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**Appendix 4a:Participant Information Sheet: PILOT STUDY (Phase 4)**

**Study Title: Co-production and evaluation of an e-learning resource to improve African Caribbean families’ knowledge about schizophrenia or other psychoses 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 involve for you. We have therefore prepared this *‘Participant Information Sheet’* to tell you about the purpose of the study and what will happen to you if you decide to take part. As well as giving information about the study, this information sheet also explains 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 or other psychoses. 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 or other psychoses 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 have therefore been working with current and 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 or other psychoses. We are now looking for people to test our new programme. 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 wards.

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

We are inviting you to take part in this phase of the research because you have a family member who has been diagnosed with schizophrenia who is of African Caribbean origin; including people who regard themselves as ‘Black British’ or of ‘Mixed’ heritage but who have at least one Caribbean parent or grandparent who was born in the Caribbean. Family members do not have to be African Caribbean. For example, you might be the White British parent of a person who is of ‘Mixed’ heritage.

We are also inviting you to take part if you are a community member of African Caribbean origin without family members diagnosed with schizophrenia or other psychoses.

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

To test our programme, we shall split the participants into two groups. One group will try out the programme. The other group will not receive it but will take part in other aspects of the study. Everyone who volunteers has a 50-50 chance of being in either group. Half of the people who volunteer to take part will get the programme straight away. The other half will receive it when we have collected all the information required for the study. We will then test everyone who takes part to see how the programme affects their knowledge about schizophrenia, beliefs about mental illness and views about their quality of life. We shall do this before the study, within 2 weeks of completing the programme, and within 3 months afterwards. We shall also interview people about their experience of the programme to find out what they liked about it and things they did not like. We would also want to know whether people think the programme would be acceptable to others and how it could be improved. As the programme will be delivered online, we shall also monitor use of the resource. For those people who do not have access to the internet, we shall provide DVDs and a workbook. We shall ask them to keep a record of how and when they used the programme and their feelings about it. This will help us to decide if it is possible to deliver the programme in the future and if we should use different formats.

**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 but one 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 interviews recorded. This will help us to make sure the information we use is accurate as it would be difficult to do this from 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?**

Thinking and learning more about mental illness and mental health services might be upsetting for some people. You can stop at any point if you feel upset. If you do feel distressed whilst using the programme; 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 the study will help you directly but we are doing this research because we believe that the programme we produce 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. Collecting information on knowledge about schizophrenia/other psychoses, quality of life etc will enable us to choose the best ways of measuring the impact of the programme in future studies. Ultimately, we hope this programme will reduce family stress and tension; which should improve outcomes for patients.

**Do I have to take part?**

No. Taking part is entirely voluntary. It is up to you to decide to join the study. We shall describe the study and go through this information sheet with you. If you agree to take part, we shall 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 change your mind at any time, without giving a reason. If you withdraw from the study, we would like to keep any information you have given 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 the next 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. You can 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)