

The role of Public/Patient Involvement and Engagement in communicating and shaping research



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UK Dementia
Research Institute



THE UNIVERSITY
of EDINBURGH



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NETWORK OF EXCELLENCE

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Federation of
European
Neuroscience
Societies

Principal funder:



Medical
Research
Council

Why is PPIE important for (dementia) research?

- Accountability to the funders (taxpayers, people who give to charity etc) and Participants/donors



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



Alzheimer Scotland
Action on Dementia



Alzheimer's Society



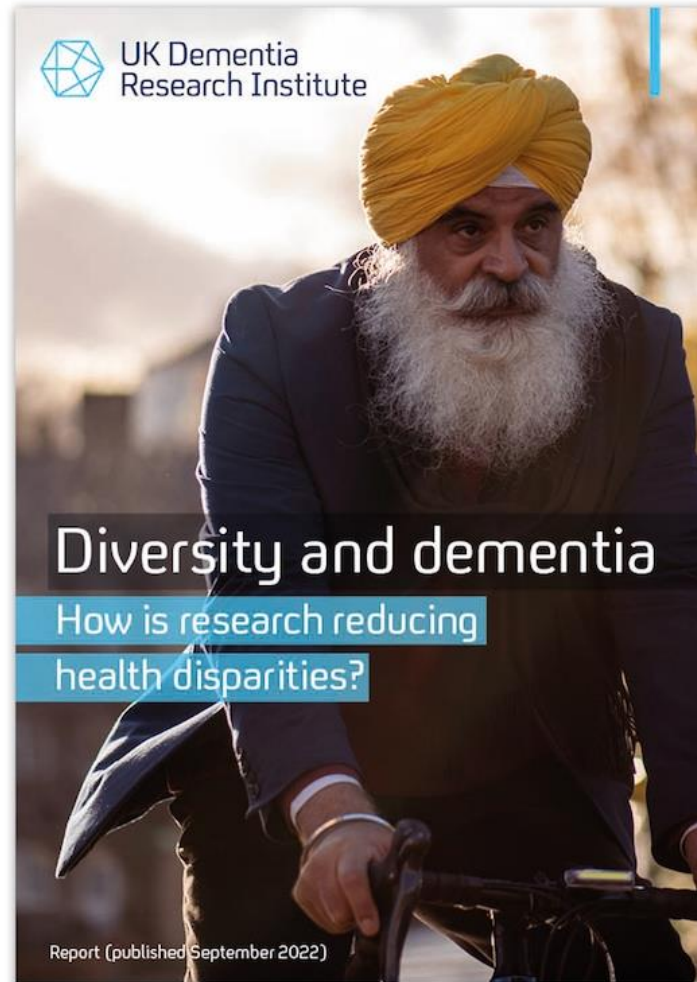
Why is PPIE important for (dementia) research?

- Shaping the focus of research
- Ensuring best research design for participants



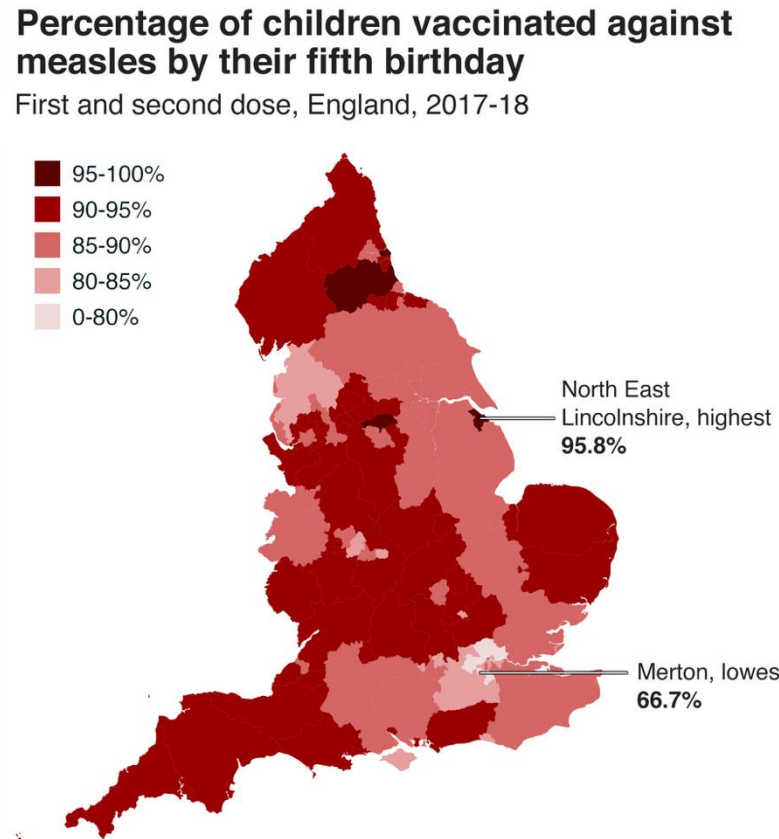
Why is PPIE important for (dementia) research?

- Ensuring impacts of research will work for everyone affected



Why is PPIE important for (dementia) research?

- Encourage TRUST in science (and future research funding)



Source: NHS Digital

BBC



“I don’t think Science knows actually”

The value of people with lived experience in fundamental research

- Helping scientists – shaping ideas, lay abstracts, communication skills, inspiration
- Helping people with lived experience – engagement is good for the brain!
- Providing hope for the future

Wider engagement with the public



MUSK START-UP INSTALLS FIRST CHIP IMPLANT INTO HUMAN PATIENT'S BRAIN
Tara Spire-Jones | President, British Neuroscience Association

LIVE
CNN
2:36 PM ET

NEWS CENTRAL
JURY HANDS DOWN \$2B VERDICT AGAINST BAYER AFTER FINDING...

— BOOK LAUNCH —

FIGHTING FOR OUR MINDS

— The Neuroscience of Defeating Dementia —

Join us for the launch of Tara Spire-Jones' new book exploring the science, hope and challenges of dementia research.

30 OCTOBER
5:00 PM

EDINBURGH FUTURES INSTITUTE

MORE INFORMATION & FREE TICKETS

SCAN ME OR VISIT EVENTBRITE

Practical tips for organising PPIE events in a fundamental lab

Jane Tulloch, Lab Manager, Spires-Jones Lab



Practical tips for organising PPIE events in a fundamental lab

1. Build trust before getting down to business
2. Make involvement accessible
3. Don't assume what someone can or cannot do. *'If you meet one person with dementia, you meet one person with dementia'*
4. Be clear about expectations and purpose
5. Consider supporters/carers
6. Make meetings inclusive
7. Build in flexibility
8. Enjoy!

