

## **Summary report: Dementia Health Information Session**

On the 16 June 2023 we were invited by The Healing Church of God in Christ (THCOGIC) Community, based in Paddington, to deliver an online health information session on dementia.

### **Background and development of the session**

We first met one of the leaders of THCOGIC Community at our Prostate Cancer Community Event in November 2022 (undertaken in collaboration with Healthwatch Brent) in Brent. They were invited to attend this session by a patient partner speaking at the event with lived experience of prostate cancer. It was at this event that the community leader sought to understand whether our team could provide any support to her community undertaking similar health information sessions. Our team offered to bring along experts from Imperial College and/or attend sessions to provide information/resources.

Following this event, we were invited to a session on prostate cancer held at THCOGIC Church in Paddington in January 2023. We had a stall and had the opportunity to meet key members of the community. At this event we were able to learn more about what the THCOGIC Church does and became aware that through COVID-19 they started a weekly Friday night Zoom 'Round Table' which provides an opportunity for those across their community to come together to learn or talk about a specific topic, for instance health, religion, life skills.

Several health topics were identified about which the community does not have enough information about, and/or there are myths held in the community about the topic. Dementia is one of these priority areas, and our team (Imperial Patient Experience Research Centre; Imperial PERC) were asked to identify a relevant expert at Imperial College to come and speak about dementia.

This was Imperial's first collaborative event with THCOGIC, and a planning meeting was held online in the lead up with our community contact from THCOGIC, Halle Johnson (Imperial PERC) and Paresh Malhotra (Imperial's Department of Brain Sciences) to set expectations for the session and plan accordingly. It was at this planning session that it was agreed that this would focus on 'What is dementia' – including the different types, signs/symptoms, risk factors and current research. A further session would then be planned to focus more on the management of dementia following diagnosis. It was suggested by the community that the latter needed to be its own session as the community do not believe in sending family to care homes or other caring facilities and will always look after them at home – increasing the burden of caring on the family themselves.

Following the advice from the community at the planning session, a 1.5 hour online session was delivered (approximately 45 mins of presentation and 45 mins of questions). The session was led by Professor Paresh Malhotra (Professor of Clinical Neurology).

### **Format and aims of the session:**

The session started with key members of THCOGIC Community welcoming the team and briefly sharing why this session was important. As this is a Church community, an opening prayer and reading was done before the main presentation started.

The broad aim of the session was to increase awareness of dementia in this community. The presentation (which included slides) provided a general overview of dementia and the rest of the time was left for questions (some of which had been collated before the session from the community).

#### Attendees:

Approximately 60 attendees joined online, this represented individuals and families across the THCOGIC Community in Paddington but also their associated Churches in Essex and Ealing.

#### Questions asked:

- What are the types of dementia?
- How do you know the type they have?
- Is memory loss the start of dementia?
- Is dementia related to mental illness? My son keeps telling my mother she is crazy and should be section.
- My mother is okay during the day, but at 6pm for the last 2 weeks, she strips herself, strips the bed, out of control. What can we do for her?
- Is brain fog in menopause leads to dementia?
- Can vitamins improve dementia and memory loss?
- I was told dementia is witchcraft and the entire family will have dementia. Is this true?
- At what age you are likely to have dementia?
- Can medication, herbal remedies and diet reverse dementia?
- My mother has dementia, first in the family. What can be done to avoid having dementia?
- How young does dementia start?
- Is there a link between air travel and dementia?

#### Reflections:

- The community were very engaged and grateful to have the opportunity to have an expert speak to them about the topic. They appreciated that this session focused purely on 'What is dementia' rather than the other aspects around living with, and caring for, someone with dementia, as this gave the opportunity to really 'deep dive' into the session.
- At the end of Paresh's presentation, he talked about some of the recent research in dementia, he presented this in an optimistically cautious way, and the community seemed to react well to the idea of research. A brief conversation took place around the idea of involving different groups of people in dementia research and this was emphasised again at the end by one of the Church leaders.

**ROUND TABLE**  
Every Friday at 8pm

**DEMENTIA**

Lets **TALK** about it with  
**Professor Paresh Malhotra**  
Date: 16/06/23 at 8pm

**HELP** **SIGNS** **STAGES**

**BRING YOUR QUESTIONS & EXPERIENCE**

**TYPES** **CAUSES** **MEMORY**

Join us **ONLINE** via **ZOOM**  
**THCOGIC's Zoom Meeting**  
Download app or join via web link  
Meeting ID: 723 346 4866 | Passcode: THCOGIC

THE HEALTH CARE ORGANISATION GROUP  
THCOGIC  
Paddington