



Realist evaluation of participation
in health and care research with
people from Black African
Diaspora Communities in the UK.

Participant Information Leaflet for Individual interviews

(For health professionals, health and care researchers, faith leaders, community leaders, research delivery staff, ethics committee members, funders and policymakers)

Study Title:

Developing an inclusive health and social care research system: a realist evaluation of participation with people from Black African Diaspora Communities (BAFDC) in the UK.

Investigator(s):

Eleanor Hoverd, Professor Sophie Staniszewska, Professor Jeremy Dale, Associate Professor Rachel Spencer, Professor Dawn Edge (University of Manchester)

This Patient Information Leaflet has been co-written with individuals from BAFDC.

Part 1

Introduction

You are invited to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully. 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. Take time to decide whether or not you wish to take part.

Who is organising and funding the study?

Eleanor Hoverd is organising the study, supported by Health Education England and the National Institute for Health and Care Research (HEE/NIHR Clinical Doctoral Research Fellowships).

What is the study about?

Background

Decades of research tells us that people who identify as being from Black, African Diaspora Communities (BAFDC) are not well represented in health and care research. BAFDC are those who identify as Black African, African-Caribbean, West Indian, Black British and individuals with dual heritage and other groups who have Black African lineage and living in

the UK. Not including people from BAFDC in health and care research can have serious consequences on the safety of treatments, and how well they may work and not least on their health outcomes.

Health and care research is a term that describes the discovery of new knowledge that can lead to new treatments, policies and care.

The problem

Little is known about what affects the inclusion and participation in health and care research in the UK, by individuals from BAFDC. Most of the research has been carried out in the United States.

Our Aim

The aim is for people who identify as from BAFDC in the UK, as well as health professionals, health and care researchers, ethics committee members, funders and policymakers, to tell the researcher what works, what does not work, and what may affect the inclusion and participation of individuals from BAFDC in health and care research.

It is unknown how many people from BAFDC take part in research. Researchers have not routinely collected information on race and ethnicity. There is some evidence to suggest that there are few people from BAFDC who take part in research. Possible reasons like lack of trust, bias towards Black people and racism may influence inclusion and participation.

Our plan

The researcher will work with people from BAFDC and other key individuals, to develop a theory that explains how inclusion and participation may work. In addition, a model for an intervention to support inclusion and participation of people from BAFDC will be designed together.

Why am I being invited to take part?

We are inviting you to the study because you:

- are a community, or faith leader who works with individuals from BAFDC, health professional, health and care researcher, research delivery staff, sit on an ethics committee, are a funder of research, or policymaker, in the UK.

Part 2

What would taking part involve?

The study is split into 5 parts, or 'work packages', as part of a larger study. **You have been invited to take part in an Individual Interview**, which is Work Package 3 of the study. The purpose of Work Package 3 is to hear from people like yourself who have experience of:

- inviting potential participants to take part in research studies
- actively recruiting participants to research studies
- supporting the delivery of health and care research studies
- have reviewed applications for ethics committees
- have designed and delivered your own research study
- make decisions about funding for health and care research
- create policies within the health and social care field, within the UK.

We want to hear your voice, to understand what your experiences have been like, to understand if there are elements of the way in which research is designed, delivered and funded may influence inclusion and participation of BAFDC in health and care research, in the UK.

Talking to people like yourself will help us to learn what is important to you as well as what you may think some of the barriers and facilitators may be to including individuals from BAFDC in health and care research. This knowledge will help us to explain what works, for whom, how and under what circumstances. The knowledge you share with the researcher will also help to create an intervention, co-designed, with people from BAFDC, aimed at improving inclusion and participation in health and care research for individuals from BAFDC.

If you agree to take part in this study, you will be asked to attend an interview via Microsoft Teams, or face-to-face if you prefer. The researcher will arrange this at a date and time convenient to you. The researcher, who is an experienced nurse in the NHS, as well as a health and care researcher, will discuss the study with you and give you the opportunity to ask questions.

If you agree to take part, you will be asked to sign the consent form emailed to you. You will be asked to take a photo of the consent form and email it to a secure email address. The researcher will talk you through how to do this if you require any assistance.

The interview will last between 60 – 120 minutes . It will be audio or video- recorded, depending upon whether you choose a face-to-face or virtual interview.

There is only 1 interview to take part in. Interviews will be held between November 2023 to end of May 2024. All participants will remain anonymous. The whole research project itself, will end on March 31st, 2025. You can access findings of the study on the Patient Public Community Research Hub on the Warwick Medical School website here: [Patient and Public Community Research Hub \(warwick.ac.uk\)](https://warwick.ac.uk/patient-public-community-research-hub). In addition, if you wish, the findings can be emailed, or posted to you.

How will I access Microsoft Teams?

The researcher will email you an invitation to join an interview at a date/time convenient to you. This link will also include simple, step by step instructions on how to join the interview (if via Teams). The researcher will be available by mobile (07867468560) or email (eleanor.hoverd@warwick.ac.uk) should you have any difficulty in accessing Teams to talk you through how to install it.

Do I have to take part?

No. Participation in this study is completely voluntary and choosing not to take part will not affect you or your health and social care in any way. You can also choose to withdraw your participation without giving a reason by contacting one of the research team. Further details about withdrawing from the study are provided later on in this document.

What are the possible benefits of taking part in this study?

We cannot promise that the study will help you directly, but your participation would possibly help us to improve inclusion of individuals from BAFDC in health and care research. We also believe that through improving health professionals, researchers, funders and policymakers knowledge about BAFDC thoughts about taking part in research, that it will improve relationships between them and these communities. Ultimately, we hope this will lead to improved inclusion and participation in health and care research for BAFDC.

What are the possible disadvantages, side effects or risks, of taking part in this study?

Interviews are a widely used method for exchanging views and experiences and giving feedback. However, we realise that talking about our experiences of research, in your role in the health and care research system could trigger upsetting feelings due to previous experiences in health care, or in health and care research that may have caused discrimination, or racism to you, or that you may have witnessed. You do not have to answer any questions you do not want to. Should you feel upset, the researcher will ask you if you would like to leave the interview and if required, signpost you to support e.g., *Black Minds Matter*, *Mind*, *Samaritans*. You can also contact the researcher, Eleanor Hoverd via email eleanor.hoverd@warwick.ac.uk.

Expenses and payments

You will be given a £25 voucher as a thank you for taking part.

Will my taking part be kept confidential?

All information that is collected during the interviews will be kept confidential at all times and held in compliance with the Data Protection Act 2018.

The video and audio recordings will be transcribed and made anonymous by the researcher, or a professional transcription company used by Warwick Medical School, to ensure you, or your comments are not identifiable.

Analysis and storage of data

Analysis and storage of the data will be carried out on an encrypted, password protected Warwick University computer.

Email addresses for the purpose of setting up interviews and for emailing findings, or results, will be electronic and stored on My files, Warwick University's secure software which is password-protected. If you prefer to have results posted, postal addresses will be stored in the same manner. These will all be deleted immediately after sending the results to you.

All documents, audio and video recordings will be electronic and stored on My files, Warwick University's secure software which is password-protected. Video recordings will be deleted from a Warwick University encrypted, password-protected laptop following transcription of interviews which will be carried out 24 hours after interviews to enable you time to withdraw your interview. You can request to do this by contacting the researcher directly (eleanor.hoverd@warwick.ac.uk) Audio and video recordings will be deleted according to data handling policies at Warwick Medical School.

How your information will be used

Data collected on the data collection forms is anonymous and therefore cannot be removed once submitted.

Anonymous written quotations may be used from the interviews to use in academic presentations or publications based on this research. When you agree to take part in a research study, the information about you may be provided to researchers running other research studies in this organisation and in other organisations. The organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. This would be anonymised information only in the form of anonymised transcripts. Your information will only be used by organisations and researchers to carry out research in accordance with the UK Policy Framework for Health and Social Care Research. In these cases the anonymised transcripts may be shared with other carefully selected individuals from the research team, for further analysis; any such sharing will be closely monitored by the University. This information will not identify you and will not be combined

with other information in a way that could identify you. The information will only be used for the purpose of health and care research and cannot be used to contact you.

No personal data will be transferred outside of the European Economic Area.

If you were to disclose that you, and/or others, may be at risk of harm, there is a duty of care to report this to the relevant authorities.

Quotes that could identify you directly, or indirectly will not be used in research reports or publications.

What will happen to the data collected about me?

As a publicly funded organisation, the University of Warwick have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, such as this, we will use your data in the ways needed to conduct and analyse the research study.

We will be using information from you in order to undertake this study and will act as the data controller for this study. We are committed to protecting the rights of individuals in line with data protection legislation. The University of Warwick will keep identifiable information about you for a minimum of 10 years after the study has finished.

- 1) Research data will be **anonymised** as quickly as possible after data collection and it will not be possible to withdraw your data after 2 weeks following the interview. Email addresses will be collected for the purposes of arranging interviews only and will therefore be deleted 24 hours after the interview has taken place.

Data Sharing

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. The University of Warwick has in place policies and procedures to keep your data safe.

This data may also be used for future research, including impact activities following review and approval by an independent Research Ethics Committee and subject to your consent at the outset of this research project.

For further information, please refer to the University of Warwick Research Privacy Notice which is available here: <https://warwick.ac.uk/terms/privacy> or by contacting the Legal and Compliance Team at infocompliance@warwick.ac.uk.

What will happen if I don't want to carry on being part of the study?

You can stop being part of this study at any time, without giving any reason, any personally identifiable information such as email addresses will be destroyed. Anonymous information will be kept as per university requirements described above.

We need to manage your records in certain 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.

Please note that if you withdraw from the study, it will not be possible to withdraw your data after 2 weeks following the interview, after which point the data will have been anonymised **OR** it will not be possible to withdraw your data which has already been collected because it has been anonymised. To safeguard your rights, we will use the minimum personally

identifiable information possible and keep the data secure in line with the University's Information and Data Compliance policies.

What will happen to the results of the study?

After the information has been collected and analysed, the information will be written up in a report for the supporters of the study. The results from this study may be presented at conferences and printed in academic journals. No names of participants, organisations, staff, or family members will appear on any report or publication arising from this work. We will provide you with a summary of the results of the study findings.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by the University of Warwick's **Biomedical & Scientific Research Ethics Committee (BSREC): BSREC 130/22-23**

Who should I contact if I want further information?

Investigator:

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Who should I contact if I wish to make a complaint?

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed. Please address your complaint to the person below, who is a senior University of Warwick official entirely independent of this study:

Head of Research Governance

Research & Impact Services
University House
University of Warwick
Coventry
CV4 8UW
Email: researchgovernance@warwick.ac.uk
Tel: 02476 575733

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter:
infocompliance@warwick.ac.uk.

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).

Thank you for taking the time to read this Participant Information Leaflet