

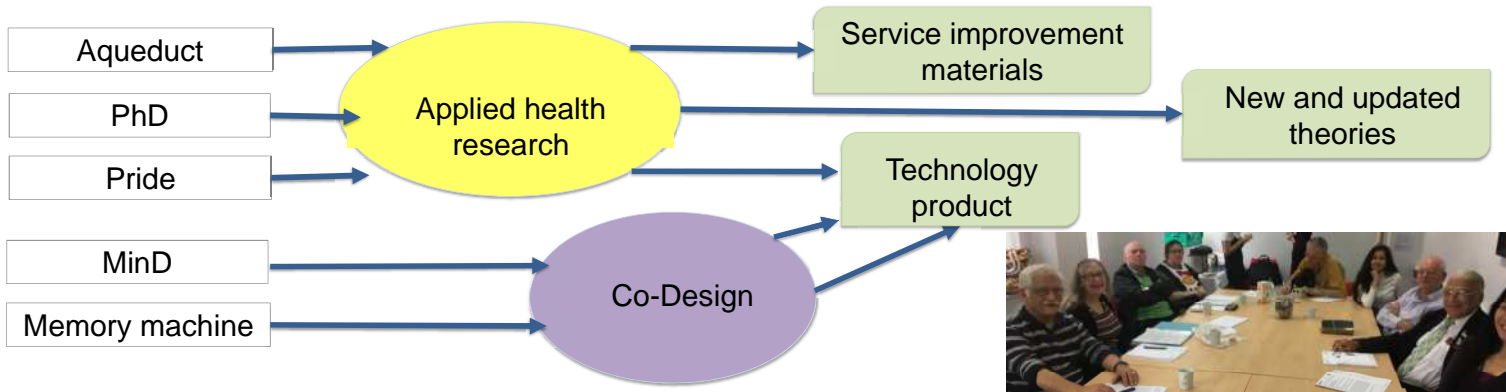
Researching *together with* members of the Centre for Dementia PPI group

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Introduction

Co-research or peer research has been core to five projects. Centre for Dementia Patient and Public Involvement group has helped develop this method and members have been involved in these projects. We explore theoretical frameworks of co-research and how these shape the practical aspects of the project; roles, relationships and governance. Our co-research activities have involved peer-facilitated interviews and

focus groups, workshops and analysis of research materials. Trust, rapport, and common insights between lived experience interviewers and research participants can enhance data collection through the creation of a shared narrative. Lived experience input enables a more nuanced exploration of the topic. Meanings and implications can emerge which may not have occurred to an academic researcher.



Values and theoretical position

- Aim**
Co-research as a development of PPI is driven by three agendas:
- Enhancing research quality by incorporating deeper 'lived experience' perspectives
 - Drawing on community-based participatory research, honouring grass roots dynamics of 'nothing about us without us'. Participatory research, whilst serving to improve health outcomes, originates from an emancipatory perspective
 - Upholding human-rights and a dementia-united approach

- Ways of working**
- Two-way interaction – academic researchers and co-researchers respect each other's contributions
 - Genuine collective input, contributing to outputs and responsibility for the project
 - Partners inspired by mutual passion and connection, valuing and supporting one another

- Consent**
- Overarching ethics – in one of co-design projects consultation-type consent was applied rather than research consent
 - Enabled creativity by avoiding labels of 'participant' or 'professional'
 - Feeling like 'standing shoulder to shoulder'

Intended outcome
Amplify voice of participant in findings

What have we learned?

Co-research involves new and emerging roles and relationships for both PPI members and academic researchers, which may be formed and renegotiated during and between projects. This indicates a need for clarity regarding the purpose of co-research as well as clear description of the role of co-researchers, and these should be clearly communicated amongst the research team, governance/sponsors, funders, and other stakeholders.

We also highlight a need for capacity-building of both academic researchers and co-researchers, involving technical knowledge about research processes and/or negotiated ways of power-sharing that recognise and reward the skills people bring. Crucially, there must be an acknowledgement of the reciprocity of learning between academics and co-researchers, where both groups have the potential to grow together by yielding power to each other. Participatory design frameworks have also been co-developed, enabling creativity and innovation between future users of technology, designers and engineers.

Processes, practicalities and outputs

'There are hurdles to co-research, but they can be overcome' – our shared reflection on our projects.

Flexibility in project design

- Preparation for co-research
- There is no guide to help researchers plan a project

Training of academic and co-researchers

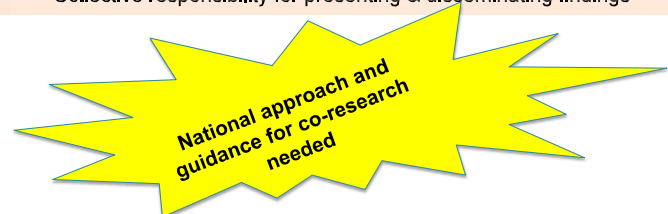
- Encouraging mutual confidence – technical skills where appropriate
- Developing culture of collaboration
- Try not to get hung up on formal training

Permissions

- Applied health research can involve checks that can feel like bureaucratic barriers- but we should see the importance & benefits of these:
 - Disclosure and Barring Service (DBS) checks,
 - Honorary contract and Research passport
 - Safety issues may be similar to academic research, and shouldn't be ignored
 - Some checks make assumption of being in paid employment which is a problem

Presenting findings

Collective responsibility for presenting & disseminating findings



Conclusions

Co-research is particularly important for dementia research where it facilitates a greater voice of people who may have differing cognitive or communication abilities, difficulties, or disadvantage. The emancipatory values of this approach, where incorporated correctly, serve to redress the balance between 'researcher' and 'researched', reduce stigma, discrimination, and exclusion to realise and build upon the mutual potential and skills of both co-researchers and academic researchers.

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