

Shaping Research Together: Our Public Involvement Impact



2019-2026

NIHR | Applied Research Collaboration
East of England

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Plain English Summary



We believe research works best when it's done **with** people, not **for** them. Over the last six and a half years, ARC East of England has invited patients, carers, and community members to shape what we study, how we study it, and how we share the results. This approach makes research more relevant and useful in everyday life.

We have partnered with people from many different backgrounds and places: young people in schools, residents in care homes, faith communities, migrant and refugee groups, and families living with long-term health conditions. Together, we have co-designed solutions, improved how services work, and made it easier for the public to understand and use research findings.

Our aim is simple: **listen carefully, involve widely, and act quickly** on what people tell us, so that health and care improves for **everyone**.

Foreword

I am delighted to introduce this report, which showcases the depth and reach of our Public and Community Involvement, Engagement and Participation (PCIEP) work across ARC East of England. It reflects the commitment, creativity and energy that so many people have contributed over the last six and a half years.

Since becoming ARC Director, one of my highest priorities has been strengthening how we involve the communities we serve. As Chair of the NIHR Regional Inclusion Steering Group, it has been a privilege to work alongside partners across the region who share a passion for ensuring that everyone has equitable opportunities to shape research. This report demonstrates what is possible when diverse voices are not only welcomed but embedded at every level of decision-making. Indeed, the very idea for this report came from our PCIEP group themselves, reflecting how deeply they are involved in guiding our work and priorities.

Our programme continues to grow in ambition and impact. The examples in this report highlight how public contributors, community organisations and researchers have worked together to change how research is designed, delivered and communicated. Whether through co-production with carers, partnerships with faith communities, or the invaluable insights of young people,



people with lived experience are shaping research in ways that make a real difference to health and care.

I am proud of how we continue to build capacity, supporting researchers, fellows and public contributors to develop the skills and confidence needed for meaningful involvement. This work strengthens not only individual projects but the culture of our organisation as a whole.

My sincere thanks go to everyone who has contributed to this programme - from our long-standing patient and public contributors to the many community groups who have trusted us with their experiences. Your voices ensure that our research remains relevant, inclusive and grounded in the realities of everyday life. It has truly been a team effort.

Wendy

**Professor Wendy Wills,
Director of NIHR ARC East of England**

Introduction



The NIHR Applied Research Collaboration (ARC) East of England is a partnership that brings together universities, health and social care providers, and communities to improve health and care through research. **Our goal is to make research relevant, inclusive, and useful for the people it affects.**

Over the ARC Programme, we have worked hard to involve patients, carers, and members of the public in shaping research and putting it into practice. This approach is called Public and Community Involvement, Engagement and Participation (PCIEP). It means that people with lived experience help decide what research is done, how it is carried out, and how findings are shared.

This summary shows what we have achieved together. It is organised using the UK Standards for Public Involvement (currently being reviewed by NIHR and the Health Research Authority) and highlights how our work supports national priorities for Equality, Diversity and Inclusion, Impact, and Collaboration.

By working in partnership, we make research more accessible, more relevant, and more likely to improve health and care for everyone.

Alongside the case studies in this report, ARC East of England's PCIEP activity spans a wide range of communities and methods. Between 2019 and 2026, our records indicate approximately 2,300 public contributors engaged across the programme. This breadth covers work with children and young people, care-home residents, ethnic minority and faith communities, people with learning disabilities and autism, and those experiencing homelessness or migration, ensuring research priorities, methods and outputs reflect real-world needs.

Our Region: Why This Matters



The East of England region is home to over **6 million people**, living in a mix of busy towns, coastal communities and rural areas. While many people enjoy good health, there are big differences.



Ageing population: By 2043, one in four people will be over 65, increasing demand for health and social care.



Rural and coastal challenges: Some communities face limited access to services, higher rates of long-term conditions, and poorer mental health.



Diverse communities: Areas like Luton and Peterborough have large ethnic minority populations, where cultural and language barriers can affect access to care.



Health inequalities: People in the most deprived areas live shorter, less healthy lives. Coastal and rural areas often experience higher poverty and fewer local services.

These differences mean research must focus on real-world needs, working within the systems to **understand local priorities**, build trust, and design solutions that improve health and reduce gaps in care.

How we involve people

Involvement is a **partnership**. We welcome people as co-designers, advisors and co-authors, and we make it straight forward to take part. We offer warm invitations and flexible options, hold sessions in familiar places, and provide clear, accessible materials. We reimburse time and expenses, aim to plan around caring responsibilities, and offer support when topics are emotive. Public contributors also take leadership roles on advisory groups and governance boards.



The [Barnet MENCAP](#) and [Lowestoft and District MENCAP](#) taking part in the [Creating Learning Abilities Partnerships \(CLAPs\)](#) project.



The Co-researchers involved with the [IncludeAge](#) project.



The [Stevenage Dementia Involvement Group](#)



Walking with our communities
📍 Greys, 2023



Hertfordshire Young People's Advisory Group
📍 Hertfordshire, 2025



Inclusive Involvement Advisory Group
📍 Chelmsford, 2026



Dementia Friendly Stevenage Workshop
📍 Stevenage, 2026

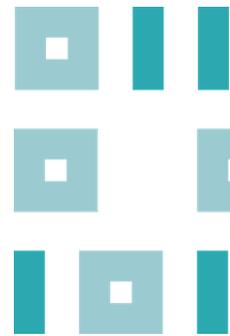


Stevenage Dementia Involvement Group
📍 Stevenage, 2022



Bella Madden, reading her poem 'Sorted' which is a response to reading research interview transcripts

UK Standards for Public Involvement



Throughout our work we have used the UK Standards for Public Involvement to guide and strengthen the quality of our public involvement. Developed through a UK-wide partnership led by the NIHR, the Standards describe what good involvement looks like across six key areas: *Inclusive Opportunities*, *Working Together*, *Support and Learning*, *Communication*, *Impact* and *Governance*. They are designed to support reflection, improve practice and encourage shared responsibility for meaningful involvement.

There is no single way to use them, and we have applied them flexibility to plan, review and continuously improve our activities.

The Standards are currently being updated with a review due in 2026, and we remain committed to using them as they evolve.



Image above: The UK Standards for Public Involvement as seen on <https://sites.google.com/nihr.ac.uk/pi-standards/home>

Inclusive Opportunities

We've worked hard to make involvement accessible, welcoming and relevant to people from many different communities. For example, we partnered with local mosques to improve bowel cancer screening among **Muslim communities**, co-designed with faith leaders and supported by peer researchers. We worked with **Gypsy, Roma and Traveller communities** to shape research on healthcare access and discrimination. **Young people** helped create teacher training on responding to self-harm. During the pandemic, **care-home residents** influenced decisions about data sharing and care quality through creative engagement activities.



“Delivering talks in mosques and using community networks made a real difference. Without this approach, engagement would have been impossible
General Practitioner

FAITH AND HEALTH - INCREASING BOWEL CANCER SCREENING IN MUSLIM COMMUNITIES

Bowel cancer screening rates are much lower among Muslim communities, putting people at greater risk of late diagnosis. To change this, ARC East of England partnered with the British Islamic Medical Association to deliver a faith-based intervention in mosques across Luton and Peterborough, areas with some of the lowest uptake. From the start, the project was built on trust. Mosque leaders opened their doors, local GPs and volunteers spread the word, and peer researchers gathered feedback. Clinicians who shared participants' faith and cultural background delivered health messages, making conversations feel relevant and respectful.

The impact was clear: people who had never considered screening began to understand its importance. By embedding health education in familiar spaces and aligning it with faith values, the project broke down barriers that had persisted for years and created a model for tackling health inequalities nationally.

Working Together

Co-production is at the heart of our approach. It means sharing ideas, decisions and responsibility so projects reflect real experiences. **Carers** helped design a new support nurse role and the criteria for evaluating its success. **People with lived experience** guided the redesign of a mental health assessment tool and **young people** and school staff co-created training and realistic video scenarios for teachers responding to self harm. In another project, **six advisory groups** worked together to develop a new measure for improving transitions in eating-disorder care. These collaborations build trust and create solutions that truly meet people's needs. Regular community walks also bring researchers, community organisations and local residents together, offering informal spaces where relationships form and new project ideas take shape.



As carers we were involved in co-producing the evaluation criteria and could assess if what we had contributed improved the quality of the service.

Carer involved in the study



THE CARER SUPPORT NURSE PILOT: HOW CO-PRODUCTION TRANSFORMED CARE

Carers often feel invisible, despite providing vital care. Many lack confidence, neglect their own health, and struggle to access help. To change this, we co-produced a Carer Support Nurse role, a dedicated professional to support carers with complex needs and raise awareness among healthcare teams. Over 100 carers shaped the role, refining language, recruitment, and evaluation. Their input made materials clearer and more practical. Carers reported feeling valued and included.

Impact: The pilot showed the role boosts confidence, prevents crises, and deserves national scale-up.

Support and Learning

Good involvement is supported through the right preparation, guidance and learning opportunities. We invest in training for both researchers and public contributors so that people feel informed, welcome and able to contribute. Our public involvement masterclass in the ARC Fellowship programme, co-delivered with experienced public contributors, offers practical advice on planning involvement, writing in plain English, and designing inclusive activities. We also support the **Population Health Data Advisory Panel**, which brings public representatives into discussions about the responsible use of data across the region. In community settings, the **Stevenage Dementia Involvement Group** provides a trusted space where people living with dementia and family supporters meet researchers, helping refine ideas and materials. During the pandemic, our care-home data project (DACHA) worked alongside **activity providers** so that residents, who could not meet in usual ways, still had a voice in shaping research about their care. Through cultural-competency workshops and simple, accessible guidance, we help ensure everyone understands the aims of each project and how contributions will be used. This supports a culture where people feel prepared and respected, and where researchers view involvement as integral to their work.

I found the Hub a very welcoming and supportive environment especially as this is my first time doing Patient and Public Involvement. It provided an invaluable opportunity to discuss the project and its clinical relevance for patients and other healthcare staff.

Research Fellow, ARC East of England



FELLOWSHIP PROGRAMME AND PUBLIC INVOLVEMENT HUB

Fellowship Programme and Public Contributor Hub Our Fellowship Programme is designed to grow the next generation of researchers who understand that involvement is not optional, it's essential. Each month, fellows visit our Public Contributor Hub, a dedicated space where members of the public review draft materials and offer practical feedback. Fellows bring plain-English summaries, recruitment posters, or even just initial plans, and leave with sharper, clearer, more inclusive tools. These sessions build confidence and ensure that research ideas are shaped by the people they aim to serve. It's a simple but powerful way to embed co-production into the heart of research training.

Governance

Public contributors play a central role in shaping decisions across ARC East of England. Members sit on our Board, our Expert Advisory Group and our coordinating group for public involvement, bringing lived experience into strategic decisions. Public contributors support activities such as Fellowship recruitment, reviewing research proposals and work closely with theme representatives to advise on impact case studies. ARC East of England also chairs the **Regional Inclusion Steering Group**, a partnership forum that provides strategic direction on inclusion, supports shared learning across NIHR organisations and has produced a regional knowledge-exchange report highlighting 18 inclusion projects and the involvement of more than 4,000 people. Public voices also extend into national organisations, with contributors representing ARC East of England at groups within the **Health Research Authority** and **national knowledge mobilisation networks**. Their involvement ensures decisions are grounded in lived experience at every level.

FROM COMMUNITY ONNECTOR TO CO-CHAIR: SHAPING RESEARCH AT GOVERNANCE LEVEL



Marie-Lyse Numuhoza
ARC East of England
Public Contributor and
PCIEP Co-Chair

I have been a public contributor with the ARC EoE and the Co Chair of the Public Involvement Coordinating Group (PCIEP) for the past 3 years. When I joined, I was curious about how research influenced policy and how they both shaped the services that met communities needs and improved the access to health and care services. I have since worked with ARC researchers in shaping how they engage with PPIE, joined the recruitment of the workforce, supported the development of the public involvement hub, represented the ARC EoE in different partnership networks, and most recently the NIHR knowledge mobilisation Network. I enjoy being part of the ARC team because I believe that as a public contributor, we are not only able to support researchers in leading inclusive/coproduced research opportunities, but we can also work with decision makers in developing strategies/action plans that reflect the people from all walks of life within our society. Together we can build robust and sustainable health and care systems.

Communications

We believe research should be easy to find and easy to understand. That principle guides our communications across projects and themes. In schools, our self-harm response toolkit was co-designed with **young people and education staff** and has reached wide audiences: more than 8,500 website visits, over 1,200 resource downloads and 1,000 completions of the e-learning module, with users reporting greater confidence afterwards. Across care settings, we produce plain-English infographics, videos and short explainers to make complex topics, such as care-home data, clear and usable. Widely adopted outputs, including the co-produced **Gypsy Roma Traveller Access to Healthcare** poster and community exhibitions, support meaningful conversations across health, care and community settings and help research reach the people who can use it.



Image above: Art informed by quotes from the Lived Experience Team. Artwork by [Beci Ward](#).

TURNING RESEARCH INTO PUBLIC CONVERSATION

When research reveals injustice, it needs to be heard beyond academic journals. Our Lost Mothers project explored the experiences of women separated from their newborn babies in prison. Instead of keeping findings behind closed doors, ARC Researchers worked with theatre professionals and women with lived experience to create a play that toured nationally and was performed in Parliament. The project sparked media coverage, radio interviews, and public debate, and secured funding to adapt the play into a short film. By using art as a bridge, they turned evidence into empathy and helped policymakers see the human cost behind the statistics.

Impact

Public involvement shapes what research focuses on, how studies are carried out and the difference they make in practice. Insights from people with lived experience have informed interventions in **faith and community settings**, guided creative work with **migrant and refugee groups**, improved transitions in **eating-disorder care** and helped shape research in **care homes, schools and local communities**. These contributions have influenced service design, strengthened partnerships and supported decisions that better reflect people's everyday realities.

I felt valued to be part of a group that looked into the difficulties faced by people living with multiple long-term conditions and how to make processes easier for us. It was great to hear the perspectives of others in the group who are in healthcare or looking after those with multiple conditions.

Public Contributor



MANY CONDITIONS, ONE PERSON: DESIGNING CARE WITH PEOPLE WHO LIVE IT

Many people live with two or more long-term health conditions, often treated in separate services with little coordination. This can make everyday care confusing, tiring and inefficient. From the earliest stages of our research, we involved people with lived experience of multiple conditions, their carers and health professionals. A core involvement group shaped research priorities and workshops revealed real world challenges like repeating stories, juggling appointments, and conflicting advice. Together, we identified key changes: joined-up pathways, better information sharing, clear coordination roles, and mental health support for patients and carers.

Impact: The workshops didn't just catalogue problems; they proposed practical fixes- simpler appointment systems, shared care plans, and routine check-ins that look across conditions rather than down a single clinical silo.

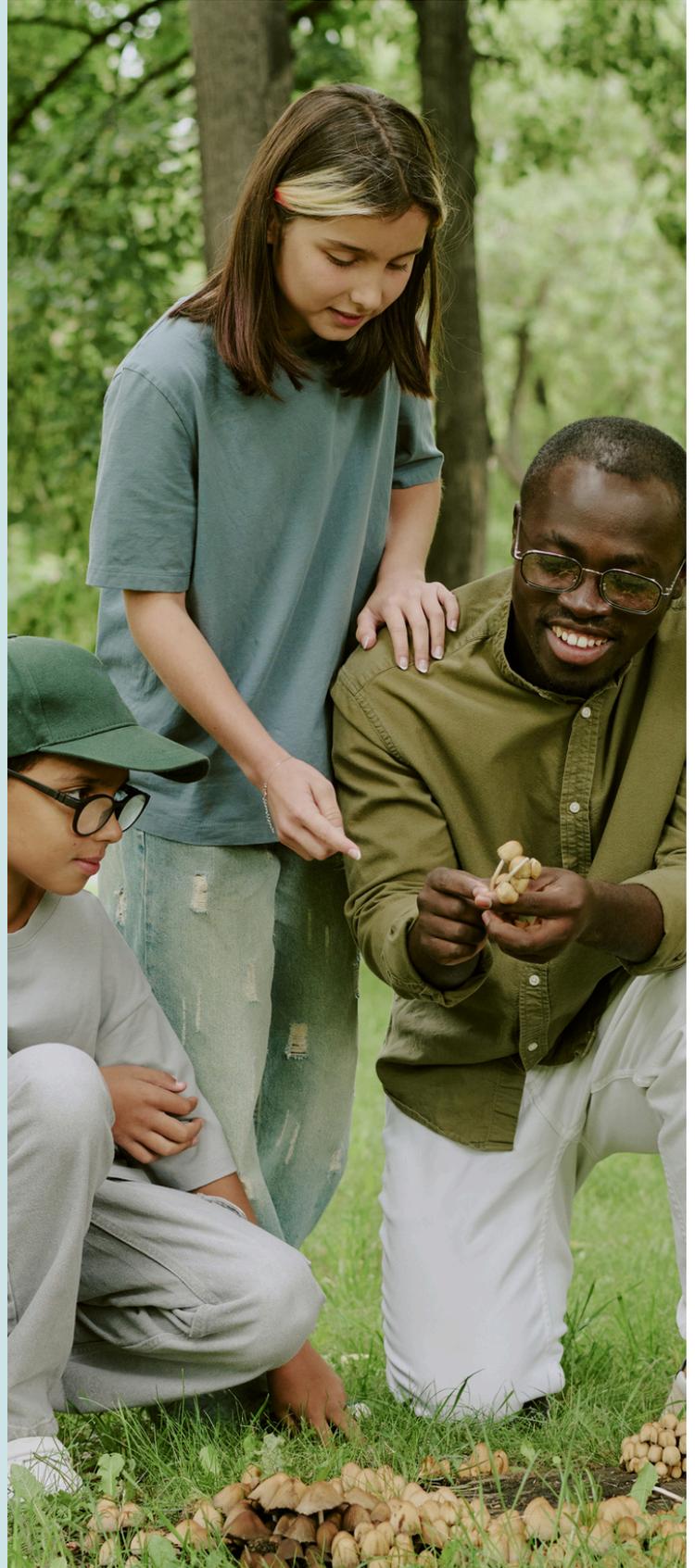


I've refreshed and gained research skills, I've enjoyed and learned from working as a multidisciplinary team, I've learned from both co-researchers and the participants about their lives, loves, struggles and successes. I hope that I have also made a valuable contribution to the academic research and LGBT+ community sectors.

Phil Eaglesham, reflecting on being a co-researcher in the IncludeAge Project

Looking ahead

As ARC East of England moves into its next phase of work, the next five years build on a simple belief: **research is strongest when people shape it**. We will keep working alongside communities, supporting public contributors to share their knowledge and lead change, and creating practical tools that make involvement easier and more meaningful for everyone. As partnerships deepen in coastal and rural areas, and as more young people, carers and community groups shape our projects, we will continue to bring lived experience and data together to guide decisions that are fair and relevant. Our ambition is to help create a region where everyone feels seen, heard and valued in the research that affects their health and wellbeing.





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