future hope
- ➢ Aspirations – linked to recovery process
- ➢ Spirituality and beliefs: Prayer/church
- ➢ Relationships and Friendships: stability, warm, trust, confidence
- ➢ Hobbies and activities e.g. art/computer, exercise
- ➢ Nutrition 'mood and food'
- ➢ Self-esteem and self-belief
- ➢ Social skills – ability to mix with people and make new friends/relationships
- ➢ Studies & work- service user experiences to benefit recovery

4. Relationships (the therapist might ask…..)
   - ▪ How important are your relationships with your family and other people to you?
   - ▪ Which are your most relationships?
     - o *Who do you go to for help and support? Who looks out for you?*
   - ▪ How does your illness affect your relationship with your family and other people who are important you?

You said, in relation to African Caribbeans, therapists should also ask specifically about
   - ➢ Shame & stigma – family and community
   - ➢ Tension in family: Blame, criticism, accusations
   - ➢ Fear – family, professionals, community
     - o *Increase isolation*
   - ➢ How service user thinks family see/treat them

- o *e.g. fear, think less capable, not to be trusted e.g. childcare, changed/'like another person', Mad/violent*
- ➤ Service user as carer (children, siblings, parents)
- ➤ Intimate relationships – Libido
- ➤ Relations with people outside the family:
  - o Problems at church/in community ; Maintaining friendships/relationships over time

Section B: Family Assessment

To remind you, **Family Assessment** helps the therapist understand *how the family understands the illness* and *how the illness affects family members*. In the current therapy, this assessment covers 6 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**:
   - o Cause and maintenance of symptoms
   - o Views on treatments e.g. medication and how to manage illness at home

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. s*ocial supports, positive relationship with the service user*).

In addition, people said therapist should ask about:
- ➤ Previous experience of services – helpful and unhelpful
- ➤ Choice – how do they want to be worked with?
- ➤ Hopes and aspirations

Section C: Psycho-education

This part of the therapy aims to work with families to gain a greater understanding about schizophrenia. It involves accepting their illness models whilst presenting alternative explanations that mediate more effective ways of managing illness in family environment i.e. to change behaviour.

This was the area that caused most discussion as people thought it was perhaps one of the most important aspects of the therapy. *(Flipchart 2: Psycho-education)*
Current therapy includes:
- ▪ Positive symptoms: hearing voices & persecutory delusions

- Negative symptoms: low mood and concentration
- Functioning: lacking motivation, social withdrawal
- Current illness models
- Current treatments available
- Beliefs about the illness – educate about what is 'helpful' for illness course and change 'unhelpful' beliefs
    - *Controllability – extent to which service users can control symptoms (e.g. difficult behaviour is controllable)*
    - *Responsibility – extent to which patient is responsible for their symptoms*
    - *Criticism (e.g. 'he's lazy – he won't get out of bed')*

In addition, people thought these areas should be included:
- Stigma (normalising symptoms/illness to reduce)
- Spirituality and belief systems
- Different perspectives/approaches/models of illness
- How mental health 'system' works
- Rights of families e.g. visits, legal representation, carer assessment, financial support/benefits
- Medication: how it affects the brain, side effects, physical effects, anxiety
- Illicit drugs e.g. Cannabis use: use as self-medication, challenge stereotype
- Roles of health professionals: psychiatrists vs. psychologists, SW, can be fearful
- Police involvement: lack of mental health training , differences between UK & Caribbean
- Challenging stereotypes: Black man is aggressive and violent
- Language and terminology e.g. CTO – Community Treatment Order, 'sectioning',
- Other treatment approaches e.g. alternative treatments, psychological therapies, hearing voices movement

What do you think are important issues to consider when presenting this information?
You said:
- Different formats – more visual, TED Talks, Patient Voices
- Sending information prior to meetings → preparation, empowerment

Alternatives to **term 'psycho-education'**:
- Psychological education
- Shared learning
- Information sharing
- Mental (ill) health awareness

Section D: Stress Management and Coping Responses

These are the areas covered in the current therapy.
- 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

- o   Monitoring daily stressors, stressful situations and ways of coping *(e.g. diary)*
- Changing unhelpful ways of dealing with stress
   - o   Relatives' unhelpful beliefs about behaviours and unrealistic expectations *(e.g. trying to change delusional beliefs/voice hearing through arguments or threats)*

Things you thought needed to be added:
- Conflict in sectioning relatives
- Acknowledging role as carer and carer burden
- Carer rights and responsibilities
- Positive ways of coping – turning negative to positive
- Resources available e.g. 'dialogue with voices'
- Boundary setting – responsibilities/roles in managing illness → reducing dependence
- Realistic expectations
- Two-way support

Section E: Problem-solving and planning for positive change

- People generally thought this was a good approach. Liked breaking goals into small, achievable steps i.e. a process.
- Contingency plans: Being explicit about what happens if someone becomes ill/goals not achieved
- Negotiated rewards for achieving goals – celebrating success
- Some people thought diagram unhelpful (suggests going round and round). What do you think?

Break (1.45)

Section F: 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.

- **What would be the most important changes or benefits you'd like to see for African Caribbean a) service users and b) their families?**

BENEFITS FOR FAMILIES	BENEFITS FOR SERVICE USERS
OUTCOMES • Different/more positive perceptions of relatives – 'illness'/being 'ill' • Ways of coping with stress • Better understanding of what contributes to wellness • Understand course of illness/difficulties	• Better relationships (all family) • Better coping • Realistic expectations • Reduce loneliness • In control of illness • Process to recovery • Understand me more

• Positive attitudes towards recovery • Feel supported by family: less isolated, family feels safe • How to manage symptoms • Empowered to access support/info • Holistic needs taken into account • Knowledge – 'schizophrenia' • Next steps • Competence ('tool kit') • Confidence • Understanding of illness and impact • Use of knowledge • Skills • Right sectioned – police/hospital • Hospital admission • Family communication	• Family atmosphere • Reduced stress • Greater understanding of families experiences and impact on them • Self-management • Measuring steps of success vs. critical voice • 'Experts by experience' feedback to others • Less reliance on medication

MEASURES

- Simple questionnaires (short, less burden to complete)
- Visualise/not written
- Self-report
- Jelly baby tree
- Questionnaire: stress, story
- Longitudinal
- Key areas: educational, social, mood, stress, relationship
- Likert/rating scale
- Resources using in community/services
- Mapping networks and changing
- Fewer hospital admissions

OUTCOMES TO AVOID

- ➢ Confidentiality: don't want business disclosed/shared
- ➢ Some things don't want family involved
- ➢ Prison
- ➢ Family breakdown? +/-
- ➢ Trust breakdown
- ➢ System/therapy does not work
- ➢ Leaving half way
- ➢ Focus away from service user
- ➢ Lack of involvement/sidelined
- ➢ Expectations to change - not under the service users' control
- ➢ Alienated from family/access to services
- ➢ Conflict
- ➢ Medication side effects

- ➢ Blame
- ➢ Guilt and negative effects of family involvement
- ➢ Barriers between service user and family/services

KEY THINGS TO CONSIDER WHEN DELIVERING THE THERAPY

- Build trust esp. over the first few sessions
- Confidentiality important
- Collaboration between therapist and families 'work together' to help the client
- Home visits – health professionals
- Cultural awareness training for staff
- Service user support – greater understanding problems
- Friendship support – easy to relate to
- Community services - support and integration
- Proxy families – trust to be part of family
- Education –how to communicate and interact with different ethnic backgrounds
- Practical considerations – importance of choice and flexibility
  - o Offer separate sessions – with/without to disclose information to different family members
  - o Offer male/female therapist
  - o Matching ethnicity? Different views – just need good therapist
  - o Family work take place in home (more in control, more accessible/practical, less cost)
  - o Family work take place in neutral place (less stigma, disruption, tension, stress)
- Feeling empowered – hand over the control to patient and family
- Early intervention – family support before crisis stage
- Training for police in mental health (p60)
- Do not expect too much from the family – support each other, continuous support outside therapy
- Language and communication styles (cultural)
- Focus on 'Recovery' and strengths
- **How many sessions do you think would be best? [10]**

Would take a lot of sessions to build trust – perhaps 'start the clock' after trust established
On-going support afterwards
- **How long do you think each session should last?**
1 – 3 hours ok with flexibility

PROXY FAMILIES
People thought this was good way of reducing stigma in the community.
Alternative names:
- Friends and family and others
- Support
- Befriending

- Substitute
- Alternative
- Nominated

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?

People said: Negative connotations with some language e.g. 'psycho'= 'psychopaths'

Instead use:
More positive terminology e.g. 'Recovery'
Less jargon
Simple explanations
User-friendly language
Schizophrenia label – some people anti- others highlight need for choice

Engagement & Uptake

What would make you want to get involved in this therapy?
People said:
Willingness to try something new
Knowing it was available

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*]