



## Participant Information Leaflet for Individual interviews

(For people from Black African Diaspora Communities who have taken part in health and care research previously)

**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)

### 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.

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

### **The challenge**

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

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 Aim**

The aim is for people who identify as from BAFDC in the UK, to tell the researcher what works, what does not work, and what affects their decision-making, to make health and care research more inclusive.

### **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.

## **Part 2**

### **Why am I being invited to take part?**

We are inviting you to the study because you:

- Self -identify as being from a Black African Diaspora Community and are 18 years of age or older.
- You have taken part in a health and care research study in the UK, before.

### **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 taken part in a health and care research study before.

We want to hear your voice, to understand what your experiences were like and what may have influenced your decision to take part in a study.

Talking to people like yourself will help us to learn what is important to you. This knowledge will help us to explain to researchers (the people that design research studies), research delivery staff (the people and teams that bring health and care research to GP practices, hospitals and communities), ethics committees (the people that decide if a research study will respect the dignity, rights and safety of people who take part) , funders (the people who decide on what research to fund) and policymakers (the people who make plans for the government and research organisations to follow) , what is important to BAFDC in regards to

taking part in health and care research studies. The knowledge you share with the researcher will help to create a model, co-designed, with people from BAFDC, to improve inclusion and participation in health and care research for others.

If you agree to take part in this study, you will be asked to attend a virtual, interview via Microsoft Teams, or if you prefer a face-to-face interview. 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 also 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.

The researcher will also ask you to complete a short, data collection form that asks you if you would provide your gender, race, ethnicity, employment, education, health conditions, disabilities and the city in which you live. This will help the researcher to understand the differences between specific BAFDC.

The interview will last between 60 – 120 minutes. A refreshment break will be provided. It will be audio or video- recorded and you may turn your camera off, after you have signed the consent form, if that is more comfortable for you.

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 31<sup>st</sup>, 2025. You will also be able to find the results on this website when it has finished in 2025 : [Patient and Public Community Research Hub \(warwick.ac.uk\)](https://www.warwick.ac.uk/patient-and-public-community-research-hub) .

If you would like the findings posted, or emailed to you, you will be asked to sign a permission to contact form, and this can be arranged at the end of the study.

### **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. The researcher will be available by mobile phone (07867468560) or email [eleanor.hoverd@warwick.ac.uk](mailto: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 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 communities and researchers. 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 experiences of taking part in health and care research may trigger upsetting feelings due to previous experiences in health care, or in health and care research, that may have caused discrimination, or racism. 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 will discuss with you how to best support you and if required, signpost you to support e.g., *Black Minds Matter*, *Mind*, *Samaritans*. You can also contact Researcher, Eleanor Hoverd via email [eleanor.hoverd@warwick.ac.uk](mailto:eleanor.hoverd@warwick.ac.uk).

### **Expenses and payments**

You will be reimbursed for your participation in this study as recognition of your time and expertise, at £25/hr in the form of a payment, or voucher. The researcher will ask your preference. Payments will be reimbursed for part of an hour if the discussion does not last for 120 minutes as follows: £13 if less than 30 minutes; £18 if up to 45 minutes; £25 if longer than 45 minutes ; £40 for 90 minutes and £50 for 2 hours. If you are receiving state benefits, it will be your responsibility to follow your benefit conditions if you are participating in research. The researcher can provide you with a list of benefit conditions, should you need one. It is best to speak to your local benefits office before accepting payment.

### **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, or 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 will be electronic and stored on My files, Warwick University's secure software which is password-protected.

All documents, audio and video recordings will be electronic and stored on My files, Warwick University's secure software which is password-protected. Audio recordings will be deleted from a Warwick University encrypted recording device (if face-to-face). 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. Audio and video recordings will be deleted according to the data handling policies at Warwick Medical School.

### **How your information will be used**

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 this point (*after 2 weeks of 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](mailto: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 address will be destroyed. Anonymous information will be kept.

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 reference number 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](mailto: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](mailto: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**