

Sustainable Prevention Innovation and Involvement Network for Dementia (SPIN-D)

Annual conference UCL-East (Stratford) 2-3 July 2025

Film Festival - One Pool Street Cinema

Connecting Communities – Wednesday 3.45pm to 17.15pm

Chair: Orii McDermott – session facilitator; timing, audience questions, panel discussion

Contributors: Subhashisa Swain, Emily Dodds, Jagdish Brar-Orgill plus Bettina Wallace and Nazia Hussain

WEDNESDAY 3.45pm to 5.15pm

1) Connecting communities

This session includes films documenting the experiences of people with dementia and carers from diverse communities, including South Asian and Caribbean. This session will include reflections from two former carers, Bettina and Nazia, who will be emphasising the importance of cultural connections.

1) Life in Embrace - Subhashisa Swain (Oxford)

This documentary delves into the lives of families navigating the realities of dementia. The film explored the emotional, cultural, and philosophical differences in how dementia is embraced in two contrasting societies: India and the United Kingdom. In India, the documentary featured families from diverse backgrounds - to highlight how caregiving is shaped by cultural traditions, intergenerational living, and a sense of community. This was contrasted with the experiences of families in the UK, revealing how cultural values and caregiving philosophies intersect with the dementia care.

2) Kiran (ADAPT team, Bristol)

Kiran is a powerful dramatisation of some of the challenges faced by South Asian carers when supporting someone living with dementia. The content of the film was informed by real life events that were shared as part of the NIHR-funded ADAPT study with close involvement with the study's public contributor team. The film is aimed at anyone with an interest in understanding more about the challenges of navigating care for someone living with dementia from south Asian communities.

Funders - NIHR research for Patient Benefit

ADAPT study team - Prof Rik Cheston, UWE Bristol, co-PI; Dr Sahdia Parveen, University of Bradford, co-PI; Dr Emily Dodd, UWE Bristol, project manager, Dr Karan Jutlla, Co-applicant, University of Wolverhampton; Dr Paula Smith, University of Bath, Co-applicant; David Truswell, Dementia Alliance for Culture and Ethnicity; Jabeer Butt, Race Equality Foundation, Co-applicant; Jag Kaur, public contributor; Manjit Nijjar, public contributor

Film maker - Bhulla Beghal, Bluebell Films

Please note that the film-makers include a warning that some viewers may find parts of this film upsetting

The film is available on the homepage of the ADAPT project:

<https://raceequalityfoundation.org.uk/adapt/>

3) **Equity in Diagnosis** (QMUL)

The film is with a GP (Danielle Nimmons) and includes points to consider in a consultation around dementia with people from minority ethnic backgrounds. We worked together with a PPIE group including participants from the EQATED study to co-produce scripts which the group felt included key messages from the findings of this study. We worked collaboratively with a small film company, the PPIE group and two participants who co-produced film scripts.

www.youtube.com/watch?v=vtDkcy2Ri4&t=3s

Note: Christine from the EQATED team will be at the festival tomorrow (Thursday) and in the 9.15am film session if anyone has questions about the project.

4) **Diversity in Dementia Diagnosis** (QMUL and Hackney Caribbean Elders; 3mins 13)

This brief film follows Charles Marshall (QMUL) as he learns from Lullynn Tavares at the Hackney Caribbean Elderly Organisation about what is important and meaningful to elders in the Caribbean community in north London.

Films followed by personal contributions from:

Bettina Wallace is a 71 year old mother of 3 and grandmother of 5. She has been volunteering for many years on issues which are close to her heart to ensure that the voice of the African Caribbean community is not left out of meaningful engagement and consultations. She currently works as a casual researcher for The University of Nottingham

looking at how dementia affects people from the African Caribbean Communities and the need for culturally appropriate services.

Nazia Hussain is a management consultant/researcher by profession, but currently semi-retired and living in London. Nazia says “in 2018 my late mother was diagnosed with Alzheimer's Dementia. I was living overseas at the time and had to move back to the UK to care for her. My lived experience led me to understand the importance of awareness and further research about this disease, especially in under-represented communities. Following my mother's passing I decided to create a blog about our journey with her dementia and provide information, research insights, and awareness to others. When I'm not advocating for dementia, I enjoy traveling, reading, spending time with friends and family, baking and crocheting.”

Bonus film:

Rural and Coastal experience (Emily Dodds, Bristol; 3 mins 31s)

This animation is based on findings from a research study looking at the particular challenges faced by people living with dementia in rural and coastal communities in accessing support and the role the voluntary sector plays in these communities.

<https://www.youtube.com/watch?v=LEbgDJDVB6s>