NIHR | Applied Research Collaboration
West Midlands

"Equal access to the knowledge table"

Scoping exercise:
Public & Community Involvement, Engagement & Participation in NIHR Applied Research Collaboration National Priority Consortium for Adult Social Care and Social Work

Summary of the main themes and recommendations

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Introduction

The National Institute for Health Research (NIHR) has funded nine Applied Research Collaborations (ARCs) with a special interest and research expertise in Adult Social Work and Social Care to form a National Priority Consortium. Led by NIHR ARC Kent, Surrey and Sussex, the Consortium will undertake applied research in partnership with people who commission, deliver, and most importantly have lived experience of social work and social care services. The initial period of the grant is from October 2020 to September 2023 and will focus on research projects to which it can add value by working on a national level or cross-regional basis.

From its conception, the Social Work and Social Care National Consortium recognised the importance of placing people with lived experience at the heart of its decisions and activities. The proposal identified dedicated resources to support this activity and selected the West Midlands ARC to lead on developing relevant governance and infrastructure. To understand how best to co-produce its work the Consortium has undertaken a scoping exercise to learn from current practice and to identify future opportunities. The scoping has built on the findings and recommendations of a previous paper, *Public Involvement in Social Care Research,* produced by the Social Care Institute for Excellence (SCIE) in 2019 for NIHR INVOLVE[1]. This report highlighted the requirement to make research more accessible to people who use social care services, the importance of actively involving seldom heard groups, the need to support user-led organisations to conduct research and the barriers to public involvement presented by some universities.

This summary report provides an overview of the insights provided through the scoping exercise. The exercise was informed by people who use services and carers who are part of West Midlands ARC Public and Patient Engagement Network. Pete Fleischmann from Co-production Works undertook the interviews and wrote the first draft of the report. The design and recommendations were overseen by a joint steering group from the Kent, Surrey & Sussex and West Midlands ARCs.

[1]Faulkner, A., Pieroudis, K., Fleischmann, P. (2019) *Public Involvement in Social Care Research: Final report to NIHR INVOLVE.* London: Social Care Institute for Excellence. This is available at: https://www.nihr.ac.uk/documents/public-involvement-in-social-care-research/27982

Objectives

- To understand current involvement, activity, and networks of those with lived experience of adult social care in the ARCs

- To understand the scale and scope of the existing national social care research networks and within national programmes such as the School for Social Care Research

- To gain the views of stakeholders within the ARCs and existing national networks regarding how best the Public & Community Involvement, Engagement & Participation (PCIEP) can add value in social care research.

- To understand the accessibility and diversity issues regarding user engagement/ co-production in social care research.

Stakeholders

The scoping exercise engaged with the following stakeholder groups:

- Public contributors with lived experience of social care (including people who use services and carers). Participants' experience might be as co-applicants, members of advisory groups, or of user/carer groups or networks.

- Public and Patient Involvement (PPI) Leads/researchers

- All participants must have experience of engaging in social care research.

In total there were twenty contributions:

- Eleven Applied Research Collaboration (ARC) Involvement & Leads.
- Five representatives of User/Carer Organisations/networks including: Shaping Our Lives, National Survivor User Network, SCIE Co-production network, Co-production Collective.
- Four national social care research organisations including School for Social Care Research, Research in Practice, Innovations in Dementia.

Appendix 1 provides an overview of the scoping process.

Main Themes

Current experience & practice in social care research

Relationship to health

Most of the ARC public involvement leads had a health focus and their roles were health-centred. There is among this group an increasing awareness of social care and the need for the inclusion of people who use social care services and their carers in public involvement. However, some interviewees are unsure how to approach this challenge.

One interviewee from a national body commented that the current approach of the National Institute for Health and Care Research (NIHR) to invite social care users to join various advisory groups could be tokenistic. This was because it is hard for social care representatives to make an impact as they were often a lone voice in a big group.

Several interviewees felt that social care research was very much the 'poor relation' of health and that one function of social care research should be to promote the understanding and visibility of social care services.

'It is about talking to people and understanding how social care is making a difference to their lives and that's where the research is needed: that's where we need the evidence.'

Lack of understanding of social care

Among a small number of ARC public involvement leads, there was quite a limited understanding of social care and there was a tendency to see social care as a sector which provided care homes and not much else.

'I think the challenge is, social care covers such a huge diversity of people and needs. So, there may be working age adults with physical disabilities, but who are otherwise capable and active members of society. And then older people, maybe living with dementia, and people with learning disabilities.'

However, one public involvement lead with a social work background had an excellent understanding of social care and a good network of people who use social care services, which consisted of users and carers involved in recruitment, teaching, and assessment of the social work degree. This is an interesting avenue to explore as social work degree courses must provide user involvement and often have existing networks.

Social care leading the way

One interviewee spoke about how social care led health in terms of a longstanding engagement with a range of public involvement and participatory research activities. These include peer research and engaging with service users and carers in service delivery.

'Health researchers kind of think they invented public involvement and participatory research.'

Other interviewees said that social work has a long tradition of pioneering work. For example, advocating for equal rights and fighting discrimination, which dates to when these ideas were not mainstream. Another interviewee spoke about how social work has always had strong democratic traditions and a recognition of the social factors which impact on peoples' lives. In addition, interviewees talked about the distinctive contributions of social care to the public sector, such as personalisation, self-directed support, and strength-based approaches.

Paradigms and terminology

Public and Community involvement, Engagement, and Participation (PCIEP), the term currently favoured by NIHR, is not felt to be helpful and most public involvement leads do not use it. Participants said that the term is too long and cumbersome and not helpful when working with members of the public. Some people shorten it to Public Involvement or use Public and Patient Involvement (PPI), which is the term still in most common usage.

When asked what concepts approaches, paradigms drove interviewees' thinking about PCIEP in research there was an array of answers including: Co-production, Substantive involvement, Public and Patient Involvement, User-led research, Peer research, Participatory research, Citizen Science, Epistemological justice. This diversity of perspectives is in many ways a strength but also a challenge as it can lead to researchers not fully recognising and understanding differences in others' approaches.

Some interviewees said that Public and Patient Involvement could be a quite a passive model, which often involved people who use services and carers only having marginal impact on studies.

Several interviewees mentioned the social model of disability as a particularly important concept in social care research and practice.

Co-production was a term which everyone recognised. Co-production was seen by some as a gold standard of involvement, which involved the genuine sharing of power. True co-production was seen as an equal partnership in the research cycle, from the inception of a research question through design, delivery, and reporting. Some people were reluctant to describe projects as co-production unless they fulfilled stringent criteria. Some participants saw Co-production as the future direction involvement in research should follow.

Underneath the myriad of models and terminology there was a shared belief in the importance of levelling the playing field between users/carers and academics. There was some clarity in how this could be achieved.

'[That] the knowledge of people on the receiving end of things, with lived experiences is given equal weight, not superior weight, equal weight, with more traditional forms of knowledge.'

From people who use services interviewed, there was a clear message, as one participant said;

'We want equal access to the knowledge table.'

Existing Networks

All ARCs interviewed had some sort of Patient and Public Involvement (PPI) panel, group, or forum. Most said that these included people who use social care services and carers. It was clear, however, the primary focus of these groups was health. None of the ARCs had a separate social care structure. Some said that this was an area in which they needed to do better.   Some were still in the process of mapping their local networks.

Some ARCs are able to give examples of social care research which involved some degree of involvement of people who use social care services. However, some of these projects were health-focussed, which also touched on social care issues.

In response to questioning about networks of people who use social care services, people mentioned the Social Care Institute for Excellence's co-production group, TLAP's (Think Local Act Personal) Co-production advisory group, Innovations in Dementia, Shaping Our Lives User Network, a network of research ready care homes and a wide range of community groups and user-led organisations. Several people mentioned INVOLVE. There was uncertainty around what role the new Centre for Engagement and Dissemination (CED) (which has replaced INVOLVE)

would take up and how effective it would be at promoting/supporting involvement in health and social care research.

It seemed that if tasked with engaging with people who use social care services and carers most ARCs will work with local and possibly national voluntary organisations and providers to access people. Some had very good links with local organisations and put time and resources into developing and sustaining them. The ways that ARCs engage people who use social care services is not uniform.

The only research-specific network of people who use social care services and carers appears to be the School of Social Care's user, carer and practitioner reference group. This is a relatively small group of 12 – 15 people.

Barriers & Enablers for Lived Experience

In general, interviewees said that having adequate time and resources to do involvement well was essential and there was concern over the lack of established methods and good practice.

Digital exclusion

The shift to digital working was seen as problematic by most participants as poverty and lack of technical know how was effectively excluding large numbers of people from involvement opportunities. However, some interviewees said that if people did have access to appropriate devices and wifi coverage then digital engagement could be liberating and made fitting participation around other commitments much more viable.

University challenge

'**...***a university can be quite an imposing place that I think adds massive barriers, even if even if the perception is not true.'*

There were lots of comments about the inaccessibility of research and universities. Universities were seen as very variable in their ability to sensitively and efficiently include people who use services and carers. Some universities have developed effective systems for everyday functions, such as prompt payment of fees and responding actively to disabled peoples' accessibility requirements. Other institutions,however, continue to struggle with this, leading to discontent and frustration among public contributors.

Some participants said that they thought universities were remote from the reality of peoples' lives, that their communities are mostly distrustful of academics and they feel that engagement is, at worst, exploitative.

ARC public involvment staff often had a very good understanding of the pressures on academics and the systemic reasons why researchers find it hard to share power.

'The way that the system is set up, and the history, means that you get a situation where often researchers find it quite difficult to, to let their guard down and to share power, because a system has brought them up in a certain way, they're expected to, to meet the requirements of the Research Excellence Framework, and to prove certain things, you know, and so they, they think about that, because that's important to their career. And when you ask them to share, and to, to allow others to make decisions, you know, that that affects their future and their career, and so they're anxious to do so.'

Capacity and relationships

The two enablers most often mentioned by participants was the ability to build capacity and develop long-term relationships with individual users, with user-led groups and community organisations. Such relationships, if successful, were characterised by trust, reciprocity, and a sensitivity to the current constraints on community groups. Interviewees said that following years of austerity and now the Covid crisis, community organisations are often focussed on supporting their constituency groups most basic needs while struggling to stay financially viable.

One interviewee described a local refugee and asylum seekers' network as being;

'...overwhelmed with requests from very well-meaning, usually white, researchers [for access to for example] a group of pregnant Muslim women or … diabetic Asian taxi drivers…'

Lots of participants stressed the importance of building trust and forming long-term relationships.

One participant gave an example of a project to build research partnerships to ensure ongoing, reciprocal, sustainable collaborations are developed with local voluntary sector organisations who have reach into marginalised communities. Others talked about paying community groups for services. There were also examples of researchers embedded in community organisations, strong partnerships between universities and voluntary organisations and other reciprocal models.

Involvement of under-served groups

There was a strong perception among almost all interviewees that involvement in research was a white, middle-class field and that opportunities for involvement were most often taken up by older, educated people.

'...there are individuals who have massive understanding of the NIHR landscape; they understand the research infrastructure much better than I do. They go along to all sorts of local, regional and national groups: their tenacity and their loyalty is fantastic. They are really committed. But they are almost all white, middle class, retired ex-professionals.'

Most interviewees identified as a particular issue involving Black, Asian and Ethnic Minority people. Many interviewees said this was an area in which ARCs needed to do better. There was an awareness that this was a long-term project and that Covid had made it even more difficult. Whilst some ARCs had built up very good relationships with for example Afro-Caribbean community organisations, others were unsure how to approach the issue.

There was also an awareness from many interviewees of the barriers to involvement in research for working class and less well-educated people.

Fully involving people disabilities and long-term conditions

Access needs of different groups, such as people with learning disabilities and dementia, was seen as big issue. Interviewees with experience in these areas were keen to emphasise that these are diverse groups of people, encompassing a wide range of vastly varied impairments. Several people gave examples of research conducted in equal partnerships with people with dementia or learning disabilities. And provided models of how to achieve this.

'It's, about people with dementia, [about] being in control and learning and developing new skills. So being able to research the questions that they're interested in, but along the way, growing in confidence.'

Priorities for social care research

Starting from where people are

A strong message from across many interviewees was about the disconnect between some research and the everyday experience of people who use services and carers:

'You need to start where they are and about what's important to them. And some of what poses as research isn't worth doing.'

'Too much research on people not enough with people.'

'I guess it's based in people's real lives, it's thinking about what would actually change people's lives.'

'What researchers seem to find sexy are these big projects that have little to do with people's lives.'

Funding and integration

Participants with good knowledge about social care said that the funding of social care and the *'dreadful separation between health and social care,'* were the most important research priorities.

There was a sense for some participants that social care was in crisis.

'We don't need small scale research trying to tell us that there is [an] easy solutions, there are no easy solutions to the crisis of social care.'

The separation between health and social care was seen by one participant as the root of many systemic issues.

It's an unintelligent system, with two key organisations that are in principle at loggerheads with each other. And, and it's unbelievably wasteful.'

The need for more research about new models of care such as independent living was a key concern of some participants

'We are not in the future going to be a population necessarily made up of people we now conceive of as the norm as able bodied. We are likely to be a population, which is older, which has more impairments, perhaps, where there is more mental distress, or where there are more people surviving to be citizens who have learning difficulties [and] with long term conditions.'

Good practice in PCIEP

Many participants said that a priority should be more research and guidance around good practice in PPI and co-production. There was acknowledgement that this was not an area were a 'one size fits all'

approach was appropriate. However, there was still a strongly expressed need for more research into the meaningful implementation of involvement and for more authoritative good practice guidance.

Implementation research

'So for me, the biggest issue in in research is, is the agenda being set by communities and not by researchers.'

There was strong support among interviewees for more implementation research in social care. Participants said that work to implement existing knowledge in partnership with communities felt more tangible and accessible:

'..blue sky thinking research is not really what people are as interested in: they want to know [that] research has got some sort of fundamental connection with people's real lives.'

The role of ARCs was seen as important by participants but there was also a concern that the public and community organisations do not understand ARC's role.

A particular interest of some interviewees was in research on the implementation of PPI and co-production.

A new network

There was a settled view that if the ARC priority set-up a network for social care PCIEP, this would be welcomed.

Most were very positive about this, though one person warned that with nine new priority areas lots of demands were being made on local ARCs from the centre, so the approach needed to be thought about carefully taking into consideration the pressures on local ARCs.

Participants said that the new network could have the following functions:

Good practice – advice support: The provision of authoritative, practical guidance about PCIEP methods and approaches.

Learning: Sharing, supporting, and disseminating learning about the involvement in research of people who use social care services and carers across local ARCs and beyond.

Systems improvement: The network could have a function to improve the voice and status of social care within research bodies such as NIHR.

Pool of people: Some participants suggested the network could form a pool of people to involve in research. However, others said that local involvement was best done at local level.

ARC governance: The network could have a role in the governance structures of the ARC priority thus helping to ensure that the voice of people who use services shape culture and strategy. This could include membership of key committees and involvement of activities such as recruitment of staff.

Improve the voice of social care: Some participants said that the network should have a role in promoting social care perhaps as part of wider movements.

Identify research priorities: Some participants said the network should play a role in helping set the research priorities of the social care priority ARC. This could also include bid prioritising.

There was a unanimous view that it should be led by people with lived experience including family carers. However, there were a range of views about who should be represented on the network. Some said that the actual make up of the group should follow its functions. Some suggested a mixture of users and carers and academics. Others said it should be user and carer only. Some people suggested flexible models for example a user, carer core membership but with academics contributing to some meetings.

Recommendations

National Priority for Adult Social Care and Social Work Consortium

1.   Lived Experience Strategic Group

The National Priority Consortium for Adult Social Care & Social Work should create a steering strategic group consisting of a diverse range of 8 – 12 people with lived experience and family carers. To enable the group to be set up in a timely fashion this will initially be drawn from existing ARC and other adult social care research networks through a transparent recruitment process.

To ensure no-one is financially excluded there should be scope to fund e.g. tablets and/or wifi costs for members of the strategic group. The Strategic Group should aim for all our communication and activities to be as accessible as possible and respond to the communication and access requirements of members. This could include, for example, providing papers in accessible formats and funding personal assistants.

In future there could be a wider recruitment process outside ARC's to support greater diversity of experience and background. Guidance and support should also be sought from NIHR ARC East Midlands as the national lead for equality, diversity and inclusion of under-represented groups.

The initial role of the Lived Experience Strategic Group should be as follows:

a.   Developing a social care lived experience/co-production strategy to be used by the ARC National Priority Consortium for Adult Social Care & Social Work programme and supporting the development of the infrastructure and capacity in this regard, including guidance and practice documents etc.

b.   Supporting the National Priority Consortium for Adult Social Care & Social Work in an advisory capacity, including helping with the preliminary identification and selection of the projects and governance of the programme.

The group members will co-produce arrangements for the coordination and running of the group e.g. if there should be a chairperson and how they would be selected.

It is recommended that a full programme of considerable time and resource is invested into the training and induction is provided for of the

group. This will include - meeting the team, providing an overview of ARCs, overview of National Priority areas, overview of ARC Priority on Adult Social Work and Social Care, NIHR UK Standards for Involvement, NIHR Co-Production Principles and Values, equality and diversity, practical issues.

2. Funding research by those with lived experience

One method of growing people's confidence in relation to research is developing a programme of small grants to groups of users and carers who wish to undertake user led research. This has worked well previously in two successful networks: the Co-production Collective and the Dementia empowerment and engagement project (DEEP). See for example https://www.dementiavoices.org.uk/dementia-enquirers/

It is recommended that the National Priority Consortium for Adult Social Care and Social Work considers developing a similar programme of small grants and support. This will build a cohort of research literate social care users and create a suite of user-led research projects.

Local Applied Research Collaborations

3. Awareness and understanding of social care

Local ARC's should reflect on their awareness and understanding of the purpose, roles, context and cultures of adult social care services and the communities that they support. ARC's should work with local practice and representative bodies to improve their connections and confidence in how to meaningfully involve people with lived experience of adult social care in all aspects of their research and governance.

4. Recruiting local people with lived experience of adult social care

Local ARC's should undertake a review of the extent to which lived experience of adult social care is included in their current networks for public involvement and actively seek to recruit people if there are obvious gaps, including those from often excluded communities.

National Research Bodies

5.   Good practice & lived experience

National bodies relating to research of adult social care should collaborate to develop good practice guidance and supporting material (including examples of where research projects have successfully involved people with lived experience), which is publicly available for researchers and people with lived experience. This should provide practical explanation of and insights into different models of lived experience and their how they can be applied within research including with often excluded communities.

The National Priority Consortium for Adult Social Care & Social Work should take a lead in coordinating initial discussions between relevant national research bodies. There is potential for the Lived Experience Strategic Group to continue beyond the life of the national priority funding to provide oversight and coordination.

6.   Evidence base of lived experience and adult social care research

Consideration should be given to strengthening the evidence base on lived experience and adult social care research in order to inform research practice. This could include formal research projects and more systematically gathering emerging experience.

7.   Networks and bodies

It would be helpful if there was a central web-based resource which identified bodies and networks currently active in adult social care research. This could be a source of information and support for researchers and people with lived experience seeking to undertake related projects and organisations representing people with lived experience of social care who want to engage with research.

There should also be consideration of developing a national network of people with lived experience of adult social care and family carers. This network could be kept connected via an ebulletin and have access to involvement, training, and networking opportunities. These opportunities should be discussed with other research bodies and existing networks[2].

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[2]Existing networks include:
https://www.coproductioncollective.co.uk/
https://www.shapingourlives.org.uk/
https://www.nsun.org.uk/

Appendix 1: Scoping Process

Stakeholders were approached through the public engagement leads within ARC's and existing social care research bodies and network,

Participation was voluntary. Scoping discussions were completed remotely by PF, recorded, and transcribed using an online application.

Key emerging trends were noted from the scoping discussions.

Key areas of discussion:

1) Can you please tell me about your role?

2) What regional and national networks are you aware of that support public and community involvement within adult social care research?

3) What do you think are the challenges of facilitating public and community involvement in adult social care research?

4) What do you think are the priorities for social care research?

5) Do you think a national ARC network for involvement, engagement and participation would add value to what already exists? If so how?

6) Anything else you would like to tell us?