



# Advance Care Planning with South Asian Elders

*Project Summary Report*

*March 2024*





Last year, you kindly took part in or supported the **Good Grief Connects** research project.

With the project coming to an end, we would like to **thank you** for your help and contribution.

We're sending you this **short report** to let you know how the project went and what we found.

# Good Grief Connects

- Good Grief Connects was a **two-year project** which started in March 2022 with funding from **The National Lottery Community Fund** (the largest funder of community activity in the UK).
- It was led by **researchers from the Palliative and End of Life Research Group** at the University of Bristol.
- The overall aim was to **shift the public conversation around death and grief** and create a more inclusive, compassionate and open society
- Working alongside charities and community organisations, **we carried out three exploratory research projects** in the UK which focused on death, dying and grief in minoritized ethnic communities.

# Research

You helped support our research about **Advance Care Planning (ACP)** within South Asian Communities.

We wanted to find out about **two** things:

The process & approach in developing and delivering community workshops on ACP

Experiences of planning for future illness, end-of-life care and bereavement for people from South Asian communities in the UK

*Ethical approval for this study was obtained from the Faculty of Health Science Research Ethics Committee at the University of Bristol (ref:11581)*



# Project team

**Compassion  
in Dying.**  
Your end of life. Your way.



Taskin  
Saleem



Naheed  
Anwar



At the University of Bristol



Verena  
Hewett



Usha  
Grieve



Jemma  
Woodley



Lucy  
Selman



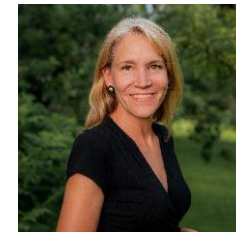
Olly  
Clabburn



Tracey  
Stone



Michelle  
Farr



Lesel  
Dawson



Sabi  
Redwood





# Data collection

- Data was collected between Nov '22 – Jan '24
- We used notes and observations from the **4 workshops** on ACP which took place at Subco Trust with Compassion in Dying
- **16 Subco members** shared their thoughts and experiences with Naheed during **3 focus group conversations**
- We interviewed **9 people** who work in Newham and support people from the South Asian community



# What you helped us find out

## The experiences of planning for future illness, end-of-life care and bereavement for people from South Asian communities in the UK

### Accessing information can be a challenge

- Information tends to be written or spoken in English which can be hard for some people to understand.
- Often people are signposted to information and resources which are online, but not everyone can use the internet.

*They say it plainly, in English. "It is your problem, you handle it".*  
Subco FG1\_P1 (Punjabi)

*The information is needed in other languages, like Hindi, Bengali, etc. For those who don't know English, so they can read for themselves.*

Subco FG3\_P2 (Punjabi)

*Sometimes it is available online. But sometimes, someone doesn't know how to go online... then it is another problem.*

Subco FG1\_P4 (Urdu)

### It's hard to have conversations about planning ahead

- Starting conversations with family and friends about future illness, care wishes and death is not easy.
- Lots of healthcare professionals are also hesitant about starting these conversations too.
- Talking about death in the community is sometimes a taboo subject.
- It can be hard to balance personal wishes with expectations and pressure from other people in the local community.

*I have told the children, (English) don't listen to anyone. (Urdu) What we have told you to do, you just do that [...] Somebody will say 'bring horses', somebody will say 'white chariots, black chariots'... no. Simple. I told my daughter don't let anyone pressurize you.*

Subco FG2\_P7 (Urdu)

# What you helped us find out

## The experiences of planning for future illness, end-of-life care and bereavement for people from South Asian communities in the UK

### Planning ahead can be a good thing

- Planning ahead isn't just about finances and having a will.
- It feels good to be able to think about future wishes and make sure this is documented in case needed in the future with things like medical care.
- Being able to learn about advance care planning through the workshops at Subco was useful and felt empowering.
- Finding out about planning ahead meant people started to talk about their wishes with family members.

*There shouldn't be any difficulty because in my heart, I know what I want, what kind of clothes, what kind of food [etc], what my children have to do after I am gone... I will tell them what to do.*

*Subco FG2\_P3 (Urdu)*

### Faith, religion and culture are important

- Faith can be a useful springboard to talk about death, dying and grief.
- Faith leaders play a vital role in supporting communities through bridging communication between healthcare professionals and community members.
- South Asian cultures are varied and everyone is different. It's important that healthcare professionals understand individual preferences and provide appropriate support.

*From a Muslim perspective, I think we try and talk about death as much as possible, well I do anyway, as an imam [...] Sometimes the reminder is about death and dying, and it's about the temporary nature of this world, the transitional nature of this world and the realities that we believe in the hereafter and this is a temporary world.*

*Stakeholder Int 5*



# What you helped us find out

## The process & approach of developing and delivering the community workshops on ACP

### Compassion in Dying & Subco Trust developing the workshops

- Good communication, trust and sharing responsibilities between organisations was key.
- Gaining feedback from Subco members helped to shape and guide what was talked about in future workshop sessions (e.g. the session for children and families).
- The format of each workshop was valued with each session being 'in person' and started with a recap of what had previously been explored.

*Face-to-face information – I can see the person, I can explain properly face-to-face, you can see facial expressions/body language – we can remember this better.*

*(Elder-workshop 2 notes)*

### Subco members experiences of the workshops

- It was valuable to have the workshops at Subco as it was a space that is familiar and feels safe.
- Having the presentations translated from English into preferred languages by Subco staff meant members could understand the content straightaway and have opportunities to ask questions.
- The workshop structure meant that members could talk to each other about their thoughts and experiences.

*Now we can talk to each other, whereas before we could not... we'd say, "Forget it, who knows why they are talking [about] all this information..." But now, we get to know, that we should sit together and discuss.*

*Subco FG1\_P1 (Punjabi)*

# Outcomes & Outputs



**Report** (Compassion in Dying)

[Advance Care Planning with people from South Asian Communities](#)



**Videos** (Compassion in Dying & Subco Trust) (forthcoming)

*Planning for future illness & ACP*



**Webinar** (Good Grief Festival)

[Talking and Planning for End-of-Life in South Asian Communities](#)



**Academic paper** (submitted)

*Co-production in practice: A qualitative study of the development and impact of ACP workshops for South Asian elders*



**Conference presentation** (EAPC seminar, 2023)

[Co-producing Advance Care Planning workshops for South Asian Elders'](#)



**Academic paper** (forthcoming)

*Exploring planning ahead, end-of-life care & bereavement for people from South Asian communities in the UK*

# Thanks...

## Compassion in Dying.

Your end of life. Your way.



Palliative and End of Life  
Care Research Group  
Bristol Medical School



compassionate cymru garedig



*Cruse*  
Bereavement  
Support



 **CHILDHOOD  
BEREAVEMENT  
NETWORK**



**Compassionate  
Communities UK**



# Contact & more information



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