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# Understanding the Barriers and Enablers of the Applied Research Collaboration (East of England) Population-in-Focus Approach

## A Qualitative Review
## 2023

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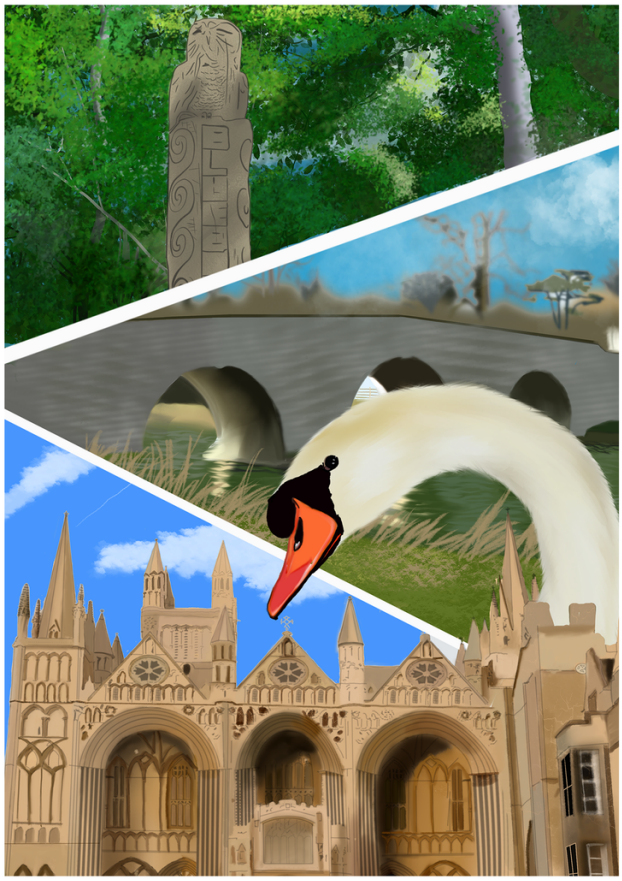


Inspired by Walks in Stevenage, Grays, Thurrock and Waveney. Image Credit: Terry Hall

# Contents

# Overview

The NIHR Applied Research Collaboration (ARC) East of England is a five-year collaboration (commencing in 2019) between Cambridgeshire and Peterborough NHS Foundation Trust, and the Universities of Cambridge, East Anglia, Hertfordshire and Essex along with other NHS Trusts, Local Authorities, patient-led organisations, charities, and industry partners across the region. NIHR ARCs support health and care research that responds to, and meets, the needs of local populations and local health and care systems.

The Applied Research Collaboration (ARC) East of England identified four areas in the region as populations-in-focus, to build relationships and develop community-driven research addressing local health and social care need. These areas are diverse places, across the large geographical footprint of the Eastern region, with a diversity of health and care needs. They include dispersed rural areas of Fenland; diverse city of Peterborough; post-war 'new-town' of Stevenage; and coastal communities with ageing populations in Great Yarmouth.

This report presents the findings of a review of this approach, to understand if it has helped to develop meaningful engagement and strong links with these areas. The review took place from May-August 2023 and we invited researchers from the ARC and people from the communities in these areas who we have worked with to take part in interviews. We interviewed 20 people from across ARC research themes and the populations-in-focus areas.

The interviews asked about experience of developing relationships and projects in a population-in-focus area, exploring the learning, outcomes and challenges. We also asked about views of the populations-in-focus approach, what helps to sustain relationships and what could be improved. Following an inductive thematic analysis, three key themes were identified engaging with communities and collaboration; enablers; and barriers of the populations-in-focus approach.

Working specifically with these areas has supported a deeper understanding of communities and the health and social care infrastructure. The community partners we interviewed also found the local focus of research valuable, helping to understand the lived experience of people in their communities and being informed about priorities for improvements in health and social care that would be meaningful to the community. Both the researchers and community partners reflected on the learning they gained and the career, personal and professional development that had taken place. A number of enablers and barriers to engagement were also highlighted and are reflected in this report.

Overall, this review has highlighted the value of a relationships-driven approach to engagement and impact as well as the need for researcher training and support to take such an approach effectively.

# Background

The NIHR Applied Research Collaboration (ARC) East of England (EoE) is one of 15 ARCs across England, funded by the National Institute of Health and Care Research (NIHR) to support applied health and care research that responds to, and meets, the needs of local populations and local health and care systems.

ARC EoE is a collaboration between four universities and providers of health and social care services in the East of England (Cambridgeshire, Peterborough, Norfolk, Suffolk, Hertfordshire, Essex and parts of Bedfordshire). This includes Cambridgeshire and Peterborough NHS Foundation Trust, the Universities of Cambridge, East Anglia, Hertfordshire and Essex, the Eastern Academic Health Science Network and other NHS trusts, local authorities, regional Integrated Care Systems, community organisations, charities, and industry partners across the region.

The 5-year vision of the ARC (outlined in 2019) is to achieve a nationally impactful, self-sustaining culture of collaborative applied health research embedded in the region, enhanced research capacity and embedded implementation practice. The aim is for deep and sustainable engagement, spreading from 'populations-in-focus', creating measurable improvements in health.

Currently, there are seven research themes with a named theme lead(s), with varying involvement with the populations-in-focus:

- Inclusive Involvement in Research for Practice Led Health & Social Care
- Prevention and Early Detection in Health and Social Care
- Health Economics and Prioritisation in Health and Social Care
- Mental Health over the Life Course
- Ageing and Multi-Morbidity
- Palliative and End-of-Life Care
- Population Evidence and Data Science

## Populations-in-Focus

When the ARC EoE applied to NIHR for funding, four populations-in-focus (also referred to as PIFs at times in this report) were identified for our research and other activity, as diverse places in our large geographical footprint, and having a diversity of health/care needs. This includes dispersed, deprived, rural areas such as Fenland; the ethnically diverse city of Peterborough; the first post-war 'new-town' of Stevenage, with an ageing population; and isolated coastal communities such as Great Yarmouth with an ageing population and socioeconomically disadvantaged adults.

# Populations-in-Focus


While the populations-in-focus were intended to be a focal point for community engagement and involvement, our engagement with the public, patients, carers and communities extends beyond these geographical areas, across the county and nationally.

The purpose of this review was to understand if the populations-in-focus approach has helped to develop meaningful engagement and strong links with these areas.

## Review aims:

- To understand the impact of working with ARC EoE for community partners in the four populations-in-focus.
- To explore barriers and enablers to the populations-in-focus approach with community partners and ARC EoE research theme leads.

# Methods

From April – June 2023 we invited research theme leads or nominated representatives (referred to as 'researchers' in this report) and people from within the populations-in-focus-areas who have been involved in ARC projects (e.g., public contributors, representatives from health and social care, or from charities or local authorities – who are referred to as 'community partners' in this report), to take part in a semi-structured interview with the lead author (BP). We also invited a representative from the ARC's Implementation workstream, led by the Eastern Academic Health Science Network, to take part.

We used a snowballing technique to sample community partners nominated by the research themes: individuals with an established relationship and who had been involved with ARC projects. We purposively sampled at least two community partners from each population-in-focus area to enable a range of representation across different types of community-based partners that we had worked with (e.g., health and social care, local authority, charity, public contributor).

Interviews took place in-person or virtually using Microsoft Teams and lasted between 30 minutes – 2 hours. The interviews asked about experience of developing relationships and projects in a population-in-focus area, exploring the learning, outcomes and challenges. We also asked about views of the populations-in-focus approach, what helps to sustain relationships and what could be improved.

Interviews were transcribed electronically and anonymised. The transcripts were analysed inductively using thematic analysis approach (Braun & Clarke, 2006). Data were analysed and interpreted as they were available, allowing for an iterative approach to the identification and development of themes. BP analysed all transcripts and WW analysed a random sub-sample of four transcripts (20%). Themes were discussed and refined within the research team as an iterative process. Direct (anonymised) quotations are used to illustrate key themes. Data management utilised Nvivo 12.

Ethics approval was granted by University of Hertfordshire Health, Science, Engineering & Technology ECDA HSK/SF/UH/05295.

# Results

We interviewed 20 people (n=11 researchers and n=9 community partners). Each research theme was represented in the interviews either by the research theme lead or nominated representatives. Community partners from each of the populations-in-focus (Peterborough and Fenland n=2, Thurrock n=2, Stevenage n=2, Great Yarmouth and Waveney n=3) were interviewed. Community partners were involved with the ARC through a local charity, as a public contributor, through local authorities, NHS primary care, an Integrated Care System representative or through Healthwatch.

## Three key themes were identified:

- Engaging with communities and collaboration.
- Enablers of engagement in the populations-in-focus areas.
- Barriers of engagement in the populations-in-focus areas.

We also asked participants about how the approach could be improved: this is summarised and presented later in the report.

# Engaging with communities and collaboration

# Engaging with communities and collaboration

This theme describes the extent to which researchers engaged with communities and organisations in the populations-in-focus areas, the collaborative approaches, and outcomes of the involvement in these areas.

Engagement within the population-in-focus areas was varied across the research themes, some had pre-established relationships in the areas and were based geographically close to them, making it easier to develop projects. Some discussed their drive to include representation from the areas in their research and were conscious of "how to include the community level of experience and activity and not just simply reducing it down to the people who we happen to talk to individually" (ID12 Researcher).

Some of the research themes have a particular focus on methodological expertise that is applied to working closely with other theme projects. These themes were mostly, but not exclusively, engaged with the areas through the projects led by other themes into which they input. For some, there was a sense of pressure to be seen to be doing something in the areas. Some commented that involvement of projects within the population in focus areas had been relatively coincidental, rather than planned.

Over time, working within the populations-in-focus areas supported a deeper understanding of those communities and the health and social care infrastructure in these areas. Some researchers described the value of the approach in helping to focus their work, encouraging them to build relationships and to develop localised projects. Some described how at the start, it felt 'disconnected from the people on the ground' (ID09 Researcher) particularly in areas without preestablished relationships, but that this had eased over time with examples of community-driven projects. The researchers were all conscious of how the approach could be seen as problematising people, through defining the communities as deprived and 'in-need', an uncomfortable and unintended consequence.

However, of the community partners we interviewed, they did regard the local focus of research offered as valuable (although the term 'populations-in-focus' was not accessible), helping to understand the lived experience of people in their local communities, through evidence-based approaches, and being informed about priorities for improvements in health and social care that would be meaningful to the community.


> As ICBs [Integrated Care Boards] or ICSs [Integrated Care Systems] we're very much championing that sort of placed based approach to reducing inequalities and therefore I think that the other work you do around it, needs to model that approach, so I think it's good to have that local research.

Community Partner
ID20

The researchers worked with the public, local authorities, charities, community groups and health and social care organisations in the populations-in-focus areas. There were a range of reported outputs and outcomes of involvement in these areas. Both the researchers and community partners reflected on the learning they gained and the career, personal and professional development that had taken place. Some commented on their confidence and understanding of community-based research, local infrastructure and health and social care systems, experience in public engagement, research funding applications, subsequent funding and future projects that emerged as part of the collaborations that were developed.

The development of relationships within the communities in the population-in-focus areas enabled opportunities for engagement with underserved communities, for both the researchers and community partners. This was particularly evident in communities where trusted individuals were the key link into working with the community and for health and statutory services, building on the links that had already been made with the community was key.

*The term 'hyperlocal' means a small neighbourhood, which might be a few neighbouring streets, a small community or geographical area. Some, but not all of the projects in these areas have worked with specific 'hyperlocal' areas.

> The biggest outcome was the relationship everyone built together. It really felt like we had created a bit of a network. So to this day I still have a really good personal relationship with [local authority], as with the University and [community organisation] as well. So building that network I think was a great outcome.

Community Partner
ID08

# Enablers of engagement

# Enablers of engagement in the populations-in-focus areas

There were several factors that supported the development of research working with the populations-in-focus, many of which also reflect good practice approaches to public involvement and engagement. They included the 5-year structure of the ARC, aligning with local and national priorities, accessibility, feeling valued and acknowledged, reciprocal and trusting relationships and managing expectations.

## The Organisational Structure

Being funded for five years provided an extended period of time during which relationships could be developed with communities and to gain a deeper understanding of the local systems and dynamics within communities. A noted challenge of the ARC structure was the high level of bureaucracy, such as the extensive requirements for identification to reimburse public contributors, reporting burden, and overly rigid co-funding or memorandum of agreements.

This ARC period also spanned the Covid-19 pandemic, which shifted the approach to working with communities to include greater use of virtual methods and different strategies for developing and maintaining engagement with communities under lockdown restrictions.

## Aligning with Local and National Priorities

The researchers and the community partners often noted the ways in which the projects had come at a fortuitous time, aligning with local and or national priorities, complementing the need for further research and the work that had been done in the area, on an academic or community level. This also encouraged investment of effort, resource, and commitment.

> It was on everyone's radar, which was helpful, because it was a consistent message, we need to do something about [priority area for research].

Researcher
ID02

## Accessibility

Ensuring that the engagement was accessible was highlighted, particularly for the community partners. This included being flexible in the method or approach used and being in a space that is familiar and comfortable.

Another community partner reflected that although they had preconceptions about what being involved with research would be like: the process was much more flexible and creative than they had expected.

It was also acknowledged that the reliance on people being digitally connected and able to engage with technology, particularly since Covid-19 could have been a barrier to engaging with communities and that a variety of approaches was needed to reduce digital exclusion.

> I think that's quite important, to meet people somewhere where they're used to within their own community.

Community Partner
ID10

> When I chip up in the meetings, nobody ever goes, oh that's nothing to do with what we're talking about, and that's nice and it gives you confidence to then come back and take part in the meeting.

Community Partner
ID13

## Feeling Valued and Acknowledged

Being acknowledged for the contribution that they were making to the project and feeling comfortable, welcomed, and able to contribute their ideas was clearly important for developing and sustaining relationships to the community partners we interviewed.

## Reciprocal and Trusting Relationships

The importance of building trusting relationships was recognised across the interviews, with some focusing on developing a connection first and foremost. Building a good trusting relationship was enabled by clear and reliable communication. This was particularly important for community partners through what can be long and drawn our research processes. It was also noted it should be a mutually beneficial relationship, whether this equated to something that was of benefit for the organisation, work supporting their priority areas, reimbursement, or resources.

## Managing Expectations

From the perspectives of both the researchers and community partners interviewed, having a clear understanding of involvement, and managing expectations about what could be achieved, enabled good working relationships. This also involved an understanding and respect that often involvement was an additional contribution of time and effort, when the time and effort required to build good working relationships and connections was often not accounted for in their workload. It was clear that investing in relationship building for the long-term benefit of community focused projects took a lot of time, resource and capacity

There was also a noted concern for the impact on the 'gatekeepers' to communities who are repeatedly approached about research or involvement, and for the communities themselves who are at risk of 'survey fatigue' and the socio-political context of this period (e.g., Covid-19, war in Ukraine, cost of living crises, climate crises).

For some, having limited expectations of the outcome of engagement was viewed as a benefit, creating space to build relationships and develop ideas from the 'ground up'. However, others did comment on the benefit of approaching community partners with something tangible and evidence based, providing a clear message and something to work with and from.

> Some people are doing this and it is an above and beyond and we all should be showing each other respect and thanks for the effort that people are putting in.

Researcher
ID02

# Barriers of engagement

# Barriers of engagement in the populations-in-focus areas

Barriers to the development of research working with the populations-in-focus were identified and included time, effort and resources, a lack of confidence in the rationale, boundaries, and conflicting research agendas. The implications of Covid-19 were also discussed.

## Time, Effort and Resource

Building and sustaining relationships within the areas required time and effort and investing in developing relationships was resource intensive. A lot of preparatory work was often required including one-to-one meetings, team meetings, working groups, presentations, phone calls, follow-up meetings and phone calls and then continued regular meetings or communication.

Additional time and effort were required to sustain such relationships and maintain that contact for future projects. Some community partners commented that it had helped to not lose touch completely after the project had finished, with the researcher keeping contact by sharing workshops or reports that may be of interest, for example.

It was noted by some participants that consideration of what happens at the end of the project and whether or how that relationship will be sustained should be made at the earliest possibility.

## Lack of Confidence in the Rationale

Most researchers were not confident in explaining the rationale for the populations-in-focus approach, although they could infer that the reasons related to deprivation, inequalities and previously underserved by research. Only some participants were aware of data from the start of the ARC about the areas to inform the rationale.

Identifying communities as deprived or in need was uncomfortable and, although well-meaning, could be perceived negatively and at times felt disconnected from communities (although this had improved over time). The researchers were conscious of who was being 'left out' in the decision to focus on particular areas, how this might widen inequalities, and that there was an uneven distribution of effort and engagement across the areas.

> It's a bit of a blunt instrument. Like I think it's worked. I think sometimes it's been a bit 'cringey' or a bit 'We're public health researchers and we love a target or a demographic', so it's not been subtle...
>
> But then maybe it needs to be like that because it has made us go into those areas and try...all right with different levels of success, but at least try and engage with those groups and I think that's a good thing, I do think that's a good thing.

Researcher
ID04

## Boundaries

The inclusion of specific areas where some work should be based was described by some as providing some helpful focus. However, it was also noted that the area boundaries could be viewed as a hinderance to collaboration and engagement if they were interpreted as strict boundary areas. It was suggested that clarity about the option for flexibility with the boundaries of the areas was important. In addition, there were changes when health care commissioning changed from the Clinical Commissioning Groups to Integrated Care Boards and some boundary areas change. It was also noted that there are some populations that are not necessarily fixed in one area.

> Very important lessons to be learned from these kind of more mobile communities if you like who might sometimes be in the populations-in-focus but sometimes not.

Researcher
ID12

## Conflicting Research Agendas

Some researchers described that it was difficult to make the case for a project specifying a population-in-focus area and that applying for funding for national priority projects was at odds with the localised populations-in-focus approach. The approach was also described by some as not necessarily fitting with university research agendas, which often emphasise the importance of looking for the national and international impact of findings. Particularly for research themes that focused on the use and analysis of health data, the method required a regional or health and care system level understanding.

They also noted that capacity to fully understand the local health and care systems was limited Attention and resource were therefore focused where it was thought it might have the biggest impact. It was noted that this might negate some in their motivation to engage in population-in-focus areas, particularly when the engagement is time and resource intensive, and on a small scale.

# Implications of Covid-19

Covid-19 became national priority from March 2020. The impact of the Covid-19 pandemic on the local community and the relationship-based approach to developing and delivering research projects cannot be understated. For the participants it was clearly a point in time that changed ways of working (e.g., moving to online rather than face-to-face) and completely stopped or altered the course of community engagement and the focus of research projects. Researchers changed their approach to engaging with communities, moving online, or using the telephone, and finding alternate methods to connect with communities such as photo competitions or creating packages to send to people in their homes. The researchers were also very conscious of the additional pressures and intense workload being put on charities, community groups, health and social care systems, and local authorities during this time.

In some communities, the desire and ability to 'go online' was not necessarily available, and the pandemic highlighted issues around health inequalities. However, the pandemic also instigated huge community effort and local support, as well as the national roll-out of a vaccination programme that was adapted to encourage uptake in underserved communities. The relationships that were developed through the community-based efforts during this time appeared to subsequently enable further relationships and engagement between the underserved communities, the community partner organisations and research teams.

Some relationships that were developed through the community-based efforts during this time appeared to subsequently enable further relationships and engagement between the underserved communities, the community partner organisations and research teams.

> We had Covid and of course that really, really impacted again this community where people were not necessarily available online or willing to go online or, you know, everything really kind of slowed down and got broken up

Researcher
ID11

# How can the approach be improved ?

## How do you think the populations-in-focus approach could be improved?

We asked the participants about their views on how the approach could be improved. This is a summary of responses:

- The terminology of 'population in focus' is inaccessible and meaningless to anyone outside of ARC. Suggestions included changing the term to place-based.

- Capitalise on the shared learning from populations-in-focus projects and focus on what difference it has made in the community. Where are commonalities and differences across the areas? What is the impact? What more can be done to share the evidence coming out from this work across ARC and beyond?

- Be clear about what the aim of the ARC is and what impact we want to have and what the aim of the populations-in-focus approach is.

- To be more explicit about how our work is addressing health inequalities to help demonstrate the meaningful outcomes of the work. For example, in applications to the ARC Fellowship Programme a question could be included to ask, "how is this going to address the inequalities you think are important in your practice?"

- Resource and support from the ARC to work with communities and researchers to support links and enable a coordinated approach in the areas.

# Summary

Overall, this review has highlighted the value of a relationships-driven approach to engagement and impact as well as the need for researcher training and support to take such an approach effectively. The approach has helped to develop a deeper understanding of the diversity of the region, providing focus and building relationships to develop community-driven research. Many of the identified enablers of the populations-in-focus work correspond with good practice for public engagement and involvement in research. We know it takes time and resource from all involved to develop sustainable working relationships, bridging the gap between research, health and social care and the community. There are lessons to be learned from taking this approach and good practice to be shared and taken forward.

Please contact Bryony (bryony.porter@cpft.nhs.uk) for further information or queries.

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‘This report is funded by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration East of England (NIHR ARC EoE) at Cambridgeshire and Peterborough NHS Foundation Trust. The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

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