Chapter 2

Co-production of a Regional Approach to Community Engagement in Health and Care Research in the North East and North Cumbria

Elaine Bidmead[a,b], *Felicity Shenton*[b], *Greta Brunskill*[c], *Kate Whitmarsh*[d], *Sharon Barnes*[d] *and Steph Capewell*[e]

[a]*Institute of Health, University of Cumbria, UK*
[b]*NIHR Applied Rresearch Collaboration (ARC) North East North Cumbria (NENC), UK*
[c]*NIHR HealthTech Research Centre in Diagnostic and Technology Evaluation, Faculty of Medical Sciences, Newcastle University, UK*
[d]*The Centre West Cumbria, UK*
[e]*Love, Amelia, UK*

Abstract

This chapter focusses on developments in the North East and North Cumbria (NENC) that strove to create more opportunities for seldom heard groups and communities to be active partners in health and care research. We focus specifically on co-production with the voluntary and community sectors, summarising the context that influenced a collective drive to do things differently. Two local voluntary, community, and social enterprise (VCSE) organisations share their insights and experiences. We outline a series of regional developments that aimed to address key issues associated with involving communities and VCSE organisations in research and focus on improving relationships and growing more meaningful opportunities

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that benefit people, communities and the VCSE sector, as well as improving the quality of research. Finally, we share some of our key learning and messages for others looking to support and develop new ways of working with communities and VCSE organisations to develop meaningful, reciprocal, and sustainable partnerships in research.

Keywords: Co-production; community engagement; public involvement and community engagement (PICE); inclusive research; voluntary; community and social enterprise sector (VCSE)

Introduction

Research is essential to delivering high quality health, social care, and public health services and interventions (Boaz et al., 2015), but there are concerns about unequal representation in research studies, and arguments that the knowledge produced by research is partial because it often excludes diverse groups who are seldom heard (Kennedy-Martin et al., 2015; Reynolds et al., 2021). This matters because the impacts of interventions may vary in different groups of people (e.g., based on their age, ethnicity, and/or gender) and geographies (such as coastal/rural/urban, north/south, and socio-economic advantage/disadvantage; Bower et al., 2020). It is therefore essential that research is equitable, inclusive, and representative of different people and places. Researchers and research institutions also need to consider issues around fairness, as Bower et al. (2020, p. 2) note, 'fairness dictates that publicly funded research' and the benefits of participating in such research 'should be accessible to all'. For research that addresses health and care inequalities to have the best possible chance of making a difference to the people and communities most affected, we must ensure that it is informed by and includes their voices. In this context, public involvement and community engagement (PICE) can play a key role by ensuring the needs and experiences of people and communities remain at the heart of health and care research (Staniszewska et al., 2018).

From its inception in 2006, the National Institute for Health and Care Research (NIHR) has developed policies to support and promote public involvement in research. It has recently broadened these to include community engagement. Many UK research funders have increasingly encouraged, and now require, PICE in funding applications. The UK Public Involvement Standards Development Partnership (2019) designed standards to improve the quality and consistency of public involvement in research. The six standards represent the foundations of good PICE in health and care research and include 'working together' with communities to build sustainable, mutually respectful and productive relationships, and creating 'inclusive opportunities' to enable diverse PICE in research.

In 2021, the NIHR reported on 'lessons learnt from the Reaching out Programme' (NIHR, 2021), which focussed specifically on working with communities not typically involved in research. It aimed to support research

infrastructures across England to develop new relationships and more effective approaches to building relationships with communities. Such relationships were seen as the 'building blocks to involvement in research and ensuring that research reflects the needs of communities' (NIHR, 2021). The programme made recommendations to support the inclusion of diverse groups in health research and highlighted the importance of creating and nurturing relationships with them. Ensuring involvement is mutually beneficial to both participants and researchers was also recommended, with recognition that it takes time and effort to make this happen.

Recently, the NIHR has renewed its commitment to public partnerships (NIHR, 2024a), restating its 'ambition to make public partnerships diverse, inclusive and impactful'. Together with the UK Standards for Public Involvement, these are the cornerstones of PICE. What the NIHR refer to as 'public partnerships' embodies a vision for research that reflects what matters to people and communities, and their lived experience of health and care issues.

Increasingly, the VCSE sector is recognised as key to engaging more diverse communities in research due to their long-standing and trusted relationships with communities, including with some of the most marginalised people. In this chapter, we describe and engage in a sympathetic critical appraisal of our own practice and developments in the NENC that have aimed to create more opportunities for seldom heard groups and communities to be active partners in health and care research. Focussing on our work with the VCSE sector, we start by summarising the background and context that influenced a collective drive to do things differently before sharing the insights and experiences of two local VCSE organisations' involvement in research. We then outline a series of developments that aimed to address key issues associated with collaborating with communities and VCSE organisations in research. Finally, we share some of our key learning and messages for others looking to support and develop new ways of working with communities and VCSE organisations in research.

Background

Since 2017, the development of PICE in the NENC has been supported by the 'Creating Connections Network'. Coordinated by the region's NIHR research support service (RSS) Hub, the Network involves PICE leads from across NIHR infrastructures and aims to share good practice, support learning and enable collaborative projects and innovation (Creating Connections, 2024). It works closely with research institutions, practitioners and VCSE partners to deliver PICE in the region. Network activity is underpinned by a commitment to ensuring that the voices of people and communities are instrumental in achieving transformational health and care research. Further, network members are committed to creating opportunities for people and communities to engage in all aspects of the research cycle (Pearson et al., 2024), not just as participants in research studies. This includes involvement in identifying research priorities, shaping research questions, designing research methodologies, conducting research, supporting data analysis, and co-producing and sharing research findings (University of

Oxford, Medical Sciences Division, n.d.). It is through this network that connections between key partners and sectors have been established and sustained over time, enabling collaborative efforts to develop new and innovative approaches to support more diverse PICE.

The NIHR Research Design Service NENC (now RSS) was an active partner in the Reaching Out Programme (NIHR, 2021). Through this work, they engaged with seldom-involved communities from Black, Asian and minority ethnic backgrounds, mental health service users, pregnant women, rural communities, working people, and vulnerable children in our region. This led to the co-production of a Community Engagement Toolkit with VCSE partners (NIHR RDS, 2022), which provides 10 principles to guide researchers in their approach to working with communities and community organisations. This toolkit and the learning from the reaching out programme formed the foundation for further innovation to engage and involve more communities in research in the NENC, which we describe later.

Context

The NENC covers a large geographical area; its local integrated care system is the largest in the country in terms of both geographical footprint and population. This presents challenges to ensuring the geographical spread of public and community involvement in research, concerns which are supported by analyses of geographical inequalities in recruitment to research studies (Bower et al., 2020). Consequently, significant numbers of communities are seldom involved in research, whether these be communities of identity, interest, or place (Banks et al., 2013). We have found that engaging these communities can be supported by developing connections with the VCSE organisations that support them and with whom they have existing, long-standing relationships built on continuity and trust. This has long been recognised by researchers who have routinely connected with VCSE organisations to recruit research participants. More recently, however, the value of developing connections with these organisations to involve communities of people as partners throughout the whole research process is being recognised.

Conducting PICE in partnership with the VCSE sector benefits from establishing and maintaining ongoing, respectful and reciprocal relationships (NIHR RDS, 2022). Within the NENC there are examples of strong links between individual researchers, research organisations, and VCSE organisations, which have supported research involvement and engagement activities with diverse communities. We are aware of examples of good practice in the region including PICE work with young people and ethnically minoritised groups, and a strong track record of supporting co-production and peer research approaches. However, we are also aware of a small number of VCSE organisations that are often overwhelmed with requests to facilitate research involvement and participation, as well as many others that are never approached. Importantly, the former organisations can feel burdened and pressured as requests for their time are uncoordinated, frequently duplicate other requests, and are usually made with unreasonably short

notice. VCSE organisations have also shared poor experiences of being involved in research, including a lack of remuneration and training, and impact from the research rarely being communicated to those that participated. This can damage the relationship between the VCSE organisation and their beneficiaries, many of whom participate in research because the VCSE organisation has introduced them to it and/or out of a sense of helping to change things for others. Through engaging, some will have been asked to share personal information about traumatic experiences which may have triggered psychological responses (see chapters by Cooper, Lhussier, Adams, and Ramsey in this collection). If public contributors never hear about research outcomes they may be left wondering if what they said made a difference and questioning whether their involvement was worth it. As the intermediary between the individual and the researcher, the VCSE organisation may be perceived responsible for the conduct of the researchers leading to feelings of betrayal towards the organisation. Individuals may then withdraw from supportive services because of this perceived association, resulting in negative consequences for themselves and the organisation.

We invited co-authors from two VCSE organisations to share their perspectives on involvement in research, including insights on how PICE can be challenging, and even a negative experience, for their organisations, and how this might be improved in the future.

VCSE Reflections From Experiences of Research Involvement

'The Centre' is a West Cumbrian charity providing social and creative opportunities for people to connect and grow, based at a community building in Maryport. Their reflections on involvement in research are not untypical.

> We believe that everyone has something to offer and that together we can build brighter and better outcomes for everyone in our community. Giving people a voice and opportunities to express their opinions is an important part of our work and so we want to support research wherever and whenever we can. With a tiny team, limited budget and an ever-increasing demand on services, we have to be selective about what we take on beyond business-critical activity. With every additional task, we must carefully weigh up what direct benefits there will be to our organisation or the community, because at the end of the day, we know we'll have to cut something to make time to facilitate each request. It's a constant juggle and it takes all our resources just to keep the doors open.
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> As with everything we have had good and bad experiences. Some researchers have 'dropped in', carried out their research and then vanished, not only leaving participants (and us) without feedback or findings – but ultimately a sense of diminished confidence and trust.

We've found that most people want to be useful and that they have a genuine selfless desire to help others – but we don't think this should be taken for granted. Lived experience clearly has a value and the best experiences we've had are those where the researchers have demonstrated an understanding of this. Researchers who have thought about why people should give up their time and can clearly explain the benefits are far more effective than those who get what they need and run.

When researchers reimburse both community members and VCSE organisations for their time, either in money or 'in kind', it supports a more accessible approach by establishing a reciprocal dynamic to the relationship. Even a minimum of reimbursing 'out of pocket' expenses can make a difference as to whether an individual or an organisation is able to participate – it is often the individuals and organisations who can least afford to participate whose voices are missing from research to begin with.

Language can also be an issue. Participants need to fully understand what they are being asked and how their answers will be used, as well as understanding why they are being consulted. Usually with research, the studies want to capture voices that are not always heard – but there's a reason that they've not been heard before and this needs to be considered. It may be confidence holding them back, it may be a lack of understanding and not wanting to ask for clarification, it may be that they don't see the point of speaking up when they've never been listened to before, or it may be that the last time they gave up some time to take part in research, they didn't get an update or conclusion … trust is hard to gain and very easily lost. The whole process must consider the needs of both sides – it's that two-way street analogy again …

We believe that involvement in research needs to be genuine, respectful and useful. There needs to be longer term engagement with VCSE organisations and their communities to be meaningful to all involved, and to avoid it becoming a tick-box exercise. To build trust, researchers must get to know the community before coming in. They need to learn our language!

Due to the current climate, we are single mindedly focused on using our scarce resources to deliver our charitable objectives, build trust and engagement in the community, and keep our doors open. Sadly, we would currently have no choice but to turn down approaches from researchers if the research cannot help us deliver those aims.

Love, Amelia is a baby bank charity that provides practical support to families with children aged 0–16 years who are experiencing poverty and other multifaceted hardships. They also reflect on their experience with researchers.

> Operating throughout the North East, we aim to reduce the impact of poverty and inequalities by providing essential items and equipment that children need to be safe, happy, and able to thrive. Our commitment to involving individuals with lived experience ensures that our work is not just **for** the community, but **with** the community, delivering outcomes that matter.
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> At Love, Amelia, we have found engaging in research offers significant opportunities and benefits, but it also presents some challenges. The families we work with are often among the most marginalised in society, and we strongly believe that giving a voice to those who use our service is crucial to designing and delivering support that is meaningful and impactful. Engaging with families and collaborating through research allows them to express their needs and preferences, shaping a service that truly reflects and responds to their lived realities. This collaborative approach has helped us improve our delivery model and create a more inclusive service that better meets the needs of families in our community.
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> However, our experience of engaging in research has not been without challenges. Some researchers, in the past, have not worked as collaboratively as we would have hoped, failing to share findings or to set realistic expectations about what our services can deliver. This lack of transparency and partnership can be disheartening for small charities like ours, where resources are stretched.
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> To ensure that research is beneficial to all parties, it is critical that the collaboration between researchers and VCSE organisations is genuine, with clear expectations, open communication, and mutual respect. Both sides need to be mindful of capacity limitations and ensure that findings are shared transparently with all involved. Only then can research act as a true driver of meaningful change at multiple levels, ensuring that the voices of those most impacted are not just heard but acted upon.

It is important to acknowledge the existence of systemic barriers to meaningful engagement with communities and the VCSE organisations that support them. The processes and systems associated with much health and care research do not create conditions that nurture meaningful, reciprocal relationships between the potential VCSE sector and research partners. The process of applying for research funding can pose significant challenges, particularly in terms of

the time and investment needed to develop meaningful partnerships and the often short timeframes for making an application for research funding. There are limited resources to support pre-application activity, which can compound the risk for all partners of investing a lot of time and effort in the pre-application phase when the research may not be funded. This investment of time can be particularly challenging for the VCSE sector, which rarely has any staff time or roles dedicated to research activities, and may already be operating at stretched capacity, as illustrated in the accounts above. Furthermore, it is common for individuals and/or organisations outside of academia to be ineligible as co-applicants, which prevents appropriate resource allocation for their roles in the research. These factors can present real challenges in developing partnerships for research. To ensure the inclusion of new and different voices, the research funding process needs to recognise the value of working with VCSE organisations to reach and involve diverse communities by enabling (rather than hindering) relationships and partnership working.

Co-developing a Partnership Approach to Community Engagement

In 2021, a working group comprised of public partners, VCSE organisations, and members of the Creating Connections network took part in a workshop series exploring the potential of commissioning partnerships with the VCSE to support PICE activity, supported by a grant from the NIHR School for primary care research. From this work, the idea of a coordinator role based in the VCSE sector to support greater connections between VCSE organisations and their beneficiary communities, as well as health and care research, was conceived.

Through joint funding from NENC NIHR infrastructures, a two-year pilot of a VCSE research partnerships coordinator was begun in July 2022. The vision for the role was to support partnerships between research and VCSE organisations, with the longer-term aim of growing the involvement of diverse communities in all aspects of the research process. Through a further grant from the NIHR Centre for Engagement and Dissemination (CED), an additional series of workshops with VCSE partners enabled the co-development of a work plan for the new Coordinator. This process involved exploring and re-visiting priorities, negotiating shared agreement about how to move forward and defining what success from the pilot would look like. Importantly, funding for this developmental work was hosted by Voluntary Organisations' Network North East (VONNE), the regional support infrastructure for the North East VCSE sector, rather than a traditional PICE or research institution.

The coordinator undertook a wide range of activities to support researchers and VCSE organisations. This included sharing research opportunities through VONNE's networks, which include representation across the NENC region and diverse communities of interest. They provided a single point of contact for making VCSE/research connections and, where interests aligned, made direct introductions between researchers and VCSE organisations, providing advice to

support early partnership discussions based on establishing reciprocal, sustainable partnerships. They also developed and delivered opportunities for training, skills, and knowledge sharing, including events for researchers and VCSE organisations to encourage adoption of the NIHR Community Engagement Toolkit to support more positive and reciprocal partnerships.

Partway through the pilot, additional funding was secured to further develop this work through an NIHR CED call for proposals 'to understand and strengthen regional infrastructure for involvement, engagement, and participation'. Work is now underway to build on the Community Engagement Toolkit (NIHR RDS, 2022) through the co-production of practical resources to enable both VCSE and research partners to develop more positive reciprocal relationships. The toolkit embodies the values and principles that underpin the approach that we are putting into practice in the NENC and is therefore central to this work. We also continue to roll out training to grow researcher awareness and knowledge about the VCSE sector, as well as VCSE awareness and knowledge about health and care research to establish a better shared understanding from which partnership conversations and relationships can develop.

The Coordinator and a representative from 'Love Amelia' reflect on the pilot role.

Greta Brunskill, VCSE Research Partnerships Coordinator at VONNE July 2022–August 2024

> From the outset, there was interest and appetite for greater opportunities to work together from the VCSE sector and researchers I met. Lots of people commented on how much my role was needed with researchers and VCSE organisations sharing that their connections had come about informally or through chance meetings. Some VCSE organisations also shared that they were interested in research but did not know where to start. The need for support was also evident in the 90 plus requests for help over the two-year pilot.
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> At the heart of the role was making connections and introducing partners with shared interests. Where I was able to support this kind of 'match' and early conversations to explore hopes and expectations of a potential partnership, it felt the original intention of the role really came alive. Another positive part of the role was developing opportunities for skill and knowledge sharing to help address gaps in knowledge, and ultimately help VCSE and research partners start their conversations from a better place. Through a serendipitous link with researchers at the NIHR ARC NENC, who also had a remit to support non-academics, we collaborated to deliver an introductory workshop on research and evaluation for VCSEs which was successfully piloted with positive feedback. With VONNE colleagues I was also involved in developing a session called 'What is the VCSE sector?' for research

and health partners, which was also well received. There were also some great examples of communities and VCSE organisations gaining wider value from being involved in research, such as having the opportunity for a health information session, or an organisation gaining access to research evidence that supported their development.

On the challenging side was balancing growing interest and enthusiasm for research in VCSE organisations that had many, many other priorities whilst also managing their expectations. The number of requests for support from research teams looking for community/VCSE partners in the earliest stages of an idea (i.e. to be included in their research funding applications) was very small, with most looking to publicise invitations for PICE contributors or research participants for an established study. My sense is that although there are researchers invested in this kind of partnership working with the VCSE sector, there are still many more who are yet to embrace it. A further challenge was around capturing impact of the role when it can take time for things to have a tangible outcome; different approaches to capturing impact from the initial two-year pilot are being explored.

With the successes and challenges of this initial pilot in mind, I think there is huge potential to further grow connections between the rich and varied VCSE and research communities in the NENC, and for us all to benefit from more impactful research driven and shaped by an inclusive array of community voices. To really get the most from PICE activity, I think taking the research **to** people is so important and working with VCSE organisations helps researchers to meet with people **where they are** in ways that can be so powerful in breaking down potential barriers and creating meaningful involvement. For me, some key next steps will be to further embed VCSE research partnerships support in structures and processes so that researchers are aware and can utilise this at the earliest stages of developing applications for research funding, together with continuing to develop positive ways (such as skill sharing) to build lasting relationships between the sectors beyond specific projects.

Steph Capewell, Chief Executive at Love, Amelia:

Working in partnership and accessing resources and support through VONNE has provided a valuable opportunity to learn from past experiences and improve the collaborative research process, ensuring more effective and mutually beneficial outcomes. The VCSE Partnerships Coordinator has been instrumental

> in fostering meaningful connections between our charity and researchers whose values and interests align with ours. She has provided an essential bridge, ensuring that communication is clear, and expectations are realistic on both sides. For small charities like ours, where time and capacity are limited, it has been invaluable to have someone advocate on our behalf, highlighting the importance of mutual respect and understanding in research collaborations. The VCSE Partnerships Coordinator has been a strong voice for Love, Amelia and the wider sector, ensuring that our time, resources, and limitations are recognised and respected.

Innovations and Lessons Learned

If health and care research is to be fairer and more representative, we believe that using a co-production approach (NIHR, 2024b) to developing ideas about how to grow more sustainable, reciprocal partnerships between researchers and VCSE organisations is fundamental. We have learnt that it is possible to build on existing networks and infrastructures (e.g., creating connections, VONNE) to bring together the perspectives of VCSE and research sectors to co-produce solutions. Joint funding for the new role was essential in consolidating a partnership with shared interests and priorities in growing greater community connections and diversity in PICE activity. It was also important to locate the resource within the VCSE sector (not in universities or NHS trusts), as this allowed greater flexibility and supported creativity and innovation. It also built on the existing trust and respect in VONNE that was held by VCSE organisations and allowed a more in-depth understanding of the sector to inform the development of the work, making the partnership more equitable. Co-production of the work programme in partnership with VCSE and research organisations helped ensure it was grounded in their experiences and the support *they* felt was needed from the outset. Offering VCSE participants costs for time, travel and subsistence, and holding events in accessible, familiar community spaces ensured that they were able to participate in the co-production process.

Conclusion

Working with VCSE organisations that have trusted and long-standing connections with communities is one important way to reach and involve those who are rarely involved in health and care research. From our collective work and learning over the last five years, we strongly advocate that partnerships need to be reciprocal and meet the needs of the community and VCSE organisations as well as the research. We have also identified the need to continue to address gaps and misunderstandings between the research and VCSE sectors to support better partnership working, including what the VCSE sector is and is not, and the differences between research, evaluation, and service monitoring.

Investment in relationships with VCSE organisations and the community members they serve is essential; these relationships take time and work best where

researchers can demonstrate interest and commitment before making significant asks. Working flexibly and creatively in these partnerships can be highly valuable, including when thinking of ways to make the research process and outputs useful to VCSEs and communities. Reciprocity is important and can come in many forms such as skills sharing by researchers to help VCSEs write bids or develop service evaluations. Fundamentally, researchers need to nurture and sustain relationships with VCSE organisations and communities, and more broadly, the VCSE and community's relationship with research. Sharing feedback on how public contributions have been used and the eventual research findings are essential to valuing involvement and maintaining a positive connection with research.

Just as partnerships with VCSEs need careful thought and collaboration, so does innovation that seeks to address historical challenges between the research and VCSE sectors. Innovation needs to be built on solid foundations and trusting, reciprocal relationships; it cannot be imposed on communities or VCSE organisations. Short-term or poorly conceived initiatives can damage and negate relationships.

We have highlighted how current research funding systems pose barriers to VCSE and research partnership working, and we challenge health and care research funders committed to involving diverse communities in research to develop funding calls and processes that encourage and enable partnership working between sectors. This is important not only in ensuring good and inclusive PICE in research, but in supporting diversity of research participants (the people who *take part* in research) by helping to ensure research is designed and delivered in ways that will reach and engage the wide and diverse public.

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