Co-Stars: A Feasibility Evaluation of a Co-Produced Mental Health Literacy Training Package to Reduce Mental Health Inequities for Black Youth in Underserved Communities

Participant Information Sheet – Community

We would like to invite you to take part in our research study. Before you decide, it is important for you to understand why we are conducting this research and what taking part will mean for you. We have provided this information for you to consider carefully before you make your decision. Taking part in this research study is voluntary. Please feel free to discuss it with others. If anything in this information sheet is unclear, or if you would like more information, please get in touch with a member of the research team.

What is this research about?

Research has shown that ethnic minority individuals and those from disadvantaged and marginalised communities are more likely to develop a severe mental illness and to experience poorer outcomes. For example, within the UK, people from Black ethnic backgrounds are 3-5 times more likely to experience a first episode of psychosis than White British individuals. Birmingham is a young, ethnically diverse city with high levels of deprivation and has one of the highest rates of psychosis in England. Although Early Intervention in Psychosis (EIP) and other specialized mental health services providing evidence-based, multidisciplinary care are available, Black youth are more likely to experience adversity in their pathways to care, such as compulsory detentions with police involvement. These experiences are disempowering and can lead to a cycle of mistrust and disengagement with services. At the same time, minority groups from underserved communities lack representation in research. This is concerning, as user participation in research increases the quality of care and improves mental health outcomes.

Previously, we worked with Black youth with lived experience of serious mental health problems and co-designed a training package aimed at improving mental health literacy and raising awareness of issues around intersectionality and barriers to mental health care. The aim of this research project is to implement this training package across marginalised communities in Birmingham as well as target mental health professionals and public organisations to verify if this training package is practical, well-received, and worth the cost.

This project is led by Dr Sian Lowri Griffiths at the University of Birmingham Institute for Mental Health as part of UKRI funding.

Why have I been invited?

You have been invited to take part in this research study because you are from a Black ethnic background aged 16-65 years. We wish to recruit approximately 120 people like yourself to take part in facilitated mental health literacy training, during which your valuable perspectives and lived experience will help inform about acceptability of the training and understanding the barriers and enablers.

What would taking part involve?

If you agree to take part, the study you are invited to will last for a maximum of 6 months. We will select different community settings, split them into groups and depending on the group, you will be asked to either participate in the Mental Health Literacy Training delivered in person or learn about Mental Health Literacy from written leaflets and posters. Which group your community setting will fall within will be randomly allocated.

Everyone who takes part in the study will be asked to complete a set of questionnaires before and three weeks after the training. These questionnaires are about your community's attitudes towards mental illness, intended and reported stigmatising behaviours and desire for social distance from someone with a mental illness, mental health knowledge questions and help seeking attitudes.

This in-person training will be delivered by young people of Black African and Black Caribbean community with lived experience. This training will last about 1.5 hours, and will be held in person in the community, in an accessible local venue. During this meeting, a member of the research team from the University of Birmingham will also be present to observe the training and take notes.

By attending this training, you will play an important role in helping us assess the acceptability of our MHL training and to better understand the barriers and enablers to accessing care, which will, in turn, support the future implementation strategy.

You may also be invited to participate in a focus group or 1:1 interview, during which a member of the research team will ask you questions about whether the training was helpful, appropriate, and capable of improving mental health outcomes for Black people. A focus group discussion will last approximately 1.5 to 2 hours, while a one-on-one interview will last about 1 hour.

Please note that the in-person training session, focus group and 1:1 interview will be audio-recorded using a secure encrypted recording device to analyse the data and monitor the quality of the delivery of the training.

These audio recordings will be securely shared with a third-party transcription service for the purposes of deriving verbatim text from recorded conversations. This service will be bound by a confidentiality agreement and the third-party transcription service will destroy all audio recordings upon verification of accuracy of transcripts. However, the research team will retain the audio recordings and store your data safely. Your anonymity will be protected throughout.

Do I have to take part?

No. Participation in this study is voluntary. If you do decide to take part, you will be asked to sign a consent form. If you give consent to take part, you will still be free to withdraw from this research study at any time without needing to give a reason.

What are the possible benefits of taking part?

You will have the opportunity to attend the training package designed to help Black youth in underserved communities receive more timely and appropriate mental health services. In doing so, you could help us better understand the feasibility and acceptability of the MHL intervention delivered to underserved communities. You will also help us assess the barriers and enablers to support the future implementation strategy.

There will be direct benefits to you and to wider community as you would help us improve the MHL education training, enable us to seek funding to scientifically prove if this mental health literacy training is more effective than routine leaflet and poster based learning, and you would help us expand this mental health literacy training to other parts of the UK and make this training as a routine in the system.

What are the possible risks of taking part?

While we do not anticipate significant risks, participants may experience emotional distress or discomfort during the interviews, especially if sensitive topics are discussed. If this occurs, participants can request to pause or stop the interview and may seek additional support. Additionally, there are risks related to data protection, which we will mitigate by following strict confidentiality protocols and data security measures. However, it is possible that sharing accounts of lived experience, if you have, or related topics may cause distress. Should it be

identified during the study that you are at risk of harm to yourself or others, local safeguarding procedures will be followed, and confidentiality may be breached in order to inform a member of your direct healthcare team.

What if there is a problem?

The University of Birmingham, as sponsor, has appropriate insurance in place in the unlikely event that you suffer any harm as a direct consequence of your participation in this study.

The University has in force a Public Liability Policy and/or Clinical Trials policy which provides cover for claims for "negligent harm" and the activities here are included within that coverage.

If you wish to complain about any aspect of the study, you should contact Dr Sian Lowri Griffiths (contact details below) or you may contact the University of Birmingham Research Ethics Governance and Integrity team by email researchgovernance@contacts.bham.ac.uk.

The Patient Advisory Liaison Service (PALS) is a confidential NHS service that can provide you with support for any complaints or queries you may have regarding the care you receive as an NHS patient. Please note that PALS is unable to provide information about this research study. If you wish to contact the PALS team, they are available on:

- Birmingham Women's and Children's NHS Foundation Trust: 0121 333 8403 or via bwc.pals@nhs.net.
- Birmingham and Solihull NHS Foundation Trust: 0800 953 0045 or via bsmhft.customerrelations@nhs.net.
- Black Country Partnership NHS Foundation Trust: 0800 587 7720 or
- via pals.officer@bcpft.nhs.uk.

Additionally, Mental Health First Aid-trained member of the research team will also be available if needed.

If you have been discharged from NHS mental health services and wish to make a complaint, you can contact the University of Birmingham's sponsor point of contact by emailing researchgovernance@contacts.bham.ac.uk.

Will my time and expenses be reimbursed?

As an acknowledgement of the time and effort involved in participating in the study, you will receive a £25 shopping voucher for each hour of your time. Expenses related to travel to the study venue will also be reimbursed, and food and refreshments will be provided free of charge during the training.

Have patients and the public been involved in this study?

Patient and public involvement is at the heart of this project. This study was designed in close collaboration with a local NHS Trusts – Birmingham Women's and Children's Trust (Forward Thinking Birmingham) and Black Country Partnership NHS Foundation Trust, and Youth Advisory Committee comprising of youth with lived experiences. Our Research Advisory Committee comprises of researchers, staff of local authorities, and volunteer organisations. We are also partnering with community mental health organizations dedicated to serving local Black communities.

Who is organising, insuring, and funding the research?

This study is sponsored by the University of Birmingham and funded by the UK Research and Innovation (UKRI) funding.

The University has in place Clinical Trials indemnity coverage for this study which provides cover to the University for harm which comes about through the University's, or its staff's, negligence in relation to the design or management of the trial and may alternatively, and at the University's discretion, provide cover for non-negligent harm to participants.

The NHS Trust has a duty of care to its patients. In the event of clinical negligence being proven, compensation will be available via the NHS indemnity.

Who has reviewed the study?

This study has been reviewed by UK Research and Innovation (UKRI) and an independent Research Ethics Committee.

How will my details be kept confidential?

All information collected for this study will be subject to the General Data Protection Regulation and Data Protection Act 2018. We will ensure your confidentiality by storing your personal data electronically on a secure network at the University of Birmingham using encrypted files. Data will only be accessed by authorised members of the research team via password-protected University of Birmingham-issued computers. Paper copies of study documents will be stored in a locked filing cabinet in a locked room at the University of Birmingham, accessible only to authorized research personnel. Any information that could identify you (e.g., name, address, etc.) will be removed from your study data, and your study data will be linked by a unique code. The document which links your unique code with your identifiable personal information will be stored separately allowing the research team to identify your data. Audio recordings will be destroyed as soon as transcripts have been generated and checked for accuracy. Any personally identifying data will be removed from interview transcripts and workshop observation notes at the earliest possible opportunity, and pseudonyms will be used instead

of real names. The third-party transcription service will be bound by a confidentiality agreement. Any demographic information reported in publications (e.g., age, sex, ethnicity) will be summarized for the group as a whole to prevent identification of individuals. We may share the data with third parties if they request raw data for their review or systematic review. In such cases, we will ensure that any data which could identify you individually will not be shared.

How long will my data be kept and how will it be kept secure?

Data will be stored electronically on a secure network at the University of Birmingham using encrypted files, and paper copies of relevant study documents, such as signed consent forms, will be stored in a secure location at the University of Birmingham in a locked filing cabinet for 10 years. Only authorized research personnel will have access to the data. Audio recordings will be destroyed as soon as transcripts have been generated and checked for accuracy, and personally identifying information will be removed from transcripts and workshop observation notes at the earliest possible opportunity.

How will we use information about you?

We will need to use your name and contact details in inviting you to attend the initial training and follow-up meeting, your age in verifying your eligibility, and information on utilisation status of mental health services such as whether you have sought help for your mental health in the past and whether you are currently receiving support for your mental health. We will use the information collected using 3 questionnaires to evaluate your understanding and awareness of mental health issues, your past behaviours and future intentions regarding mental health, attitudes and perceptions towards individuals with mental health conditions, and your intentions and behaviours related to seeking help for mental health issues. We will use the information gathered using the other questionnaire after training programme to evaluate your acceptability of the organisation, delivery, and quality of content of the mental health training and your suggestions for further improvement.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We want to share the results locally, nationally and internationally through journal papers, presentations and workshops with health practitioners, communities and researchers. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used?

You can find out more about how we use your information:

- by asking one of the research team
- at www.hra.nhs.uk/information-about-patients/
  A leaflet available from www.hra.nhs.uk/patientdataandresearch
- by sending an email to the University of Birmingham's Data Protection Officer: dataprotection@contacts.bham.ac.uk, or
- by contacting the researcher in charge of the study, Dr Sian Lowri Griffiths, at s.l.griffiths@bham.ac.uk

What happens if new information becomes available?

If any new information becomes available which might affect your participation in this study, a member of the research team will discuss this with you.

What will happen at the end of the research?

At the end of the project, if we demonstrate that the training package is feasible and acceptable to professional systems, public organisations involved in mental health care pathways, and the community, we will seek funding to progress to Phase 3, which is planned to take place across all four nations in the UK, involving numerous NHS trusts and communities in a randomised controlled trial to verify if this intervention is more effective than routine leaflet and poster based learning.

Where can I get further information?

If you would like to speak to someone about this research study, please contact the researcher in charge of the study, Dr Sian Lowri Griffiths, at s.l.griffiths@bham.ac.uk.

Thank you for taking the time to read this information sheet.