



Involving people who are less socially connected in research

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

Project Team:

Dr Adam Wagner, ARC East of England Health Economics and Prioritisation (HEP) theme / University of East Anglia

Professor Peter Moffat, University of East Anglia

Professor Fiona Poland ARC East of England Inclusive Involvement in Research for Practice Led Health and Social Care Research theme/ University of East Anglia

Dr Linda Birt ARC East of England Inclusive Involvement in Research for Practice Led Health and Social Care Research theme/ University of East Anglia, University of Leicester

Dr Louise Lafortune, ARC EoE Population Evidence and Data Science (PEDs) theme / University of Cambridge

Dr Jennifer Whitty, Evidera

Alice Wreford*, ARC East of England Health Economics and Prioritisation (HEP) theme / University of East Anglia

* **Contact:** a.wreford@uea.ac.uk

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 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 who are less socially connected in research.

Project Title:

Valuing the outcomes of social connection interventions for use in economic evaluation

What problem is this research addressing?

Social connection is the feeling we get from our relationships with other people. It can take many forms and is made up of lots of different things and feelings (for example: if we feel like we can trust another person; the number of people we know; and how often we are in contact with people we care about). Social connection changes over time and can affect our health and wellbeing. Importantly, as we get older, we can be at risk of declining social connection – because of things like retirement, bereavement, or mobility issues. Many argue that the less involved we are with friends, family or our community, the less healthy we are, both mentally and physically. However, some people suggest this depends on the type of person we are – for example some people prefer to be alone and feel uncomfortable in bigger groups.

Community activities – such as support groups for substance abuse, walking groups, gardening clubs or drop-in services – can be used to help people create connections and friendships. These connections can help people feel supported, share information, and increase confidence; these in turn support people in making healthier choices. Whilst meeting new people and creating friendships may not be the main focus of such groups (as, for example, at a walking group) they are often the main reason people enjoy these groups and continue to take part. One-to-one activities or classes might offer more introverted individuals the opportunity to connect to their community by becoming a valuable access point to the community.

These activities are usually paid for by local authorities or charities. The decision about which activity to fund is usually made by comparing how well the different activities work. However, these activities are rarely compared on the strength of the connections and friendships they create. For example, a walking group may be judged based on the distance people walk, assuming that improvement to their health is mostly because of an increase in physical activity. However, if the activity creates good relationships, friendships may reduce stress-levels, allow for knowledge to be shared between activity members and improve members' confidence, supporting people to make healthier choices.

Social connection created within these activities is easy to talk about but can be challenging to measure. This makes it difficult for decision-makers to compare and prioritise which activities should be funded to help people stay social connected as they age. This project used various approaches to better understand and address this problem for those aged 50 years and older. Approaches used included discussion groups with public members and interviews with key funders in the East of England. Next, a survey will be created to understand which characteristics of the community activities have the most impact on people's willingness to participate. Recognising this might be different for different people, as people value social connection differently, we collected information about people's character. The findings will be shared with decision-makers and group organisers to help improve the prioritisation of community activities across the East of England.

Project aims

This project explored three key questions:

1. What do individuals over the age of 50 in the East of England identify as the key elements of social connection?
2. Understanding the funding landscape in the East on England: who funds interventions which impact on social connection and what influences their decision-making?
3. Which attributes of social connection do individuals over the age of 50 in the United Kingdom prioritise in community interventions?

How were the public involved in this research?

PPI and stakeholder involvement has been key in developing this study which looks to improve the value of social connection. This study began in February 2021, during the United Kingdom's third national lockdown to address COVID-19 pandemic. At the time, we were facing new rules and restrictions on the way we could create and maintain social connections. This changed how people saw, experienced and talked about social connection. For this project to be meaningful it was important that the research was up to date with these changes. As the world changed and adapted to COVID, so too did this project. To enable us to do this when there was no evidence or literature to guide us (because it had not happened before), we turned heavily to PPI and stakeholder collaboration.

It was suspected that the effects of the pandemic were disproportionately impacting individuals already at risk of poor social connection or loneliness. This included, for example, people who were not able to use, or access, digital technology; those with already very limited social networks; and those considered particularly vulnerable to the pandemic, like the elderly or immunosuppressed. It was important that these individuals, and other seldom heard voices, were included in the research to

create a true and current picture of social connection in the community. The challenge being: 'How do you safely *identify, access and engage* the people [in research] who are typically disengaged from social situations... during a pandemic?' To answer this, we considered a range of PPI and stakeholder experiences to inform the design, methods and interpretation of results.

We employed creative and flexible methods for engagement of PPI and stakeholder contributors. Community groups that aim to work with people experiencing loneliness or poor social connection were identified. Various approaches, including introductory emails and calling using publicly available telephone numbers, led to successful engagement of: AgeUK; Active Norfolk; Norfolk County Council; Suffolk Libraries; Norfolk Libraries; Luton Roma Trust; Health Watch Suffolk; and, Salvation Army Thetford. Individuals within the organisation with relevant experience, perspectives and available capacity were identified for ongoing consultation. The opinions and perspective of the community group allowed for efficient gathering of information (by them sharing their 'lessons learnt' and observations as service providers). As well as highlighting community access points and service-user experience, engagement of these stakeholders also aimed to map the funding landscape and decision-making process. This was crucial to ensure the valuation methods developed in this study would be applicable in practice.

Stakeholders will also be crucial in the dissemination of the study's final results. Lead researcher, Alice Wreford, participated in (and continues to participate in) multiple one-to-one conversations with each organisation. The frequency of meeting flexed, adapting to stakeholder capacity and project demands. At project design, each organisation took part in a minimum of two consultation meetings. Following this, there have been regular meetings with AgeUK, Norfolk County Council and Suffolk libraries to support project development.

Beyond stakeholder contributions, the project benefits from ongoing support from three individual public members who have contributed from project conception to the present. These contributors represent a range of perspectives including a working mother, an ethnic minority refugee and an individual who is aging and childless. Alice Wreford has virtual one-to-one consultation with each, eliciting feedback on overall study design and public facing materials (for example, flyers, recruitment posters, participant information sheets, questionnaires and the survey).

We also engaged the public through the NIHR ARC EoE network; at an in-person poster stall for the project at a local library; and, via social media posts.

The project has also been presented at several work-in-progress appointments, and to established groups, for example NIHR ARC EoE Inclusive Involvement in Research for Practice's 'Advisory Group'. At all opportunities the project has sought and obtained valuable feedback from public members.

What were the outcomes of public involvement in this project?

PPI and stakeholder collaboration resulted in many positive changes to the project.

- Stakeholders helped map the funding landscape for social activity interventions. This was used to develop the sampling and recruitment strategies for funder interviews.
- Initial insights into the challenges faced by organisations (statutory and non-statutory) influenced the topics investigated in interviews.
- Stakeholders contrasted idealised outcomes versus practical constraints (success of a social activity intervention is always shaped by participant dynamics – this uncertainty must be considered). This nuanced difference was captured in the updated wording of interview questions: for example, 'Do you think social activity interventions *should* be funded?' is followed by 'Is this practical in reality?'

- They highlighted where industry specific jargon could be used in the interviews, improving the flow and communication in interviews.
- Stakeholders also supported survey development by suggesting questions and updates to the wording (for example, Norfolk County Councils Digital Exclusion Project Manager suggested wording, and answer options, for question related to digital technology use).

All public facing materials have received significant updates following input from public members. This included updates to length of text, language, ordering of text and overall aesthetic.

For example:

This study used a 'Nominal Group Technique' method to answer research question 1. After describing the process to a PPI partner, they helpfully raised that this could simply be called a 'discussion group'. This was very well received by others in the PPI group, and we believe helped recruitment considerably.

How did public involvement influence the project overall?

PPI and stakeholder collaboration has steered this project from its outset. The project evolved during the midst of the ongoing pandemic, with the ever-changing 'needs' of the East of England community illustrated through the experiences of our group of contributors (both funders and public members).

In earlier project stages, it was thought that this would be a low-burden study for respondents, as we were not asking for personal accounts; rather a conceptual understanding of social connection in the community. Very quickly our contributors helped highlight the potential impact of addressing loneliness, the subsequent impact on individuals and the need for a highly sensitive approach to conversations. Upon reflection, we now see loneliness and social connection to be extremely emotive topics for many. To help mitigate this, and ensure a positive research experience, careful attention was given to the framing of conversations with individuals (for example, we asked respondents 'What could be done in your community to help people feel more connected?' rather than 'What makes you feel socially disconnected?').

Further, the broad range of perspectives represented in our PPI group, and the time spent learning about PPI members experiences, ensured appropriate support and preparation for conversations with participants. An example of this, was the impact of the passing of Queen Elizabeth II: this happened at a time when we were due to collect data at in-person discussion groups. This was particularly moving for individuals who were experiencing loneliness and had felt a lifelong connection to Queen Elizabeth II – an experience shared by one of our collaborators. Researchers were well equipped to support respondents in these conversations, how they linked it to loneliness and, where appropriate, signpost them to additional sources of support.

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

A public contributor's motivation for taking part in this project was described as follows:

"The reason I want to take part in the research for NIHR, is because I feel it is very unique actually. And I feel we need to raise awareness for people like myself, who are not just ageing without children, but who are alone in communities and in society. We need to reach out to them. **We need to make other people aware that there are people like this, like me, like them, in their community who don't have a voice. And we need a voice. And that, community can be our voice. So we need the research.** I think it would, probably, it would be surprising how many people there were living alone, without support or awareness of their situations. I am. So there will be many others. So I look forward to seeing the results, and thank you very much for allowing me to take part."

- *Public Member Contributor*

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

Relationship building (with both stakeholders and individual public members) has been particularly successful throughout this project. Many contributors to this project had little to no prior experience in research and/or the academic setting. This was a huge asset to the project, as it provided a real-world 'lens' on how people would view this project when first introduced to it. Consequently, the language and narrative of the project improved, leading to a more accessible project. Successful engagement of this kind involved significant time to:

- Identify key players and community access points;
- Write introductory emails, tailored to each community organisation;
- Design posters and flyers to invite individuals to participate as PPI;
- Attend in-person events/ community sites to speak with public members and describe the PPI process;
- Conduct follow-up conversations with potential PPI members/ stakeholders who expressed interest in participating;
- Describe the remuneration process, and impact of claiming on individuals;
- Explain a complex multi-phase project, including health economics methodologies in lay terms;
- Schedule multiple one-to-one meetings with individuals (while remaining flexible to the frequent cancelling and rescheduling of appointments) – including, appointments outside of typical working hours to meet 'real life' constraints of PPI members;
- Attend stakeholder meetings, to offer support/ share learnings across the region;
- Support PPI public members to develop, where such an interest was indicated (for example, providing a platform to share their personal accounts; and, introducing PPI members to other research activities and projects);
- Act as a point of some social contact for those experiencing loneliness (researchers allowed space for individuals to share their stories, but signposted to support services as needed).

As a PhD project of 3-4 years, the main researcher (a student) was able to more easily ring-fence the time required to successfully engage individuals. However, in projects with shorter timelines, this may not be possible. Further, it is important to note that stakeholders' interest in participation was centred in their need to find a solution to the problems addressed in this project: to evidence the economic impact of complex social activity interventions. Designing the project to directly meet the needs of the community, helped validate the time stakeholders invested into the project – resulting in beneficial synergy. In situations where a project may be less aligned to the priorities of some stakeholder outputs/ deliverables/ reporting, their involvement may be less forthcoming as they have to focus their efforts on delivering their priorities.

For more information, visit the [project webpage](#)

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

Contact: ARCOffice@cpft.nhs.uk