

# Equitable bereavement care for all: assessing bereavement needs of ethnically diverse communities

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Co-Leads



# Overview

- **Context** of the study
- **Share key learning**
- **Update** about what will be happening next

# Why is this research needed?

**Longstanding inequities in health outcomes** for ethnically diverse (ED) communities

**COVID-19 worsened inequities** (*Mamood F 2021, Bajwah S 2021*)

- Number of deaths
- Policies put in place to restrict spread of virus

**Pre-existing issues for bereavement support** (*Selman L 2022, Mayland C year*)

- Unequal and inequitable access

# What was our overall aim?

- Understand experiences & needs from bereavement support services for **people from ethnically diverse (ED) communities**
- Begin to identify **solutions** to address **shortfalls** and **unfairness**

# What did the research involve?

- Three study work packages (WPs)



➔ WP1: **Group discussions** & individual **interviews** with **bereaved people**

WP2: **Interviews** with **bereavement support services**

WP3: **Workshops in partnership** with key stakeholders



- Production of a **short film**
- **Key recommendations** for policy and practice

# WP1: Bereaved people from ethnically diverse communities

- Partnership with **community groups**
  - Bespoke training and support for community researchers

## Recruitment

- **Nationally** via social media & webinars
- **London**: focus on **Black African, Black Caribbean & South Asian** communities
- **Sheffield**: focus on **South Asian, Somali & Chinese** communities
- **Luton**: focus on **Polish, Pakistani & Bangladeshi** communities
- **Leicester**: focus on **Indian & Bangladeshi** communities

# Key learning 1: Study challenged the belief that people are 'hard to recruit'

- **120 participants** recruited from 13 ethnic groups
- **Largest & most comprehensive qualitative bereavement study within UK**
  - Good representation from first-generation migrants (69%), non-English speakers (55%), or those who only had primary/secondary education (38%)
- Ages ranged from **21-80 years**
- Majority were **female** (73.3%).

# How was this achieved?

- The Respect-Trust-Equity Model of Inclusive Recruitment

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参加者将获赠 20 英镑的代金券。






请访问以下链接了解更多信息。

[www.kcl.ac.uk/research/equitable-bereavement-care-for-all](http://www.kcl.ac.uk/research/equitable-bereavement-care-for-all)

或者发送电子邮件至: [bereavement.study@kcl.ac.uk](mailto:bereavement.study@kcl.ac.uk)



Easy Read Participant Information Sheet for Equitable Bereavement Care for All study: V1.5 (10.10.23)

 <p>1) We want to find out about the bereavement experiences of people from ethnically diverse groups so we can develop better services to support these groups.</p>	 <p>2) We would like to invite you to take part in an interview within a research study about improving bereavement services for those from ethnically diverse groups.</p>	 <p>3) You can be interviewed in your preferred language. You can be interviewed alone, or you can be interviewed alongside a family member or friend. You can choose where to be interviewed (including at home).</p>
 <p>4) We would like to record our conversation so that we can fully understand the information shared.</p>	 <p>5) We may use some of your words for our project, but we will make sure that no one can tell who said what.</p>	 <p>6) Talking about serious topics can be upsetting. You do not have to take part if you don't want to. You can stop, pause, or decide not to take part in the interview at any time.</p>



# Role of community researchers



Shirin Shahid



Riffat Mahmood



Monika Afolabi



Gurpreet Grewal-Santini



Rukia Saleem

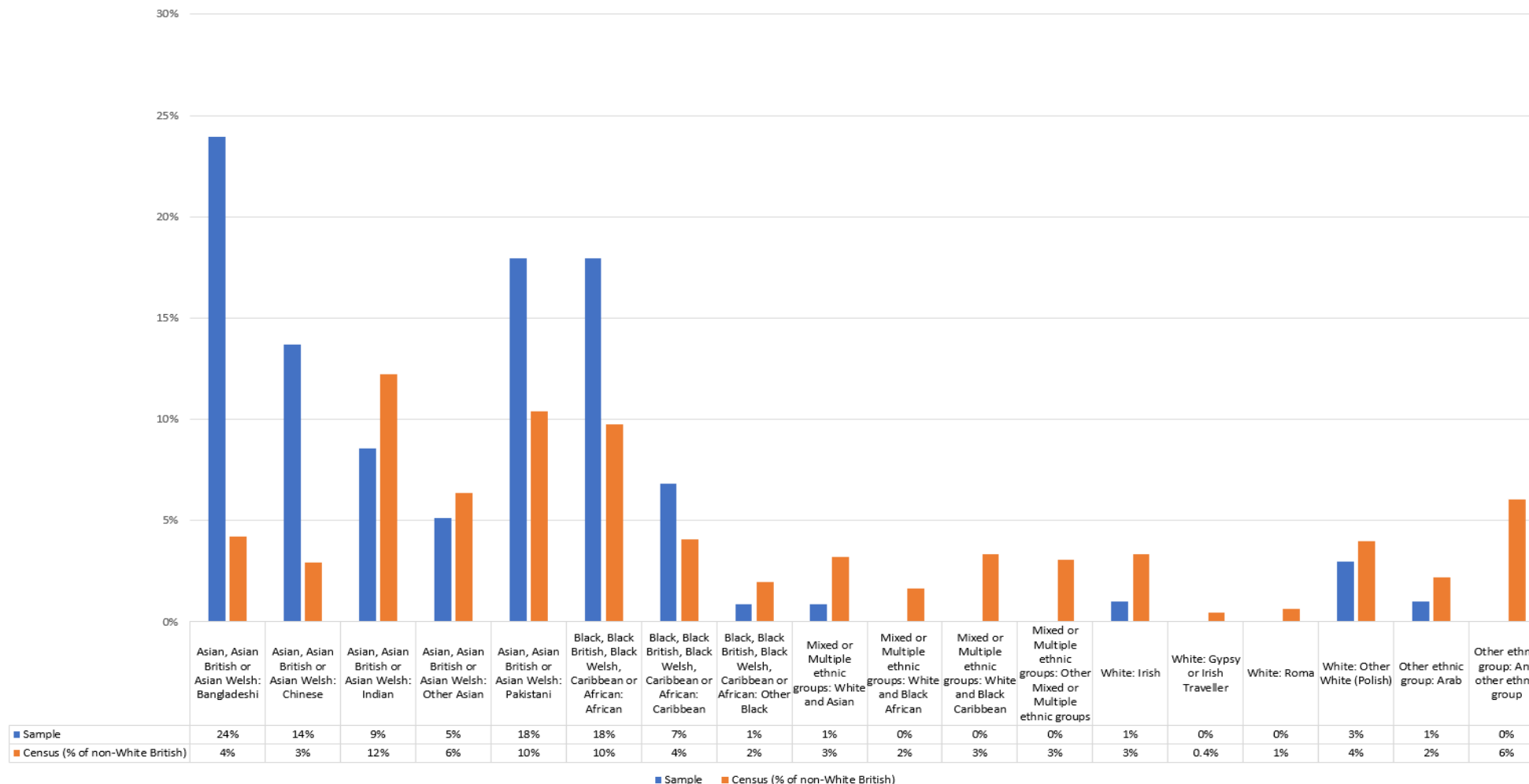


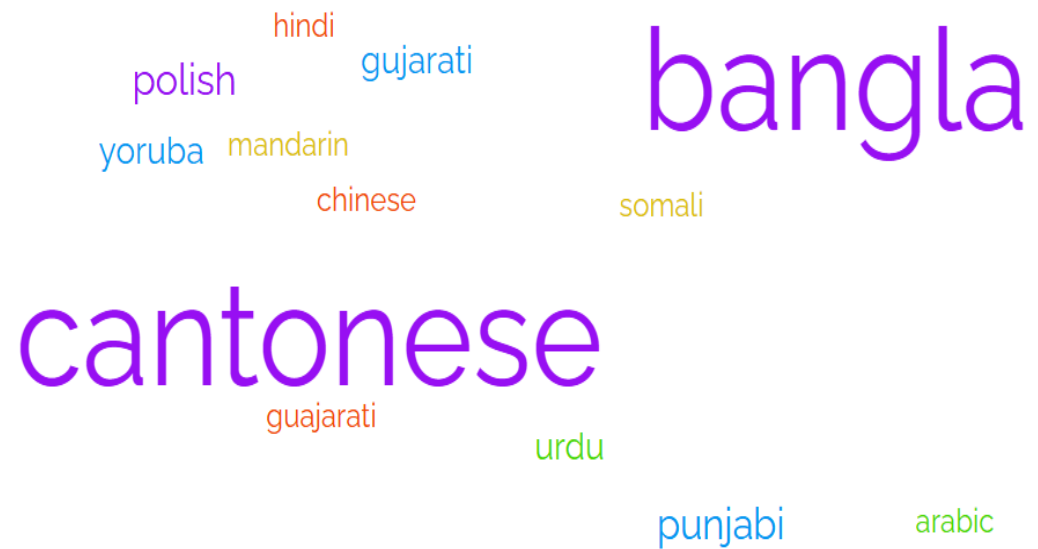
Naureen Khan



Adejoke Oluyase

# Study sample comparison to 2021 census data (N=120)





A word cloud featuring various languages. The words are arranged in a loose, organic shape on the left side of the image. The colors of the words are: 'bangla' (purple), 'cantonese' (purple), 'polish' (purple), 'gujarati' (blue), 'yoruba' (blue), 'mandarin' (yellow), 'chinese' (orange), 'somal' (yellow), 'guarati' (orange), 'urdu' (green), 'punjabi' (blue), and 'arabic' (green).

bangla

cantonese

polish

gujarati

yoruba

mandarin

chinese

somal

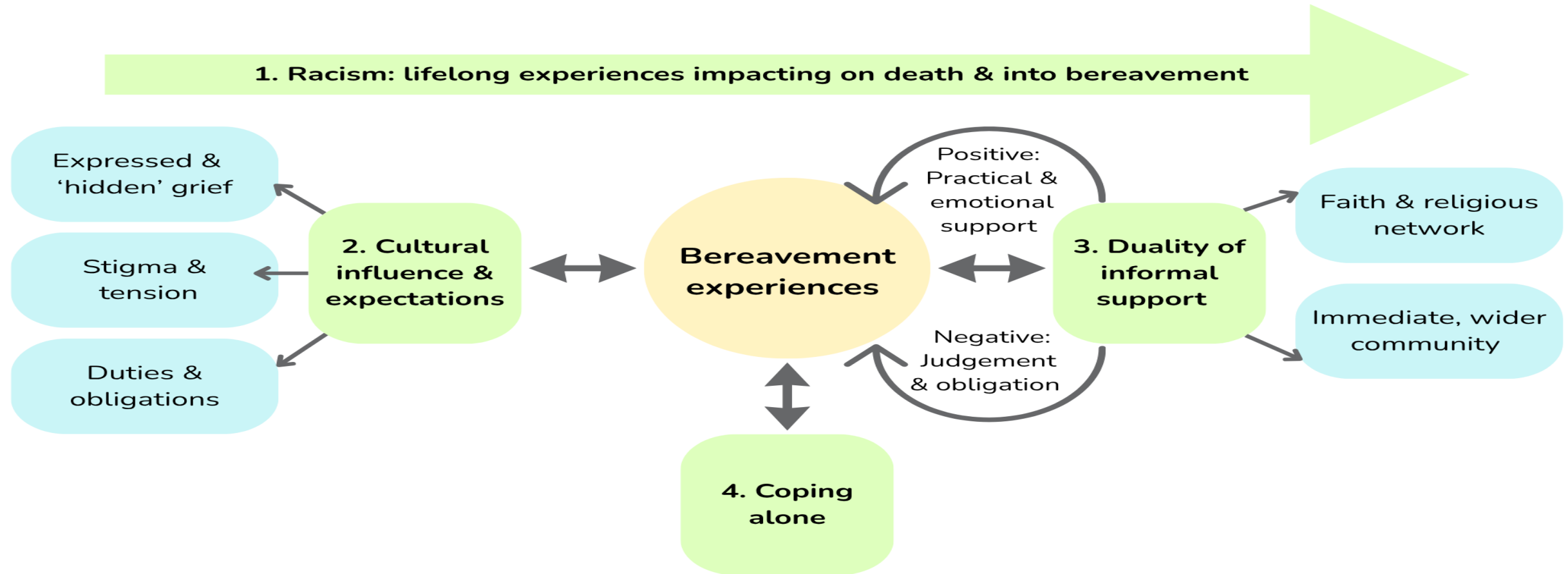
guarati

urdu

punjabi

arabic

# Key learning 2: Results challenge White Euro-centric models of grief



# 1. Racism

- Participants shared **lifelong examples** of **interpersonal & institutional racism**
- Influenced healthcare
  - Assumptions
  - Mistreatment
- Included direct experiences of **bereavement support services**

*'The man at the job centre said that if I could not speak English, I should go back to Poland. I felt terrible.'*

*(female, 41-60, Christian, 'Other White Background')*

*'...the chaplain sent across someone who looks like us because they're brown. But then we realised that he was an imam...for them to not know the difference even was pretty upsetting...'*

*(female, 41-60, Indian, Hindu)*

*'I recorded him (counsellor) saying to me, 'You can talk about your sister dying, but you won't be able to talk about the racism.'*

*(female, 41-60, Black Caribbean, no religion)*

## 2. Cultural influence & expectation

- **Expressed grief**
  - Personal
  - Collective
- **‘Hidden grief’**

*‘There is a bigger grief going on here. There is a loss of culture. There is a loss of knowledge. There is a loss of the community who would ordinarily support us through our grief.’*

(female, 21-40, Christian)

*‘I feel like, especially in Pakistani Muslim families, this concept of grief just doesn't exist. It just gets buried.’*

(male, 20-40, Pakistani, Muslim)

## 2. Cultural influence & expectations

- **Stigma & tension**
  - Mental health
- **Duty & obligations**

*'...because culturally within African Caribbean families, a lot is expected of the eldest child to take the lead. And that's what I found quite pressurising. But you just got on with it...And there was nobody to say, well, I'm actually finding this quite overwhelming.'*

(FG, 21-80, Black Caribbean, Christian)

*'I actually started researching and looking at how many other Muslims have been through this, have experienced or are survivors of suicide bereavement. And I could hardly find any. Because I think a lot of people don't talk about it.'*

(female, age 41-60, Pakistani, Muslim)

### 3. Duality of informal support

- **Faith & religious network**

- Structure & connection
- Purpose & meaning
- Judgement

*My faith is literally my anchor, and it helped me in so many ways.'*

(female, 21-40, Bangladeshi, Muslim)

*'...this is all happening to you because you don't practice your religion enough.'*

(female, 41-60, Pakistani, Muslim)



### 3. Duality of informal support

- **Wider community**

- Practical & emotional support
- Obligation
- Don't have time & space to grieve

*'Yeah, the Chinese community was very helpful. I think without them, I would struggle. Both organising the funeral and in the cultural context as well..... they understood that and know how to advise me on doing it the right way..'*

*(male, 41-60, Chinese, no religion)*

*'.....they're not there to listen to you cry or support you. They're just there because of this obligation. Oh, this person's died. Now we have to be seen to go and visit.....'*

*(female, 21-40, 'White and Asian', Hindu)*

## 4. Coping alone

- Determination to manage grief privately
- **Underlying loneliness & marginalisation**
- Not being part of the dominant culture

*'If we can handle it ourselves, it's fine. We just don't want to trouble people. Because when you deal with these things, you have to ask others for help, especially when we don't know the local culture or language'*

(female, 61-80, Chinese, no religion)

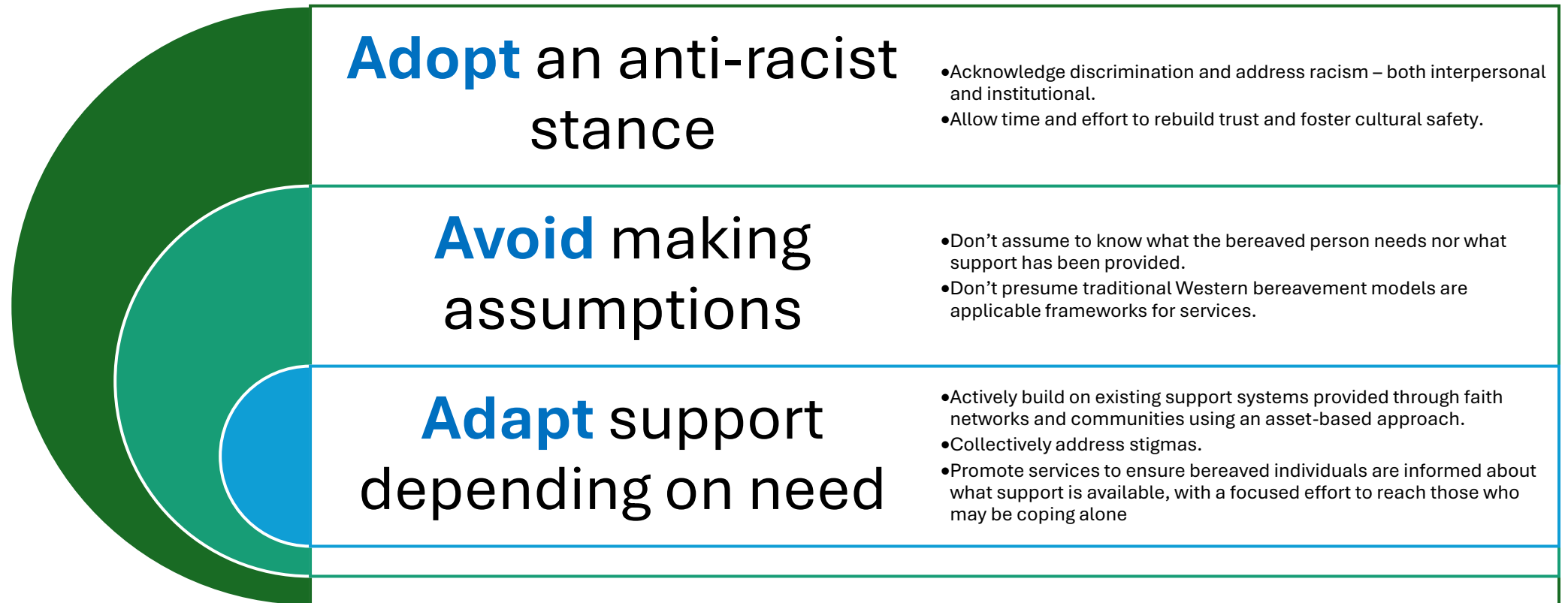
*'I wanted to feel accepted... to find people who look like me, who speak my language.'*

(female, 41-60, Arab, Muslim)

# Key learning 3: What can we take from this?

## Recognise that:

- Each bereaved person may have **lifelong experiences of racism** which impact on their bereavement.
- Each bereaved person will have experienced **a complex interplay** of individual, social, cultural, economic, and environmental factors which impacts on their grief.
- A death can represent the **loss of community** and threaten the continuing of cultural knowledge and traditions.



# Adopt an anti-racist stance

- Acknowledge discrimination & address racism – both interpersonal and institutional.
- Allow time & effort to rebuild trust and foster cultural safety.

# Avoid making assumptions

- Don't assume to know **what the bereaved person needs** nor **what support has been provided**.
- Don't presume traditional Western bereavement models are **applicable frameworks** for services.
- New conceptual model of experience of grief developed.

# Adapt support depending on need

- **Actively build on existing support systems** provided through faith networks and communities using an asset-based approach
- Collectively **address stigmas**.
- **Promote services** to ensure bereaved individuals are informed about what support is available, with a focused effort to reach those who may be coping alone

*‘Do they exist, the bereavement services? Then there's your answer. Nobody knows about it.’*

(female, 41-60, Pakistani, Muslim)

# Context of the wider study

WP2: **Interviews** with **bereavement support services**



WP3: **Workshops in partnership** with key stakeholders

- Production of a **short film**
- **Key recommendations** for policy and practice

[https://www.youtube.com/watch?v=\\_AlM4veYA94](https://www.youtube.com/watch?v=_AlM4veYA94)

# More information

- [c.r.mayland@sheffield.ac.uk](mailto:c.r.mayland@sheffield.ac.uk)
- [sabrina.bajwah@kcl.ac.uk](mailto:sabrina.bajwah@kcl.ac.uk)
- [linkedin.com/in/catriona-r-mayland-09825736a](https://www.linkedin.com/in/catriona-r-mayland-09825736a)
- **Film launch during Grief Awareness week Thursday 4<sup>th</sup> December**



Thu 20th Nov 2025


**UoB Grief Seminars: Dr Sabrina Bajwah & Dr Catriona Mayland, Equitable Bereavement Care for All Ethnicities: Learning from a National NIHR-Funded Study [Webinar]**

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Health

### Equitable bereavement care for all



- We thank the bereaved individuals, community organisations & faith leaders who generously shared their time, experiences & expertise.**
- We are particularly grateful to the community researchers whose commitment & cultural knowledge made this study possible.**



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