

NIHR Biomedical Research Centre: Newcastle

Communicating Science and Shaping Research

The role of PPIE

Calum A Hamilton



Background

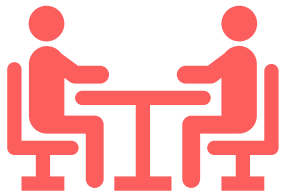
PhD

Post -
Doc

ARUK
Research
Fellow

Patient-facing

PPIE



Identifying opportunities to shape application

Lay proposal As you have indicated that human volunteers will be involved in your study, your proposal will be sent for lay review in addition to scientific review. Lay reviewers are volunteers who have personal experience of dementia, either through caring for a family member or close friend with the condition, or because they are living with dementia themselves. For further information and guidance please click the help icon.

What are the aims of the study?
Clearly state what you are trying to achieve and why it is relevant to your audience

How will the research have an impact on people with dementia?
People are interested in how your work could lead to a preventative measure, treatment or new diagnostic technique, so try to frame your work in this context. Remember to discuss why this work is necessary. You need to say why your project is important in helping us defeat dementia and how this particular study will take us closer to that goal.

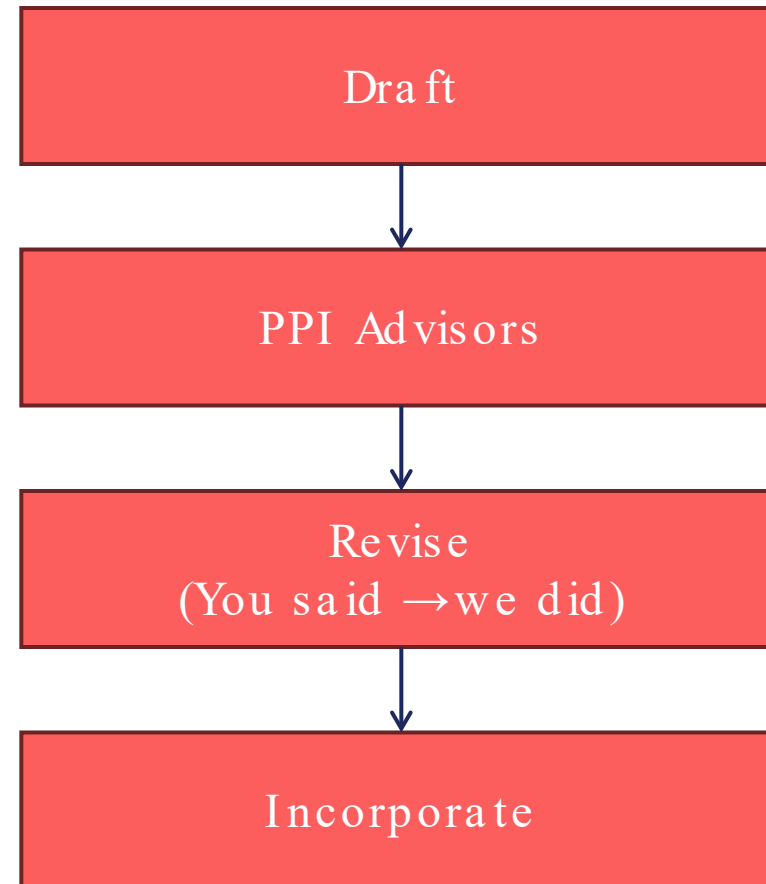
What does the research involve for people taking part?
Explain what tests the people in this research study will have.

Will people have to travel to take part?
Give details of where the people taking part will have to go. If travel is required, will their expenses be covered?

How many visits will the person taking part need to make?
Give details of how many times the person will be asked to take part. Does the study involve a one off visit or do they have to make a number of visits at different intervals throughout the research study.

How long will the person taking part be involved in the study for?
Provide details of how long each individual participant session will take and whether participants will be required to have multiple tests in one visit. If the person taking part is required to attend multiple sessions, provide details of the duration of the research study.

What information will be collected, and how will it be used?
Describe the information that the people involved in your research will provide you with and how this relates to the aims of the research study.



However...

Patient Information Sheet

Baseline Assessment

Imaging Assessment

Follow - Up

Pre-Existing Data

Deceased Participants

“Stick of rock”

What research needs to be done?

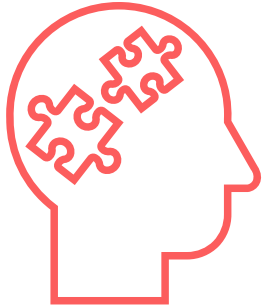
How should it be carried out?

How should results be shared and applied in practice?



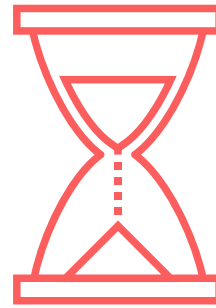
What research needs to be done?

Early Symptoms



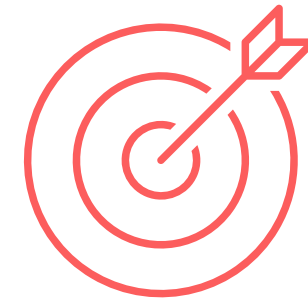
Population: Mild
Cognitive Impairment

Prognostic Uncertainty



Design: Disease
progression

Actionable Insights



Exposures: Modifiable
vs fixed risks

How should it be carried out?

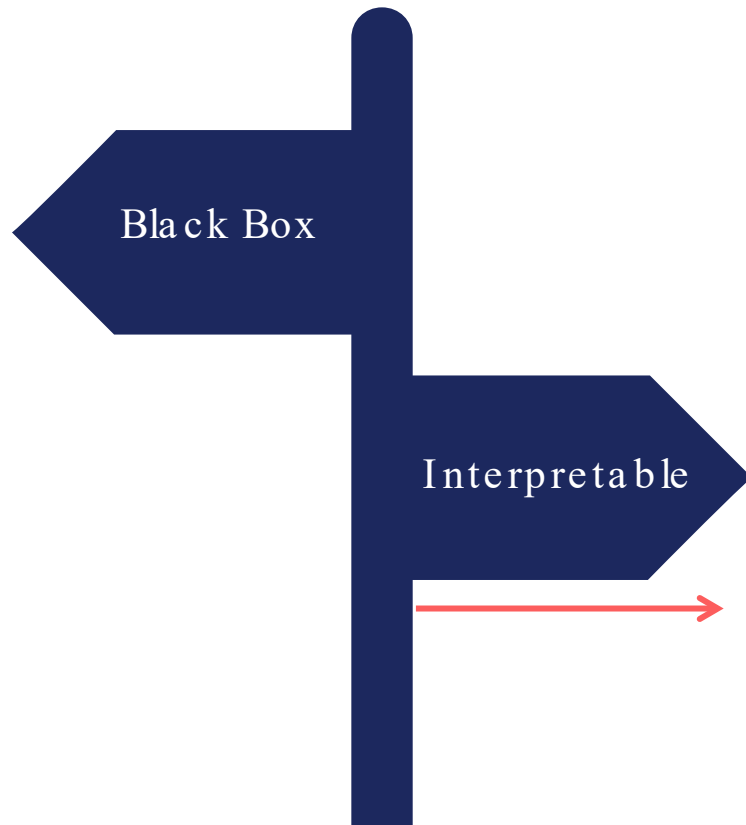


Photo Credit: Elliot Manches (Centre for Ageing Better)

How should it be shared/applied in practice?

Investigation A

Lumbar puncture
More invasive
Once and done
Highly accurate

Investigation B

Blood draw
Less invasive
Might be repeated
Slightly less accurate

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My understanding ≠ Stakeholders'

Finding partners and funding



Finding partners - facilitators

Claire Airey
Clinical Trials Network Nurse

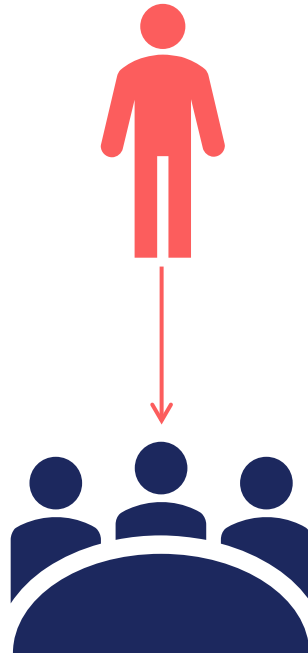


Dr Allison Killen
NIHR Biomedical Research Centre

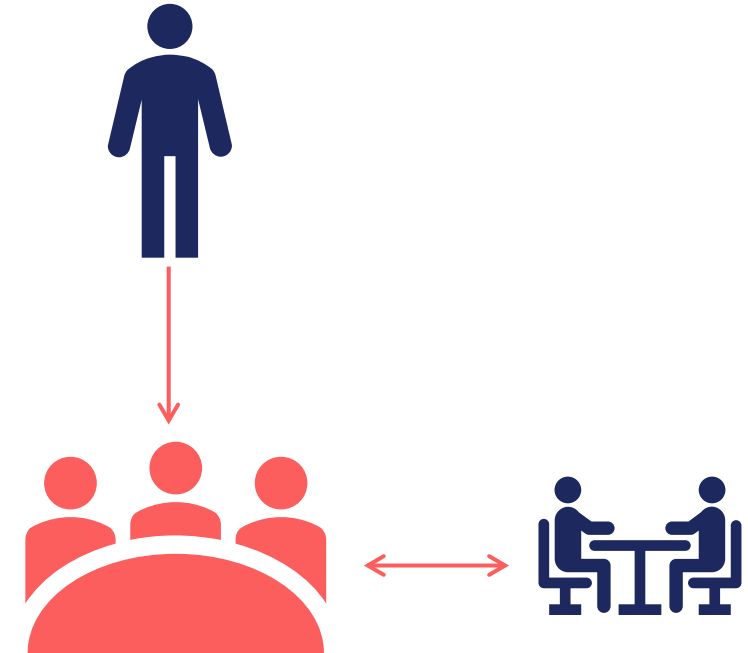


Facilitating conversations in the community

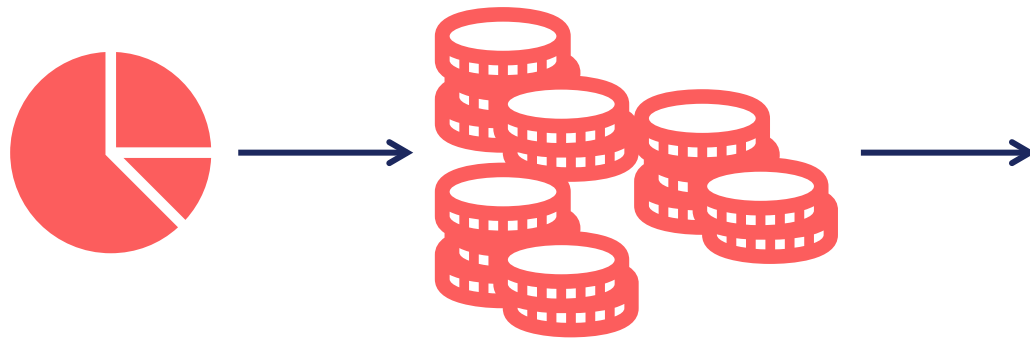
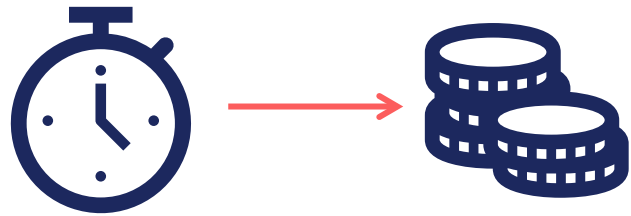
PPI Advisor



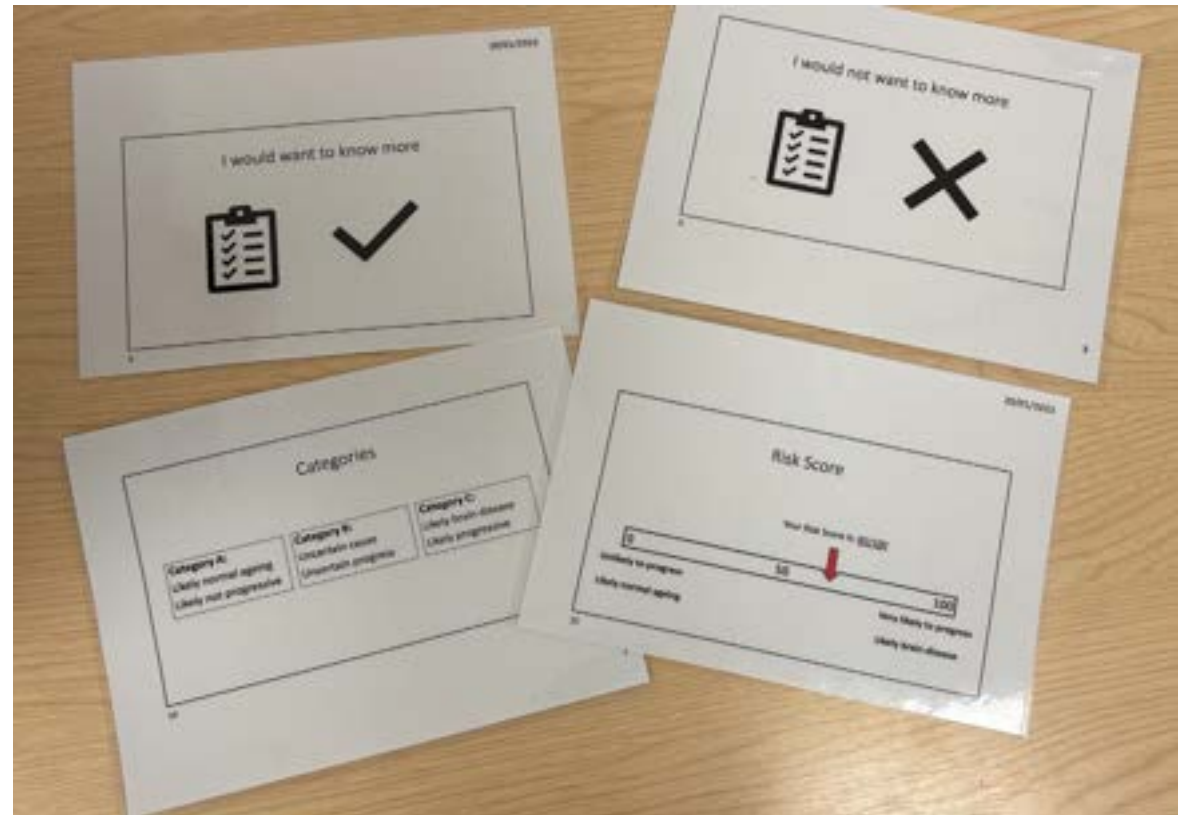
Researcher



Flexible reimbursement for time



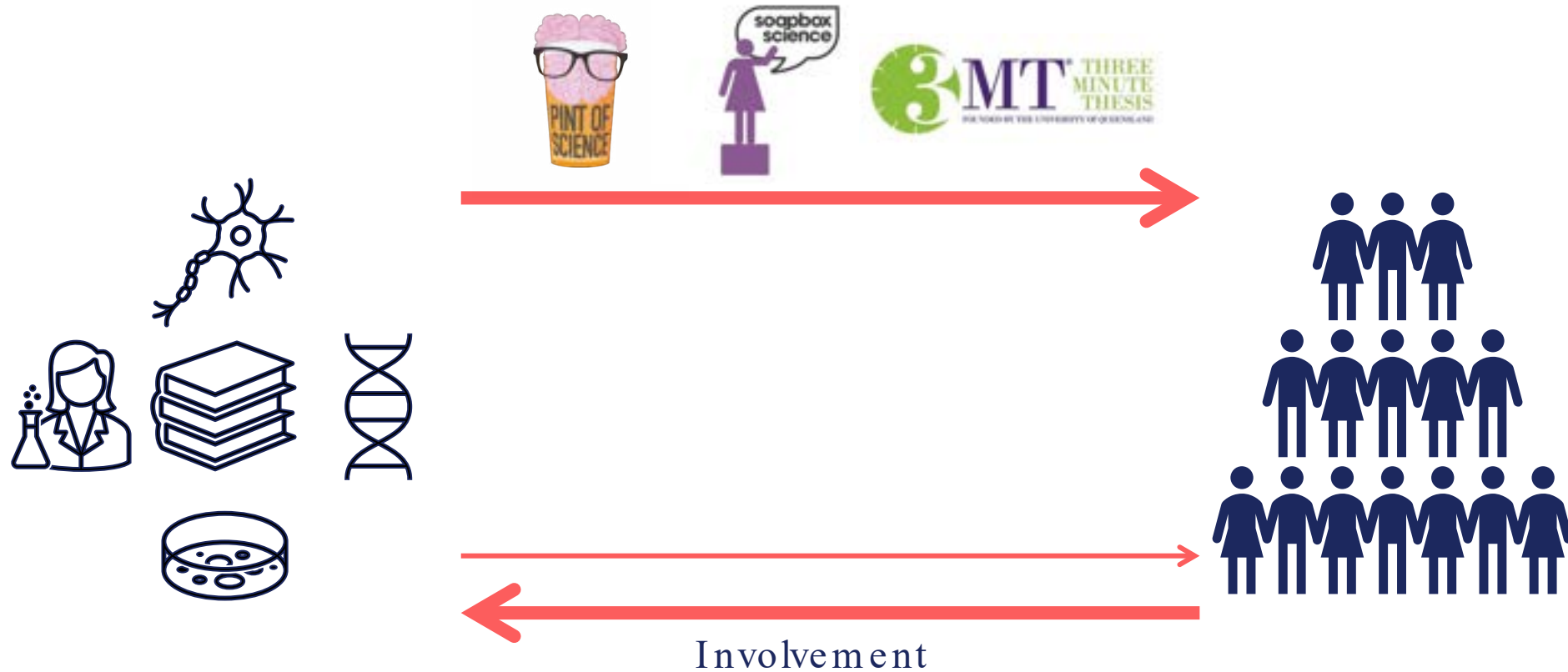
Involving people with additional needs



Cue cards help include people with cognitive impairments in complex discussions

Top tips

Direction of information flow



*Definitions vary

Not a 'box - ticking' exercise



Mind the (communication) gap

Supplementary Table S1. Simulated pathology weights.

Simulated Weight
0
0.25
0.5
0.75
1.64



Use the support available to you

BRCs (£)

RSSs (£)

ARUK Network Centres (£)

BNA

Colleagues

Other networks

1. EAST

University of Cambridge
Babraham Institute
University of Essex
University of East Anglia

2. WALES

University of Cardiff
Swansea University
Bangor University

3. LONDON

University College London
Imperial College London
Kings College London
Queen Mary University of London

4. NORTH WEST

University of Manchester
Lancaster University
University of Liverpool
University of Salford

5. MIDLANDS

University of Birmingham
Aston University
University of Leicester
Loughborough University
University of Nottingham
University of Warwick

6. NORTH EAST

University of Newcastle
Durham University
(and Teesside,
Northumbria, Sunderland)

7. NORTHERN IRELAND

Queen's University, Belfast
Ulster University

8. THAMES VALLEY

University of Reading
Oxford Brookes
University of Oxford
Rosalind Franklin Institute

9. SCOTLAND

University of Dundee
University of Aberdeen
University of Edinburgh
University of Glasgow
University of St Andrews

10. SOUTH COAST

University of Southampton
University of Sussex
Bournemouth University
University of Portsmouth
Brighton University

11. SOUTH WEST

University of Bristol
University of Bath
University of West England
University of Exeter
Plymouth University

12. YORKSHIRE

University of Sheffield
University of York
University of Leeds
University of Bradford
University of Hull

