NIHR | Applied Research Collaboration East of England

Involving people with impaired capacity nearing the end of life in research

Changes, Benefits and Learning from Public Contributors: Public Involvement Impact Case Study

Project Team:

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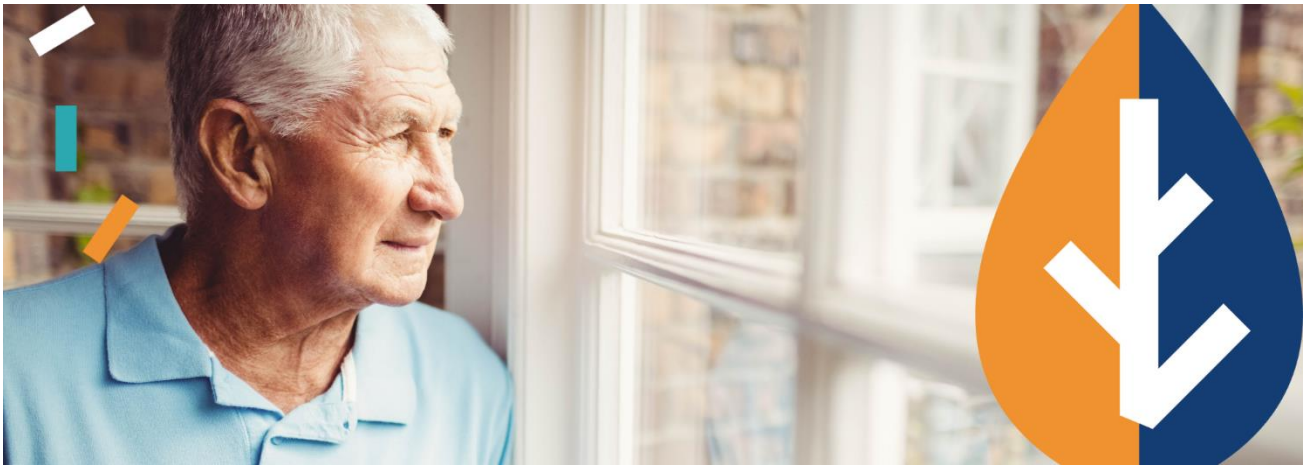
Introduction

The UK National Standards of Public Involvement are used as a framework for the ARC EoE Public, Community, Involvement, Engagement and Participation (PCIEP) Strategy and includes 'impact'. We define 'impact' as "**the changes, benefits and learning,** gained from the insights and experiences of patients, carers and the public when working in partnership with researchers and others involved in NIHR initiative's" (*NIHR Patient and Public Involvement Impact Working Group, 2019*). Through this, we seek improvement by identifying and sharing the difference that public involvement makes to our research.

The ARC EoE PCIEP Impact Case Studies are used to evaluate the impact of PCIEP on ARC EoE research and to highlight the changes, benefits and learning gained from partnership working and public involvement in ARC EoE.

Public contributors have been invited to co-produce the case studies and the perspectives of public contributors are included in the case study.



Public Involvement Impact Case Study: Involving people with impaired capacity nearing the end of life in research

Project Title: No Voice, No Choice? Reducing system factors that form a barrier to research for those with impaired capacity nearing the end of life

What problem is this research addressing?

Impaired capacity to consent to research is a significant barrier to participation. It is essential to involve those who lack the ability to provide informed consent **within** research to improve care and treatment, so that our research opportunities are inclusive and our evidence base for care and treatment is fully representative of the population who will receive it.

The aim of the project was to develop transferable solutions to address the inclusion barrier of people with impaired capacity towards the end of life across care settings in research. This was an exploratory project, which aimed to identify, define and develop plans to remove/mitigate barriers for a largely underrepresented group in research. We aimed to convene a broad multi-disciplinary project group who were positioned to inform, lead and champion change. We wanted to develop an understanding of the existing research in this area and work with people affected to produce recommendations that could raise awareness of the challenges of inclusive research for those with impaired capacity. The aim is to support researchers and clinicians to generate evidence more closely representative of the population they serve. If these people are routinely excluded from research that concerns the care and treatment they receive, we may not know which treatments are safe and effective for them.

This project was funded by the NHS England Research Engagement Network (REN) Programme.

How were the public involved in this research?

A major barrier within research for those facing impaired capacity towards end of life are ethical concerns about their perceived vulnerability, and the "protection imperative" which many researchers experience. Therefore, a core aim of our project was to amplify the voices of those with relevant lived experience who may view research differently.

Working with a national charity, the Anne Robson Trust, we engaged with participants who had been affected by death, dying and bereavement (particularly those experiencing social isolation) to understand their perspective on health research, and consequently explore opportunities for volunteer-supported interventions to increase participation in research. We wanted to understand possible authentic and ethical participatory engagement approaches that were most appropriate for those who could not express willingness via conventional means, and to identify preferred styles of engagement/communication, particularly for those living in residential care.

Specific PPIE activities included:

- Public questionnaire obtaining views about palliative care research and proxy consent was hosted and disseminated by our voluntary sector partner.
- Five focus groups/workshops with over 40 carers (active and bereaved), volunteers and people living with terminal illness to understand what successful participatory engagement looks like, and to co-produce a 'theory of change' as to how research participation can be more inclusive.
- Observations from those working closely with those at the extremes of impaired cognition and frailty, such as those who work and volunteer in a care home setting.

What were the outcomes of public involvement in this project?

Working with both the Anne Robson Trust, and gathering results from our own workshop and survey, we were able to identify some of the public's attitudes and behaviours surrounding researchers' approaches to the subject, which they deemed essential in fostering the trust necessary to undertake research around such a personal and sensitive topic. They were:

Respectful Responsiveness: being able to adapt research methods to a person's unique and evolving needs.

Trust and Connection: being able to build a human relationship, and to recognise and respect a person's value.

Balancing Power and Reciprocity: Demonstrating equality in the relationship between researcher and participant.

Representation: Where possible, researchers need to be culturally and /or ethnically representative of participants

Those with lived experience informed our development of a strategy to improve inclusion within research. Our work with these groups emphasised the importance of sharing our findings in more accessible format, beyond the written word (Figure 1). We therefore developed both a visual theory of change model (Figure 2) and a simplified version (Figure 3). Thanks to funding from a NIHR Clinical Research Network PPI Innovation Grant, we were able to work with an illustrator to summarise our findings in a "rich picture" for clinicians and researchers. We also co-produced a poster for display in care homes, designed to encourage conversations between those living in care

about the importance and impact of research (Figure 4). This is currently being used by the ENRICH team who support research in care homes to future increase conversations about research for those with impaired capacity.

Figure 1: Description of an ideal researcher - by workshop participants

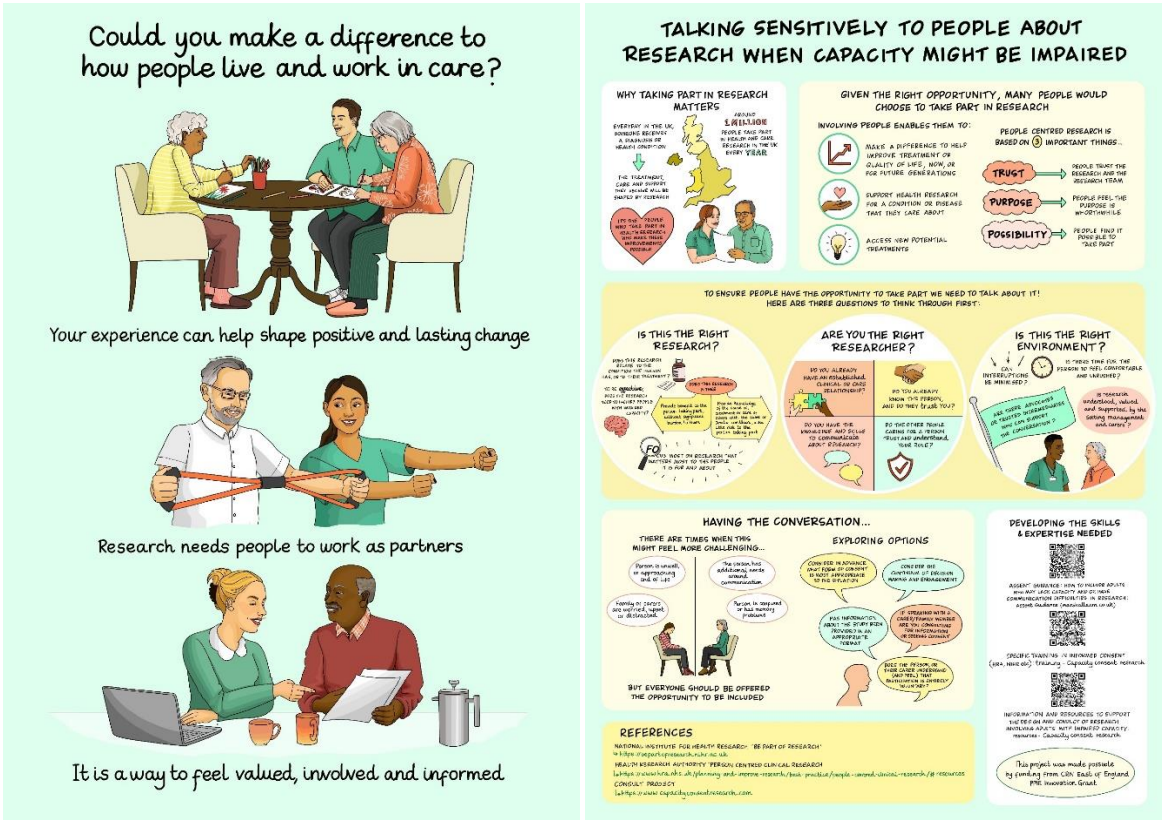


Figure 4: Co-produced posters for display in care homes

How did public involvement influence the project overall?

PPIE was an essential part of this project and their contributions have greatly shaped its work. Some of our strongest insights have come from community engagement with patient, carers, and the volunteers and voluntary sector organisations who support them. Our main challenge was the short time frame over which the project was delivered. As authentic engagement and participatory approaches are often developed over a longer timeframe than a few months, the short-term nature of funding meant that we felt less able to build longer term relationships that are essential to build trust and effective collaboration. This reflection shaped our recommendations and plans in the second stage of the project – to increase the opportunities for conversations about research within trusted relationships, for adults at risk of impaired capacity, by embedding research opportunities within existing or new trusted relationships for people with impaired capacity towards the end of life.

What was the feedback from public contributors involved in this project?

"This is an aspect of research which I hadn't - but should have - considered before. Conversations have been fascinating, and it's been a privilege to be included as a lay person. It's made me look differently at the ecologies of care in care homes and examine how voices and wishes are heard and respected" – Public Contributor

What are the reflections and learning from public involvement in this research?

This project provided a unique opportunity to explore and attempt to overcome some of the challenges in providing inclusive research opportunities towards the end-of-life care. NHS England (the project funders) were hugely supportive and proactive about incentivising the gathering of community insights. The key challenge was the limited time frame. This meant we had less time to develop trusted relationships, but also to sequence exploration and development of hypotheses, in addition to scheduling workshops. We deliberately tried to gather the voices of those from diverse cultural and ethnic backgrounds, however the short time of the project did not allow us to develop this fully. To address this in the future we would proactively identify people or groups already working with, and trusted by, different communities to ensure wider involvement.

Theory of Change Models

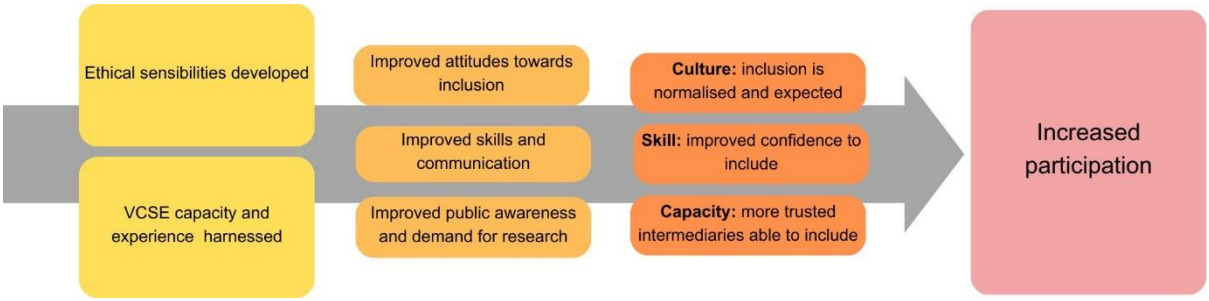


Figure 2: Simple Theory of Change showing how ethical sensibilities and voluntary, community and social enterprise (VCSE) relationships improve rates of participation

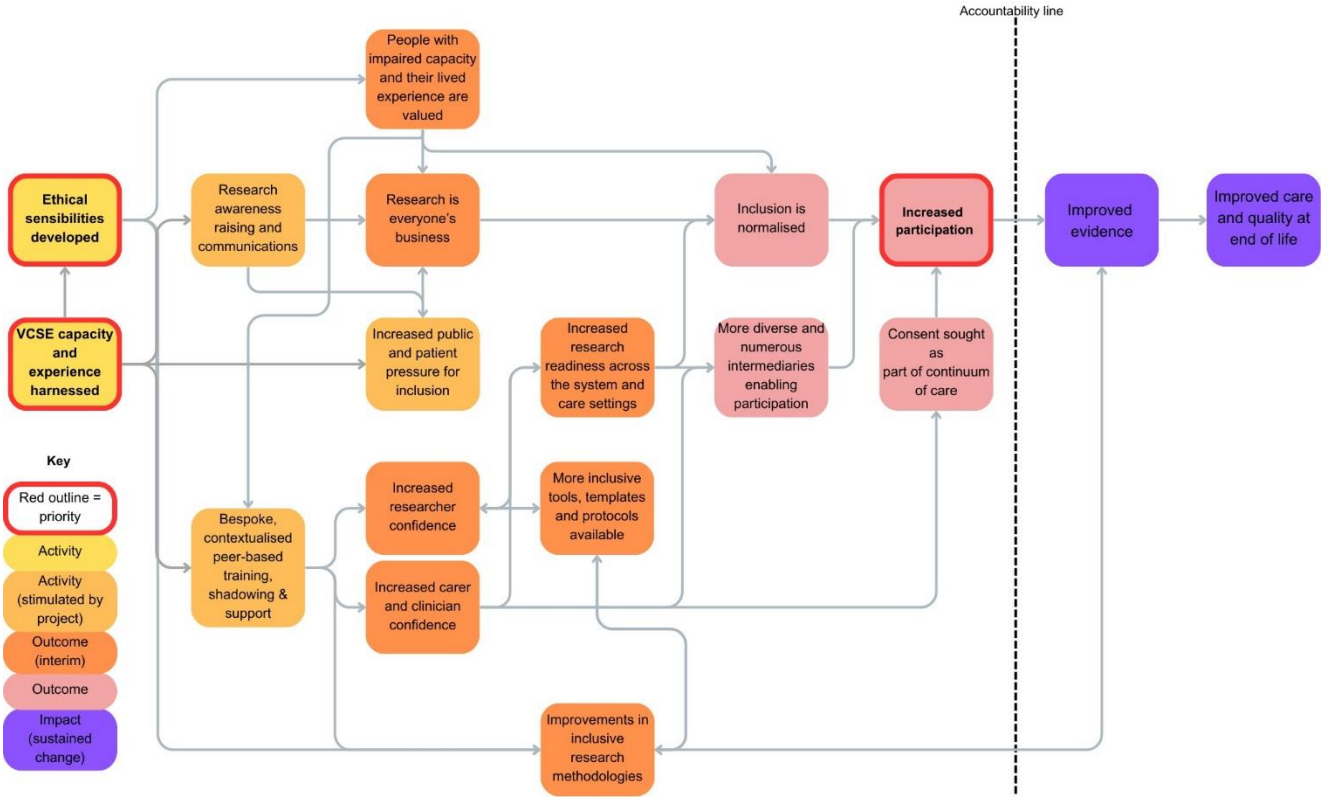


Figure 3: Full Theory of Change to achieve increased participation in end of life research for people with impaired capacity

For more information, visit the project webpage

Visit our website: arc-eoe.ninhr.ac.uk

Contact: ARCoffice@cpft.nhs.uk

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