



## Participant Information Leaflet

### **Study: COVID-19 - Palliative and End of life care experiences of people of African and Caribbean dEscent (PEACE)**

We are inviting you to take part in a research study. Before you decide if you would like to, we will give you some more information.

#### **Who is organising the research?**

We are researchers from Newcastle University and the University of Manchester. We have received funding for this research from the National Institute for Health Research.

**Feel free to ask any questions you may have to the researchers, in person or via:**

Email address: [PEACE@newcastle.ac.uk](mailto:PEACE@newcastle.ac.uk)

Tel no: 07708 649459

#### **What is the research about?**

We will be conducting interviews to learn about the experiences of people of African and Caribbean descent in the last year of life particularly when this was during the COVID-19 pandemic. We want to give a voice to bereaved relatives, listen to their views on the care their relative received and how it could have been improved.

#### **Why were you asked to volunteer?**

We are asking you to volunteer because your relative died during the COVID-19 pandemic. We know that people from African or Caribbean descent face more difficulties in accessing end-of-life-care services and are less likely to receive good care than the general population, but we don't know why this is. We want to change this. So we would like to know about the difficulties you may have encountered and to hear your ideas about how care can be improved.

#### **What will happen if I take part?**

- A researcher will contact you to confirm that you are happy to take part.
- We will ask if you have any questions about the study.
- We will arrange for you to sign a consent form.
- We will also ask your permission to collect information about your age, gender, the area where you live and details about your relatives' medical condition.
- We will arrange a time for the interview that is convenient for you using a language of your choice. This will take place on the telephone or by video call. It will last around an hour.
- We will explore which services your relative did and did not use in the last year of life, and the reasons for this.
- We will also explore how you felt about the care they and you received, and what you would change.
- We will audio-record the interview and then type it out afterwards.
- If you do not want to answer a question you do not have to.
- You can stop the interview at any point.
- We will offer you bereavement support follow up with a trained team if you would like this or if we feel it is something you would benefit from.
- We will also ring you back one week after your interview to check how you are.

**Will my taking part be kept confidential? How will we use information about you and your relatives?**

Yes. All identifiable information (for example your name) will be removed from any reports. Your data will have a code number instead.

Confidentiality can only be broken without your consent in very exceptional circumstances, for example, if we are told something that raises serious concerns about your safety or the safety of others.

Once we have finished the study, we will write our reports in a way that no-one can work out that you took part in the study.

**What if I decide I don't want to be involved anymore?**

You are free to withdraw at any time. Any information which you have already shared up to that point will be destroyed if you wish.

**What will happen with the findings of the research?**

- Once all the data has been collected and analysed, a summary of the findings will be available for you if you want.
- The results will be used to suggest ways of improving care to the Department of Health and Social Care, Public Health England and charities including Hospice UK.
- We will use social media and local events to share findings with communities.
- We will also write research reports for conferences and scientific journals.

**What if there is a problem?**

- If you have a concern about any aspect of this study, then you can speak to us at any time.
- If you would prefer to speak to someone other than the research team then please contact [katie.brittain@newcastle.ac.uk](mailto:katie.brittain@newcastle.ac.uk)

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

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

- At <https://www.ncl.ac.uk/data.protection/>
- By asking any of us
- By sending an email to the Data Protection Officer [rec-man@ncl.ac.uk](mailto:rec-man@ncl.ac.uk)