|  |  |
| --- | --- |
|  |  |

**Participant Information Sheet: FOCUS GROUPS (Phase 2)**

**Study Title: Co-production and evaluation of an e-learning resource to improve African Caribbean families’ knowledge about schizophrenia and engagement with services**

We would like to invite you to take part in our research study. Before you decide whether or not you wish to take part, we would like you to understand why the research is being done and what taking part would mean for you. We have prepared this *‘Participant Information Sheet’* to tell you about the purpose of the study and what will happen to you and any information you share if you decide to take part. This information sheet also provides more detailed information about the study such as telling you about the purpose of the research study and how you can expect to be treated if you agree to take part.

**If you wish, one of our team will go through this information sheet with you and answer any questions you have.** We think this should take about 15 minutes. To help you decide whether or not to take part, please feel free to talk to others about the study if you wish. Please ask us if there is anything that is not clear or if you would like more information. It is important that you take time to decide whether or not you wish to take part.

**What is the purpose of the study?**

Over several decades, research has consistently shown that people with an African Caribbean background are more likely than any other ethnic group in the UK to be diagnosed with schizophrenia. However, their experience of mental health services is generally poor and they have worse outcomes than other ethnic groups. Fear of mental health services, lack of knowledge about the condition and stigma in the community contribute to African Caribbean people who have been diagnosed with schizophrenia having delayed contact with services. Prolonged untreated mental illness is tremendously stressful for both people experiencing symptoms of schizophrenia and their families. This increases tension in the home and families perception of their ‘burden of care’, which can cause family breakdown. This is important because we know that not having contact with their families makes patients socially isolated and increases the length of time before they get help. Social isolation keeps people in hospital longer and increases the risk of going back into hospital. We therefore plan to work with former African Caribbean service users, their families and members of the community to develop a programme that will help to improve carers and families’ knowledge about schizophrenia. We anticipate that better understanding of the condition will lessen family tension, improve communication and reduce the risk of people diagnosed with schizophrenia becoming unwell and being readmitted to inpatient psychiatric wards.

**Why have I been invited to take part?**

We are inviting you to take part in this study because you fall into one of three groups of people:

1. ***Former service users*** who regard themselves as being from African Caribbean backgrounds (including people who see themselves as ‘Black British’ or of ‘Mixed’ heritage but who have at least 1 parent or grandparent who was born in the Caribbean).
2. ***Carers and families*** (including paid support workers, family and friends) who have experience of working with African Caribbeans. Unlike patients, carers and family members need not be African Caribbean.
3. ***Community members*** we would like to include a range of community members who have an interest in mental health and the potential to improve access and help tackle stigma and discrimination. These might include; ‘community leaders’ (such as religious leaders), community workers, health professionals, police and probation services, advocates and people working in the media.

**What will I have to do if I take part?**

The study is divided into 4 parts or ‘phases’. **You have been invited to take part in FOCUS GROUPS, which is Phase 2 of the study.** For information, the purpose of Phase 1 is to find information that will help us develop our e-Learning resource; including previous research among other ethnic groups.

In Phase 2, we want to conduct **Focus Groups.** These will enable us to talk with people like you to hear about your experiences and find out what is important to you in terms of schizophrenia. Specifically, we shall ask you what kind of information should go into a programme to increase African Caribbean people’s knowledge and understanding of schizophrenia. We will also ask you to help us decide what kinds of things we should measure in Phase 4 of the study when we test the programme and the best way of doing so. We will also use the information you provide to make sure that e-learning programme is workable and likely to be acceptable to African Caribbean people. Individuals who agree to take part in these Focus Groups (**Phase 2** of our study) will work in three separate groups: 1) former patients 2) families and carers and 3) community members. There will be 6-10 people in each group (18-30 people in total). After these three focus groups, we will form a fourth group made up 6-10 representatives from each of the first 3 Focus Groups. This fourth Focus Group will review findings from the previous 3 groups and agree the key items that we shall take forward to the next phase of the study. All focus groups will last around 60-90 minutes. They will be led by the main researcher (Dr Dawn Edge) with support from a research assistant.

**Will my taking part be kept confidential?**

Yes. If you agree to take part in the study, any information you give the researcher will be kept strictly confidential. However, we do have a responsibility to disclose information that suggests you or someone else might be harmed. All information about you will be kept in accordance with in the Data Protection Act of 1998. This means that your ‘personal identifiable data’ such as your name, address or contact number will be stored in a locked filing cabinet separate from any information you share in the focus groups. Only the lead researcher (Dr Dawn Edge) and the research team will have access to the locked filing cabinet. Your name will not appear on any of the forms we use to collect information or in anything we publish about the study. Instead, we will give your information a study number or use a made up name that is nothing like yours so it will not be possible to identify you in anything that we publish.

You will be asked to give consent to having your conversations in the Focus Groups recorded. This will help us to make sure the information we use is accurate as it would be difficult to do this from taking notes alone. The recording will be destroyed after it has been used and your personal details will never be disclosed. With your permission, we would also like to make it possible for other researchers to use your information in the future. Before doing so, we would remove all information that could make it possible to identify you. Responsible individuals from the University of Manchester may also check the research records to audit the conduct of the research.

Information from the research also known as ‘study data’ may be looked at by individuals from the University of Manchester, from regulatory authorities or from the NHS trust, for monitoring and auditing purposes, and this may well include access to personal information.

**What are the possible risks of taking part?**

Talking about experiences of mental illness and of mental health services might be upsetting for some people. There is also a risk of disclosing personal or private information during the Focus Groups. We will remind you that you do not have to answer any questions or share any information that you do not want to. You can leave the Focus Groups at any point if you feel upset. If you do feel distressed after the focus groups, you can contact the lead researcher, Dr Dawn Edge at the University on 0161 275 2570. We shall also provide a list of organisations that are able to provide support to all participants. We shall help you to get support if you wish.

**Are there any possible benefits of taking part?**

We cannot promise that taking part in the study will help you directly but we are doing this research because we believe that the information we collect will help us improve care and support for African Caribbean patients with schizophrenia and their families. We believe that improving carers and families’ knowledge and awareness of schizophrenia and understanding of health professional roles will improve relationships within families. Involving community leaders and community members should help reduce stigma experienced by people diagnosed with schizophrenia and their families. We also believe this will improve relationships between mental health services and this ethnic group. Ultimately, we hope this resource will reduce family stress and tension and community-level stigma; which should improve experiences and outcomes for people of African Caribbean backgrounds diagnosed with schizophrenia.

**Do I have to take part?**

No. Taking part is entirely voluntary. It is up to you to decide whether or not to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will ask you to sign a consent form. If you are a carer and do not wish to take part, this will not affect the standard of care and support that you or the person you care for receives.

**What happens if I change my mind?**

You are free to withdraw at any time, without giving a reason. If you withdraw, we would like to keep any information you have given us up to that point. You can still ask for information about how the study turns out and what we find. Changing your mind will not affect the standard of care and support that you or the person you care for receives. In the unlikely event that you lose the capacity to consent during the course of this study, you will be withdrawn from the study but we will continue to use the information we have already collected.

**Expenses and payments**

Reasonable travel expenses will be paid in exchange for travel receipts. ‘Permitted payments’ for service-users, honorarium for carers and volunteers will be paid at £10/hour (max £50 per session). ‘Permitted payments’ means that taking part in the study should not affect any benefits you receive.

**What do I do now?**

A researcher from the study will contact you in a few days. He or she will go through the information sheet with you and answer any questions you have. We think this should take about 15 minutes but we are happy to take longer to make sure we answer your questions. You can then let the researcher know if you are interested in taking part. The researcher will give you more time to think about being in the study and, if you are still interested, ask you to sign a consent form to show that you understand what the study is about and that you are willing to take part.

**What do I do of something goes wrong?**

If you have a concern about any aspect of this study, please ask to speak to the lead researcher, Dr Dawn Edge (0161 275 2570) or Dr Henna Lemetyinen (Research Project Manager) (0161 275 7435), who will do their best to answer your questions. If they are unable to resolve your concern regarding the study, please contact a University Research Practice and Governance Co-ordinator on 0161 2757583 or 0161 2758093 or by email to [research-governance@manchester.ac.uk](mailto:research-governance@manchester.ac.uk) or by writing to 'The Research Governance and Integrity Manager, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester M13 9PL'. If you wish to make a complaint about the research, you can do so by emailing: [research.complaints@manchester.ac.uk](mailto:research.complaints@manchester.ac.uk), or by telephoning 0161 275 8093 or 275 2674.

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Manchester or Manchester Mental Health & Social Care NHS Trust, but you may have to pay for your legal costs. The normal National Health Service complaints procedures will still be available to you.

**Who has reviewed the study?**

This study has been reviewed by the University of Manchester & NHS Research Ethics Committees.

**Who is sponsoring the study?**

The study is being sponsored by The University of Manchester

**Thank you very much for considering taking part in our research.**

**Please discuss this information with your family, friends or mental health team if you wish.**

**Please feel free to contact me or Dr Henna Lemetyinen (Research Project Manager)** **should you require further information, clarification or advice on how to take part:**

**Dr Dawn Edge Tel: 0161 275 2570**

**Email:** [**dawn.edge@manchester.ac.uk**](mailto:dawn.edge@manchester.ac.uk)

**Dr Henna Lemetyinen Tel: 0161 275 7435**

**Email:** [**henna.lemetyinen@manchester.ac.uk**](mailto:henna.lemetyinen@manchester.ac.uk)