

Mindful Conversations:

Rethinking Community Engagement in Dementia Research

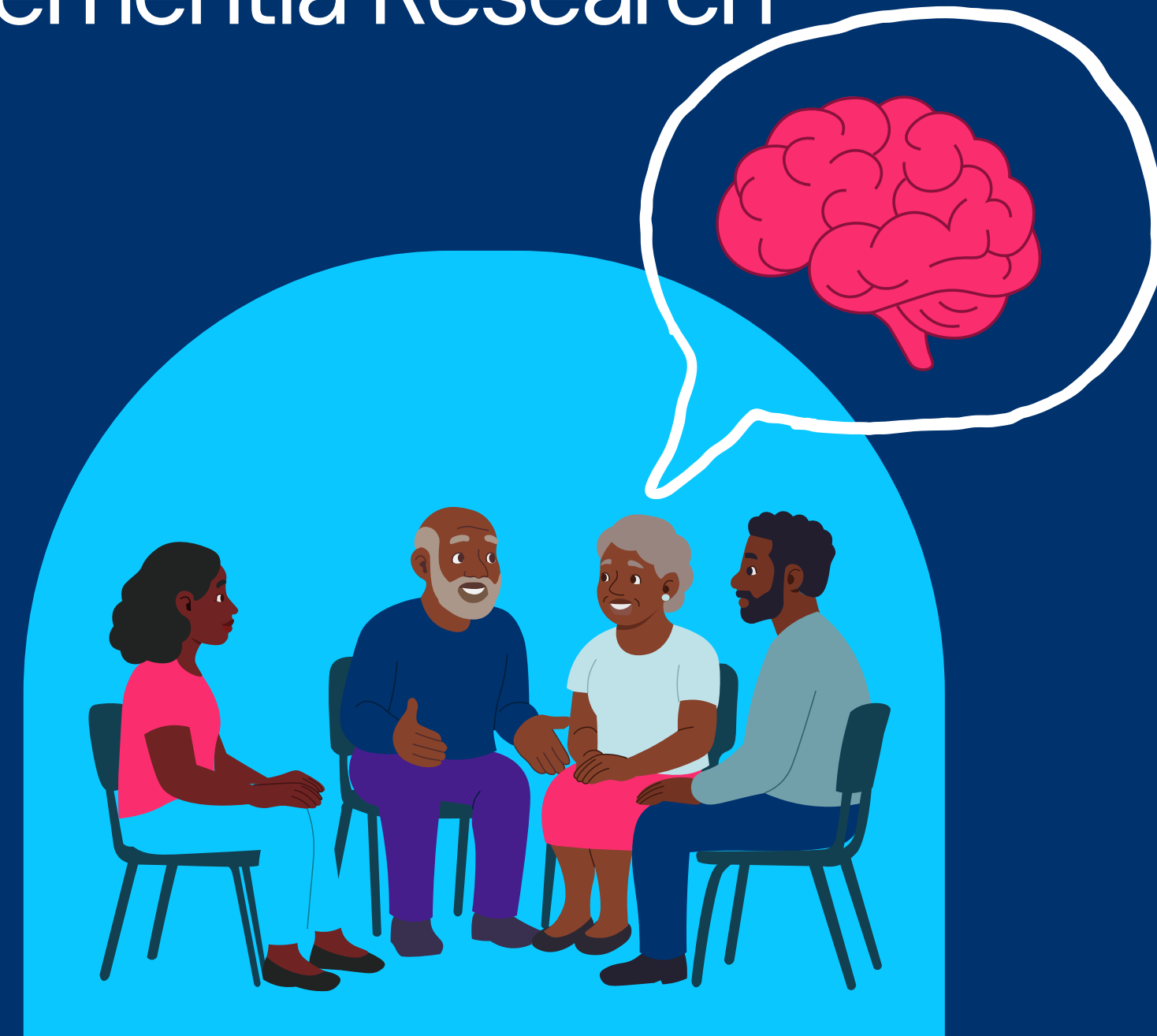
Dr. Nathasia Mudiwa Muwanigwa

Alzheimer's Research UK Fellow
UK DRI at UCL – Duff lab

Project Lead – *Mindful Conversations: Black Communities Talk Brain Health and Dementia*

ALZHEIMER'S
RESEARCH UK FOR A CURE

BNA British
Neuroscience
Association



Why I started doing PPIE as a lab scientist

14 years, 4 countries, 5 labs



Most biological samples and datasets used in GLOBAL research come from people of European ancestry!



This creates huge knowledge gaps and health inequities. !!!

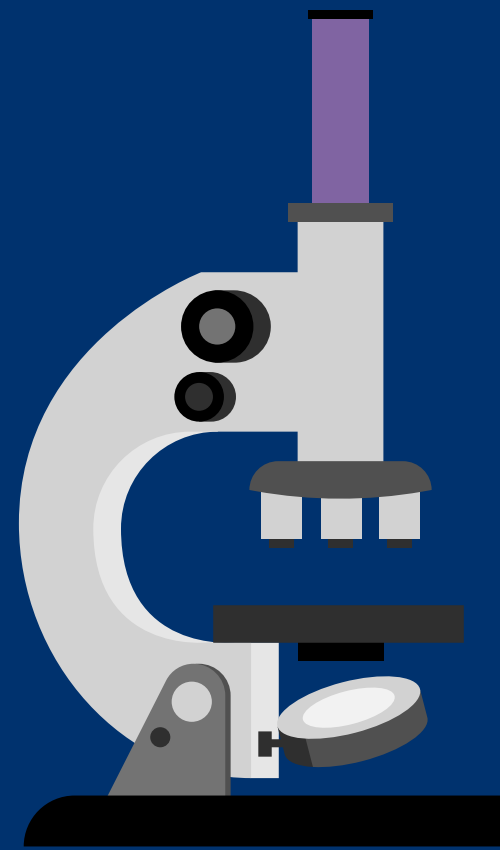
Dementia is the leading cause of death in the UK

7-fold increase in Black, Asian and minority ethnic groups 2010 – 2050

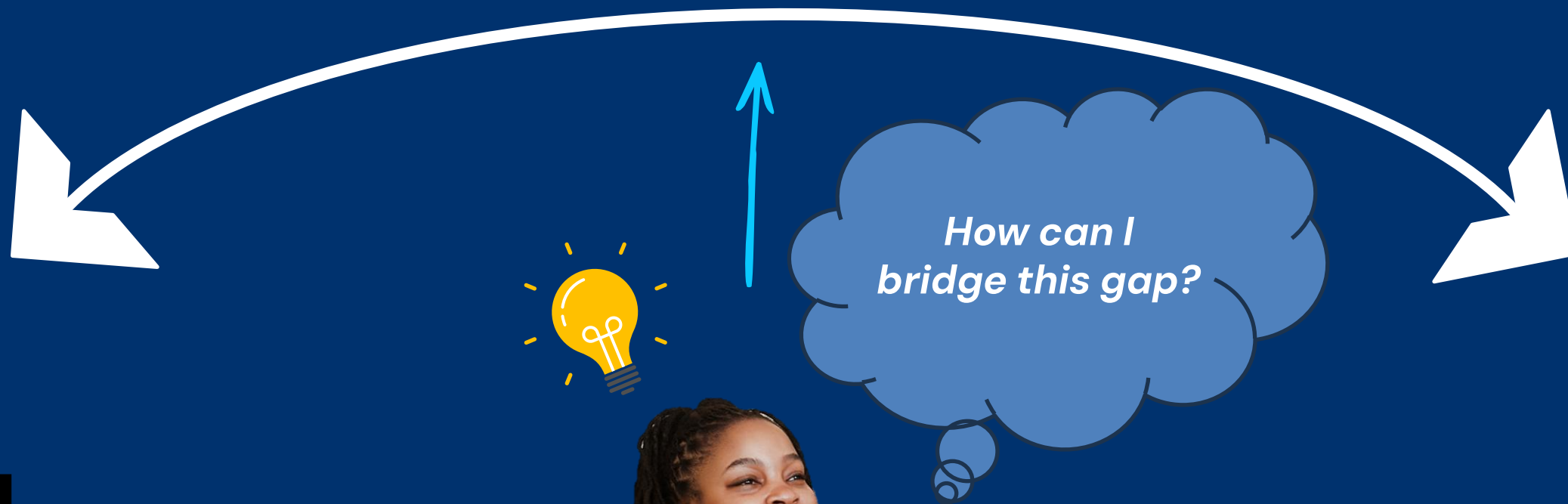
22% higher incidence among Black people vs White population

Black heritage communities are poorly represented in dementia research...

Why I started doing PPIE as a lab scientist



Research



Black Heritage
Communities



Mindful Conversations: Black Communities Talk Dementia and Brain Health

Workshop Series on:

- Raising dementia awareness
- Promoting brain health and risk reduction
- Understanding the Black community perspective on dementia & brain health
- Getting involved in research

Target Audience

- Black African, Caribbean or Mixed Black
- Aged 40+
- Based in London



Key Elements of Meaningful PPIE



Understand Your Audience



Logistics



Communication



Compensation



Evaluation & Feedback



Support & Partnerships



Understand Your Audience

Start with relationships, not recruitment.

Who are you trying to reach?

Age, culture, language, location

Existing community structures



UK DRI Volunteer

Lambeth Country Show
2025



Dementia Consultant

Miss Myrtle's Garden
Bush Theatre 2025



Lead and Facilitator

Black Community Conversation
on Dementia, Bush Theatre 2025



Invited Speaker

Hillview Men's Health and
Wellbeing Conference
2025



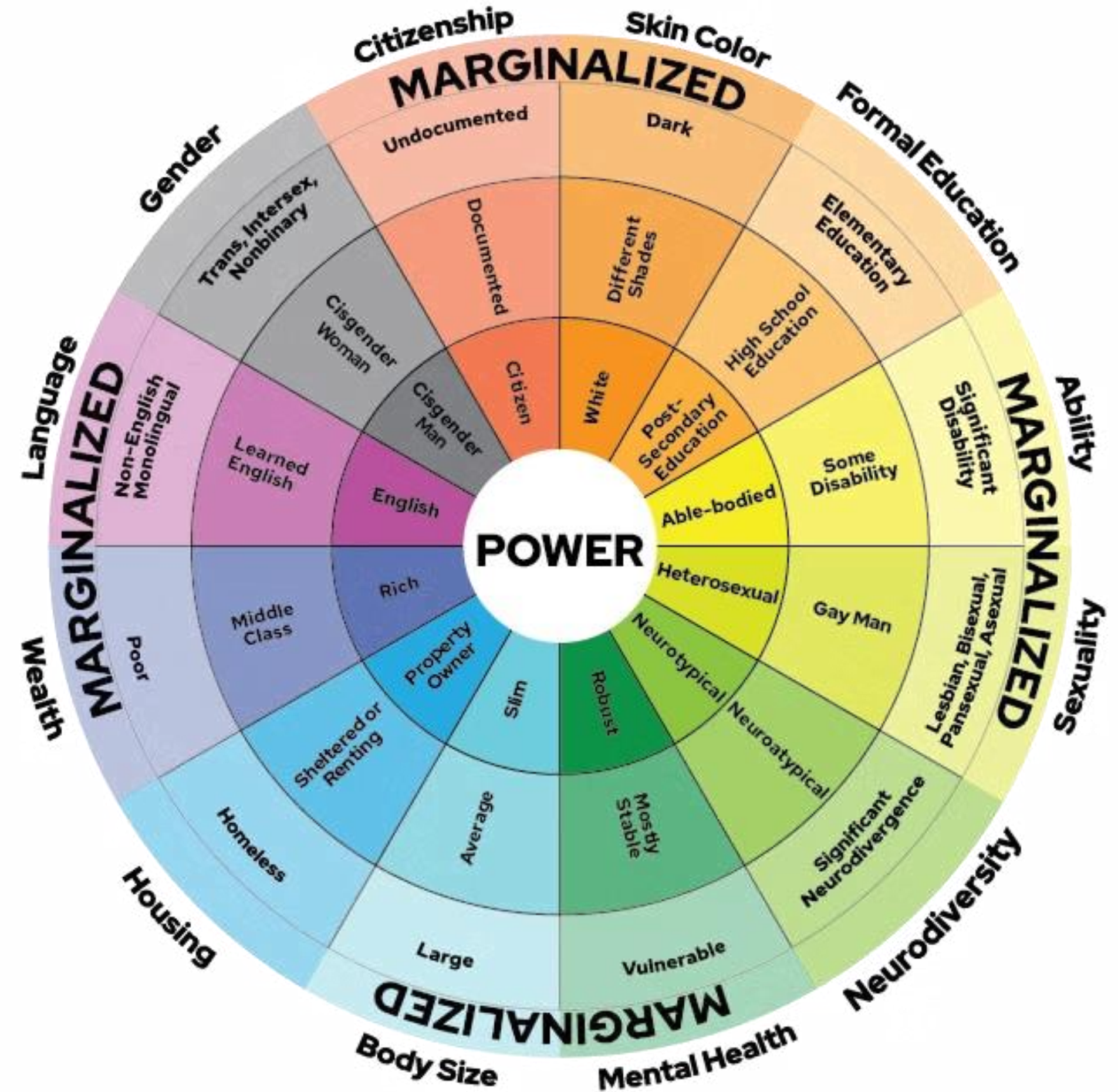
Consultant and Co-Facilitator

Alzheimer's Research UK
Dementia Community Champions
2026



Understand Your Audience

What is your positionality?



Adapted from James R Vanderwoerd ("Web of Oppression"), and Sylvia Duckworth ("Wheel of Power/Privilege")

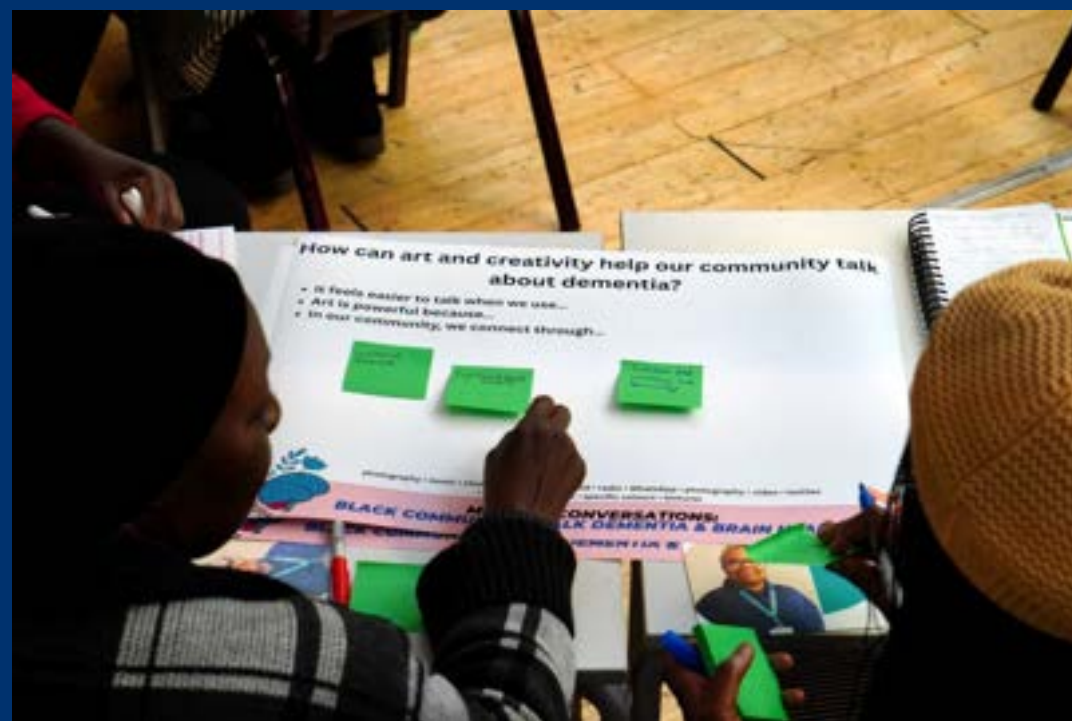


Understand Your Audience

Focus Group



UCL East Community
Seed Fund



MINDFUL CONVERSATIONS

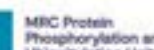
BLACK COMMUNITIES TALK
DEMENTIA & BRAIN HEALTH

Focus Group Report



Project Lead
Dr Nathasia Mudiwa Muwanigwa
UK Dementia Research Institute at UCL

APRIL 2026



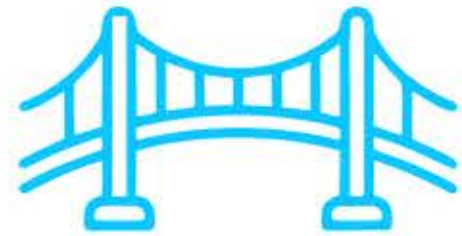
What the Community Recommended

1



Integrate Cultural
and Creative
Mediums

2



Address Spiritual and
Supernatural
Misconceptions

3



Shift Focus from
Isolation to Social
Inclusion

4



Combat Stigma
through Education
and Training

5



Foster
Community-Led
Advocacy

6



Use Multi-Sensory
Take-Home
Resources

7



Create Safe Spaces
for Emotional
Connection

Lay Dementia Science Talk



Breakout Group Discussions



Community Lunch



Art Activity



MINDFUL CONVERSATIONS

BLACK COMMUNITIES TALK DEMENTIA & BRAIN HEALTH

Focus Group Report

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February '26

Focus Group



March '26

Caring for Body & Brain



Staying Sharp



April '26

Staying Connected



May '26



Lived Experience Workshop

Community Reunion & Social

September '26



September '26



UK Dementia
Research Institute



ACADEMY
OF MEDICAL
SCIENCES

Practical Considerations



Communication

Mailing list
Word of mouth
WhatsApp groups
Community radio
Social media



Logistics

Transport
Timing
Accessibility
Venue familiarity



Compensation

Payment for time
Travel reimbursement
Vouchers
Transparent budgeting





Evaluation & Feedback

*Did participants feel heard?
What changed because of their input?
Participant acknowledgement*

During the Workshop (In-Person)



PRE-WORKSHOP CHECK IN

This quick check in helps us understand where you are starting from and see if anything shifts during the day. There are no right or wrong answers.

1. How much do you feel you know about dementia and how it affects the brain?

- ☐ Not much at all ☐ A little ☐ Some
☐ Quite a lot ☐ A lot



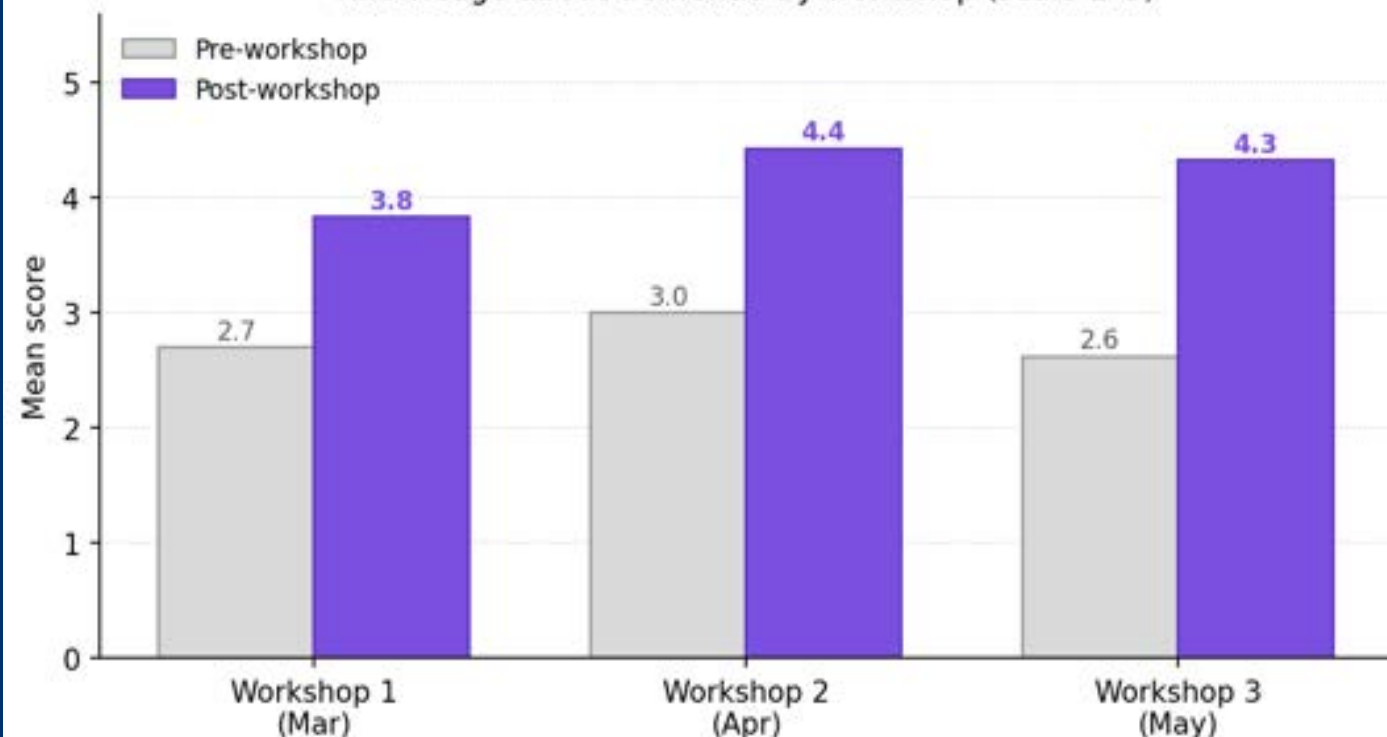
POST WORKSHOP FEEDBACK

Thanks for being part of *Mindful Conversations* today! This quick check in helps us understand what landed — there are no right or wrong answers.

1. After today, how much do you feel you know about dementia and how it affects the brain?

- ☐ Not much at all ☐ A little ☐ Some
☐ Quite a lot ☐ A lot

Knowledge about dementia by workshop (scale 1-5)



After the Workshop (Online)

% who agreed or strongly agreed	WS1 (n=6)	WS2 (n=6)	WS3 (n=7)	Pooled
Venue felt welcoming and accessible	100%	100%	100%	100%
Day felt well organised	100%	100%	100%	100%
Felt comfortable sharing in discussions	100%	100%	100%	100%
Would recommend to someone they know	100%	100%	100%	100%
Art activity added something meaningful	83%	83%	100%	89%
Happy with the food provided	83%	100%	71%	84%

"No complaints. Perhaps a little longer in the discussion segment. People like to be heard."
— Workshop 1

"The art activity was a surprise to me but turned out as the highlight of the day." — Workshop 2

"The creative piece was such a lovely thing to do — it really tied the whole day together very nicely." — Workshop 3



Support & Partnerships

UCL



UK Dementia
Research Institute



**COMMUNITY
AFRICAN
NETWORK**



**Black
Health
Legacy**



University
of Dundee



MRC Protein
Phosphorylation and
Ubiquitylation Unit



**ACADEMY
OF MEDICAL
SCIENCES**



UKDTN
Dementia Trials Network



Alzheimer's
Society

**ALZHEIMER'S
RESEARCH UK** **FOR A
CURE**

Funder
Focus Group

Funder
Workshop 1–4

Recruitment
& Outreach

**DIVERSE
BRAINS**



Initiatives Working For
and With The Community

*Charities, Funders, Universities,
Community Organisations,
Faith Organisations, Patient
Advocates, etc.*



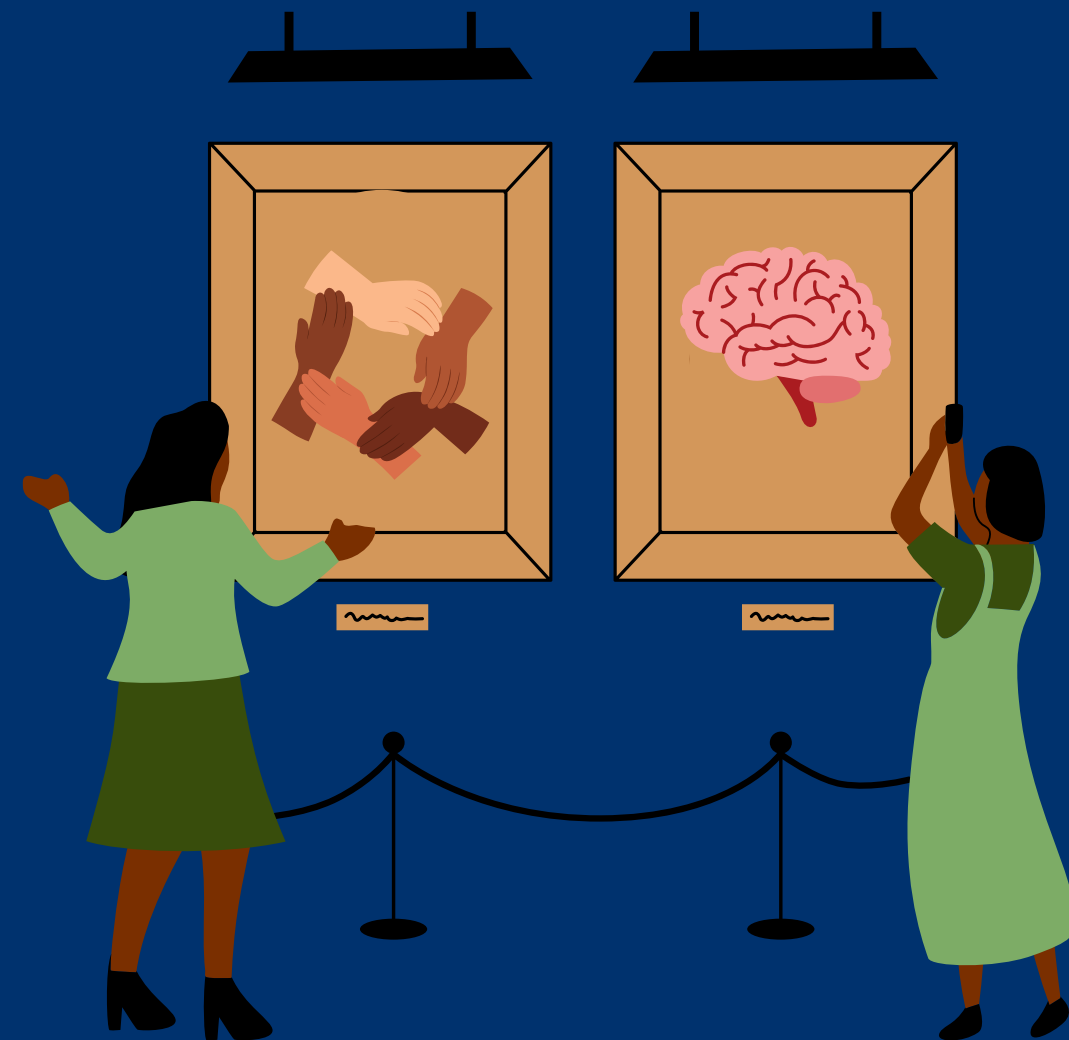
Extra Tips

- Start small and build momentum.
- Building relationships and trust takes time.
- Be transparent about expectations and outcomes.
- Recognise and value lived experience.
- Think long-term, not just project-by-project.

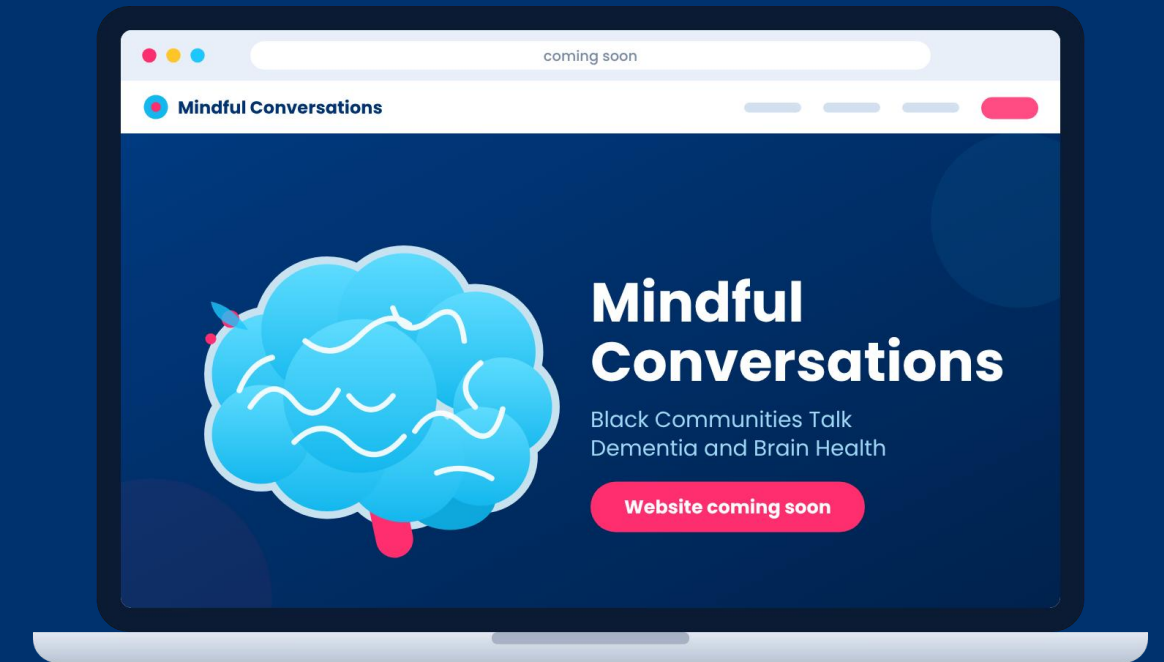
What's Next?



Full Reports
Workshop 1-4



Community Exhibition



Mindful Conversations
Website

Acknowledgements



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All the phenomenal volunteers
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Seiwa Cunningham
Vivien Kintu
Molly Andrews & Alex Collcutt
Janet Murungi*

PPIE is not a tick-box. It is a relationship.

Dr Nathasia Mudiwa Muwanigwa

n.muwanigwa@ucl.ac.uk

Connect with me on LinkedIn!