



NIHR | Applied Research Collaboration
East of England

Annual Summary 2024



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East of England

Foreword



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

I am delighted to introduce this summary of ARC East of England's (ARC EoE) achievements over the last 12 months.

One of the things that I am most proud of is the way ARC EoE continually looks at how to work with the diverse populations we have in this region. There are excellent examples in this year's report, including our projects addressing the physical and mental health needs of Muslim communities and the impact on a woman's health when they give birth in prison and have their babies removed from their care. Our researchers are highly attuned to the needs of the groups they undertake research with, which requires skill and experience. ARC has a well-established and vibrant programme to build capacity for research through its training initiatives; this includes supporting PhD students, early career researchers, as well as practitioners and professionals from a wide range of backgrounds as part of our Fellowship Programme.

It is important that ARC EoE looks at how to use its research findings to benefit as many services and populations as possible. Examples in the report include a project that involved developing a toolkit based on

research evidence to help people with chronic pain who take opioid painkillers to reduce their usage.

All such projects rely on the strength of the relationships ARC builds with communities, services, commissioners, and third-sector organisations, including charities. This year's report is packed full of examples of how we collaborate and build meaningful networks. One way we do this is through our annual walks, which take place across the spring and summer in diverse locations each year. They are open to everyone and are a good way for ARC to learn more about issues and priorities that local people care about and for partner organisations to learn more about how to work with us to benefit the places that they work in. Tea and cake are always involved afterwards!

I hope you enjoy reading about the work we have been doing and would like to take this opportunity to thank all the wonderful team members who are part of ARC EoE for their continued hard work, as well as the partners and communities who ensure that we can do research that makes a difference.

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About us



The NIHR ARC East of England (ARC EoE) is one of 15 ARCs across England funded to support applied health and care research.

We are a collaboration between Cambridgeshire and Peterborough NHS Foundation Trust, and the Universities of Cambridge, East Anglia, Hertfordshire, and Essex, along with other organisations, including NHS Trusts, Integrated Care Systems (ICS), Local Authorities, patient-led organisations, charities, and industry partners across the region. We have collaborated with 204 different organisations across our projects, ranging from social enterprises to national charities.

We believe that to make a change, we need to think on a national scale while acting on a local level. Our aim is to increase the sustainability of health and care systems and improve the lives of our local communities. To achieve this, we develop deep and sustainable engagement with local populations, build research capacity and support implementation practice to create measurable improvements in health and care.

Our real-world impact



29
formal partner
organisations



204
collaborating
organisations



110
funded people
across the ARC



40
Fellows and
PhD students



1+ million
in co-funding from university and health and care
partners



Over 450
individuals across the region were consulted to
inform the future of the ARC EoE



35 individuals

joined the new ARC EoE Carer Research Network to conduct and promote carer research



150

people attended the ARC EoE virtual showcase



£10+ million

awarded in research grants



44

peer reviewed publications



£3 million

awarded for the first NIHR Policy Research Unit for Palliative and End-of-Life Care, which commenced in January 2024



10


members joined our new Public Involvement Hub



82

research projects across our research themes





ARC East of England's research themes and key workstreams aim to address and respond to the critical health and social care needs of our communities. We aim to tackle the challenges faced by local health and care systems, ultimately enhancing their sustainability and improving the overall health and wellbeing of our region.

Engaging with diverse and underserved communities



ARC East of England (ARC EoE) serves a diverse population of approximately six million people. We actively seek to engage with individuals from various backgrounds and experiences, ensuring their unique perspectives shape our research to enhance health and care outcomes for all across the region.

We are committed to fostering inclusivity across our organisation, from diverse involvement in research projects to governance structures. This year, we welcomed 10 members of the public to the newly developed ARC EoE Public Involvement Hub, where they have been supporting ARC fellows to shape research projects. Additionally, the Stevenage Dementia Involvement Group has shared their experiences of living with dementia with the Mayor of Stevenage, aiding the city in its efforts to become a dementia-friendly community. Their insights have also played a significant role in the development of NHS England's Dementia Urgent Care Plan, launched in early 2023.

Our research actively engages with diverse and underserved communities to ensure it remains relevant to the communities it impacts. For instance, ARC EoE has partnered with the British Islamic Medical Association (BIMA) to



Engaging with marginalised groups highlights gaps in understanding and provision, and how they might be addressed.”

Dr. Claire Thompson, University of Hertfordshire

study the effectiveness of cultural interventions in improving bowel cancer screening uptake within the Muslim community. The findings were presented at an event held at a local mosque attended by commissioners, screening services and community leaders. Our researchers have recently commenced a collaborative project with Inspired Minds, aimed at exploring the effectiveness of faith-based cultural programmes that resonate with the Muslim faith and culture. This initiative seeks to improve mental health outcomes for young Muslim women.

Our researchers have identified common barriers to healthcare access across diverse communities. For instance, engagement with the Gypsy,

Roma, and Traveller (GRT) communities highlighted communication challenges and mistrust, which impacted their healthcare access and outcomes. To develop effective research relationships, peer researchers were recruited and trained to conduct interviews within the GRT community.

Another ongoing project aims to understand the impact of experiences of feeling included and excluded on 160 LGBT+ individuals over 40 years old and individuals with learning disabilities. This study involves nine experts-by-experience as co-researchers to ensure the project is shaped by the people it affects. The research aims to inform policy decisions and empower the LGBT+ community.



Joined collective pledge to improve public involvement across health and care research



Continued community walks in the local areas that we work in, including Peterborough and Thurrock



Involved in a regional NIHR group to develop strategic approaches to increase diversity in research

Exploring the impact of enforced separation of incarcerated mothers and newborn babies

In the UK, incarcerated women give birth to an estimated 100 babies each year. The separation of mothers and newborns in prison presents emotional, psychological, and social challenges. Understanding the experiences of healthcare professionals and prison officers is paramount for informing policy and supporting initiatives.



Collaborated closely
with Birth Companions
and individuals with
lived experience



Visited four prisons
across the UK to
gather diverse views
and experiences



Led by
Dr. Laura Abbott,
University of
Hertfordshire

The Lost Mothers project aims to explore the effects of mandatory separation of imprisoned women from their newborn babies through the lens of midwifery, social work, health visiting, and criminal justice professionals. This is the first project to link all involved in this process, including women who have been in prison.

The compulsory separation process poses a substantial risk to women's mental health, as described by a social worker involved in the project "it changes how you view the world...to go through that process of removing a baby, a child, because of imprisonment, that significantly changes you...The pain and desperation, absolutely

gut-wrenching...experience for those women." In partnership with Birth Companions, this project has been shaped by a lived-experience team consisting of mothers with experience of the criminal justice system. The team has conducted 73 interviews with those involved in this process to understand their experiences, particularly with regard to the impact of loss and grief. This project has provided insights into the emotional and psychological impacts of enforced separations to inform policy changes that enhance support for incarcerated mothers and their newborns, improve support systems within prisons, and promote a more compassionate approach to care to reduce the negative impacts.



The **Lost Mothers project** is something very close to my heart. I am very grateful to be able to be a part of it and use my lived experience to make an impact with this project and have a voice to try and make change for all the other mothers that have been through the criminal justice system and the mothers that are currently in it.”

Lived experience team member, Lost Mothers study

Addressing healthcare inequalities for Travelling Showpeople

It is acknowledged by public bodies that there is limited evidence regarding the healthcare needs of the Showmen community, estimated to comprise around 250,000 individuals in the UK. Without this knowledge, the Showmen community faces barriers to healthcare access.

In partnership with Showmen's Mental Health Awareness Charity, the In Fair Health? study, led by Anglia Ruskin University, investigated the mental and physical health status of Showmen communities and proposed solutions to improve access and health outcomes for this population. This is the UK's first known study of the physical and mental health of Travelling Showpeople.

The project involved members of Showmen communities throughout its entirety, from design to delivery. This included co-production in creating surveys with members of the Showmen communities, designing questions for focus groups and arts-based interventions aimed at identifying work-related health issues. The study revealed the community's health needs and inequalities in healthcare access, which has led to a limited awareness of risk factors related to prevalent health conditions, including diabetes, arthritis and



First known study
into the health and
wellbeing of the
Showmen community



Photo by Mary Humphrey via www.maryhumphrey.co.uk

“

Health professionals who took part indicated that they are now considerably more informed about the Showmen population and recognise that their experiences are different from other populations.”

Professor Margaret Greenfields,
Lead Researcher

cardiovascular disease and low participation in preventative screenings. In addition, it highlighted a lack of understanding among healthcare professionals about the population and that their exclusion from healthcare datasets only increases these discrepancies, leading to significant inequalities in healthcare outcomes. This project has proposed a number of recommendations, including co-produced training and resources for professionals and cultural interventions for the community.



Co-produced research
with the Showmen
community and healthcare
professionals



Led by
Professor Margaret
Greenfields, Anglia
Ruskin University

Using research evidence in everyday practice



ARC East of England (ARC EoE) continues to work closely with Health Innovation East, who support us in putting our research into practice. This collaboration focuses on research that shows strong promise to address health and care challenges while also building implementation knowledge and skills.

Our collaboration with Health Innovation East remains instrumental in supporting evaluations: The NHS Insights Prioritisation Programme (NIPP), which was designed to evaluate and implement remote monitoring and virtual care settings, has shared findings along with two informative blogs. This work has actively contributed to the NHS England New Hospital Programme and the research team are finalising an implementation guidance infographic to support remote monitoring practices in real-world settings. The CHARMER trial, which is supporting geriatricians and pharmacists to work with patients to deprescribe inappropriate medication in hospitals has worked with twenty-two hospitals to test the approach.

As an ARC, we have multiple examples of evaluating innovative healthcare solutions. The MELODIC study spoke with 49 people with professional and personal experience of dementia to co-



It is fantastic to support the adoption of evidence-based practice from ARC research and to extend the impact to more of our populations.”

Dr. Sarah Robinson, Health Innovation East

develop a new music therapy intervention for NHS dementia wards. This is now being piloted in two settings to make sure it is possible to deliver and has potential to be helpful for patients, family members and staff.

Following the development of a specifically designed cognitive test for driving, the INDICATE project has partnered with Driving Mobility, who will use these tests as part of their cognitive assessment for people with Mild Cognitive Impairment or Dementia across their 17 UK centres. ARC EoE researchers will conduct follow-up testing of the same people after 12 months to determine whether cognitive challenges are predictive of future road traffic incidents in this population.

Another development is a web application (app) called ARTEMIS-A, which is a mental health assessment that has been co-produced with school staff and pupils to ensure it is appealing and easy to use to help secondary schools identify young people who may need additional support for their mental health. The research team is planning to develop a social enterprise to distribute the app to schools at the lowest cost and aid schools in monitoring the impact of whole school policy changes on wellbeing. The findings are crucial in promoting the successful implementation of web-based mental health assessments in school settings.



**Co-funded
two
Researcher
posts at
Cambridgeshire
and
Peterborough
NHS Trust**



**Provided
evidence for
the first ever
Parliamentary
inquiry into
young carers
using the Carer
Support Nurse
research**



**Bridging role to
build
implementation
capacity across
the region with
Health
Innovation
East**

Reducing opioid prescribing rates by a toolkit to improve outcomes for patients

Opioids are painkillers that are effective for short-term pain relief. If used regularly for long-term pain, however, opioids often stop helping with the pain and start causing health problems. Therefore, they should be slowly stopped for most people and other solutions found to help manage the pain.

ARC EoE researchers have developed a toolkit to improve the quality of life for patients with multiple long-term conditions by reducing the use of opioids to manage chronic pain. The project combined research evidence with the experiences of health practitioners to collate five key components to effectively reduce opioid prescribing across the country. Health Innovation East led the implementation of the toolkit.

Since its release, the toolkit has been making an impact in Norfolk and Waveney by improving care and addressing rising prescribing rates. Between April 2022 and March 2023, approximately 939 patients (4%) were deprescribed from opioids. This was followed by a further 165 patients in 2023/2024. It is estimated that for every 62 patients with chronic pain who can be supported with alternatives to long-term opioid analgesia, one life can be saved.



15 lives saved

(an estimation based on the 4% reduction in prescribing in the area)



We estimate that for every 62 patients with chronic pain who can be supported with alternatives to long-term opioid analgesia, one life can be saved.”

Sophie Knight,
Principal Advisor at Health Innovation East

The 4% reduction in prescribing equates to an estimated 15 lives saved in 2022/23 and 12 lives saved in 2023/24. Alongside this, high-dose opioid intake has reduced year on year, with a 6.3% reduction (119 patients) in 2022/23 and an 8.8% reduction (157 patients) in the last year. This equates to 276 patients who have their risk of death from opioids halved. The findings from this study were published in the British Journal of Clinical Pharmacology and Prescriber and are being shared widely.



Downloaded by 1300
organisations across the
world within the first five
months of its release



Led by
Professor Debi
Bhattacharya, University
of East Anglia (honorary)



Working in partnership with schools to support children with anxiety

Anxiety problems are the most prevalent mental health difficulties in childhood. Evidence-based treatments exist, but children and families are frequently unable to access them due to these services having long waiting lists. The number of pastoral and support worker positions in schools is on the rise, and within this role, there is an opportunity to support a child's wellbeing.



125 Primary schools involved including 216 school staff trained in PL-CBT



189 families received the intervention to reduce childhood anxiety



Led by Dr. Tim Clarke, Norfolk & Waveney Integrated Care Board

The Working on Worries (WoW) project is a cross-sector collaboration between health services, academia and the educational sectors in Norfolk and Waveney.

This project aims to increase access to Parent-Led Cognitive Behavioural Therapy (PL-CBT) by training practitioners from the local mental health system to train primary school pastoral and support staff in PL-CBT. After receiving training, PL-CBT trainers lead Collaborative Learning and Support Sessions (CLaSS) to provide ongoing support to the school staff. So far, the study has trained 33 PL-CBT trainers within the local mental health system, who in turn have trained 216 school staff from 125 primary schools in

Norfolk and Waveney. The PL-CBT intervention has been implemented with 189 families, demonstrating that with support from the health sector, school-based pastoral and support workers can effectively intervene in cases of childhood anxiety and reduce its impact on children's lives.

The study team has received funding from the Norfolk and Waveney Integrated Care Board to continue training and expand the offer to schools with access to Mental Health Support Teams. In addition, they intend to develop an implementation guide and toolkit.



“

It has helped me take a step back and look at anxiety in general, which has led to me understanding it more...The course has made us as a family feel so much more confident in helping our daughter and given us the tools to help her, which in turn helps the school and her teachers. This course is amazing and will help so many other families just like us.”

Parent participant, WoW study

Supporting the health and social care workforce



ARC East of England (ARC EoE) provides evidence-based support to ensure the sustainability of our local health and care systems. Our research addresses areas of need for service improvement, improves outcomes for our communities, and supports the development of this workforce.

By understanding the dynamics of the health and care workforce, our research can help identify issues and enable the development of strategies to improve working conditions and retention. For example, ARC researchers are currently collaborating with the Cambridgeshire and Peterborough NHS Foundation Trust to assess the effectiveness of the Staff Mental Health Service. This service was launched in response to the increased workforce need for mental health support during the COVID-19 pandemic. The study will evaluate the mental health outcomes of staff who access the service while also assessing its cost-effectiveness. The findings will inform the NHS on how to effectively safeguard staff mental health, particularly during crises such as future pandemics. Our researchers have recently commenced a qualitative study that involves GPs and palliative care teams to understand their pivotal role in end-of-life care. This study aims to improve and inform future



We support and direct people to the newest opportunities to develop their research skills to support them in their career.”

Professor Eneida Mioshi, University of East Anglia

service design.

Our research also includes supporting the care home workforce. As part of this effort, the FluCare study is establishing on-site clinics to boost flu vaccination rates among care home staff, which is currently less than 30% in the UK.

Other developments include the ongoing success of the ARC EoE Fellowship programme. Our programme develops the research or implementation skills of health, social care, and third-sector professionals to encourage the use of research in everyday practice. This year, we have welcomed 14 individuals from a diverse range of backgrounds to our twelfth cohort. Around 80 people attended the Fellows Showcase, where the previous

cohort presented their findings to health and care professionals and members of the public.

Our DEM-COMM programme, which aims to improve services and care for people living with dementia, has made excellent progress, such as securing ethics approval.

Finally, we are pleased to share that we have been awarded funding for two years from the NIHR to strengthen research capacity in adult and children's social care. This funding will support the delivery of practice-based research and the use of evidence in the commissioning and delivery of care services. We look forward to sharing more with you once this has commenced.



**Over 140
ARC**

fellowships

have been awarded since 2010 to health and care professionals



**Held two
virtual
events**

to share research opportunities



**Worked in
partnership
with**

NHS Norfolk and Waveney Integrated Care Board to improve social prescribing

Fighting fatigue in the NHS ambulance sector using sleep science

In acute and emergency healthcare settings, poor sleep and fatigue are common issues that can impact an individual's ability to perform tasks and affect their overall health. Understanding the extent of this problem is crucial to ensuring the safety of both the ambulance sector workforce and patients.



114 staff and patients have given their views through interviews, workshops and surveys



Over 1500 people attended the projects knowledge exchange events, including staff



Led by Professor Kristy Sanderson, University of East Anglia

The CATNAPS project aims to develop a fatigue risk management system for the NHS ambulance sector, addressing fatigue issues and promoting better sleep health to improve patient outcomes and staff wellbeing. This project is working in partnership with eight organisations, including a number of NHS Trusts and ambulance services and is supported by a Patient Co-Investigator Lead.

The study has four phases, including: exploring how other sectors, such as aviation and transport, manage fatigue practices; conducting interviews with the ambulance workforce and patients on the different strategies to manage fatigue;

observing frontline staff to gain insights into their experiences with long shifts and providing design recommendations. The study conducted an extensive consultation with all NHS ambulance services across the UK, including Scotland, Wales, and Northern Ireland, to inform the research proposal and better understand the issue. While the project is ongoing, there is a strong interest in re-evaluating fatigue management from a systemic perspective rather than focusing solely on isolated changes like reorganising rosters. This project hopes to encourage more holistic approaches across all aspects of ambulance service operations, identifying opportunities for Trusts to implement practice changes and support the workforce.



Fatigue can impact on your health in terms of catching simple infections and stuff...so if you're less fatigued, you're probably less likely to go off sick because you're not gonna pick things up. If we can evidence [fatigue management] in CATNAPS it's a very positive thing to do."

Frontline staff participant, CATNAPS study

Developing research knowledge and skills in the social care workforce

Adult social care faces challenges, including a lack of funding and an increasing demand. This makes the need for evidence-based practice even more important. We aim to increase the number of social care professionals who are either involved in or using research to inform delivery.

In 2021, the NIHR awarded around £1million for the SCRiPT (Social Care Research in Practice Teams) study to build research capacity in adult social care and social work across Hertfordshire and Norfolk. The aim was to integrate evidence-based practice into social care teams and develop a research-orientated culture.

This project has five work packages, including the development of Research in Practice Teams (RiPTs), each of which has social care practitioners from Hertfordshire and Norfolk County Councils and experts-by-experience. The four leads were Chris Metcalf, Tom Swinson, Toby Connell and Sophie Tooke. The leads joined the 2022 ARC Fellowship training programme to learn about research methods so they could develop and deliver their own research project. They selected their topics based on practice priorities across the participating local authorities to gain a deeper understanding of the areas and improve



Shaped by experts
in social care, including
service users and
practitioners



This experience has given me an appetite to continue developing my research skills as a means of enhancing the impact of social work, and social care practice, in people's lives."

Toby Connell,
Research in Practice Teams (RiPT) Lead



social care. The topics were occupational therapy services for people with learning disabilities; hospital discharge to assess pathways; tools to assess outcomes of reablement services; and understanding people's views around the sharing of activity monitoring data with social care services. SCRiPT also established a Researcher-in-Residence role who was an academic based within adult social care in a local authority to encourage and sustain the use of evidence in social care delivery.



Overall evaluation
identified lessons learned
and effective ways to
build research capacity



Led by
University of Hertfordshire
and collaborating with the
University of East Anglia

Addressing health and care inequalities



Addressing health and social care inequalities is essential for identifying differences in access to healthcare services and outcomes. ARC East of England (ARC EoE) is committed to addressing these differences through research that aims to ensure everyone has fair access to health and care.

Our efforts aim to ensure that our research stays responsive to current needs and can adapt to the ever-changing landscape of socioeconomic issues affecting our communities.

Amidst the challenges posed by the rising cost of living, ARC EoE's research into Universal Free School Meal schemes in England is timely. The widely shared findings from this study have shaped the thinking of groups campaigning for extended free school meal entitlement, including the National Education Union, School Food Matters, and Biteback 2030. Local authority officials in areas where universal free school meals are already in place have also used the project's findings to inform decision making.

We are actively working to identify and address gaps in healthcare services across the East of England. To address the reported fragmented access to health services for people with



I feel it is vital that we coproduce research in order to address health and social care inequalities, such as digital access.”

Dr. Elspeth Mathie, University of Hertfordshire

neurodiversity, our researchers mapped the local services for mental health and neurodiversity to create a directory of services that provide support for this population.

Additionally, our collaboration with Cambridgeshire and Peterborough Integrated Care System led to the development and widespread distribution of a leaflet highlighting the available palliative care services across Peterborough and Fenland in response to our previous study highlighting inequalities in access to hospice services in the UK.

This year, we also concluded the award-winning Carer Support Nurse pilot, which established a dedicated nursing role to support unpaid carers in acknowledging and addressing their own health-

related needs that could not be met by their usual healthcare teams. Health, social care and voluntary organisations deemed this role necessary, as it received 124 referrals in the nine months that the service was open. In addition to winning the NHS Parliamentary Award for Nursing and Midwifery for the East of England in 2023, this project was also shortlisted for a Royal College of Nursing Award.

We have continued our research on the impact of digital inclusion and exclusion in social care settings. We are actively developing recommendations for policy and practice that support the design, evaluation, and implementation of digital technologies to promote social wellbeing.



Successfully sold out tickets

for the Carer Support Nurse Pilot knowledge sharing event in February



Facilitated a listening event

with the Asian Women's Cancer Group to discuss their cancer journeys



Research findings published

in the Guardian on Universal Free School Meals

Improving the quality of data to address health inequalities in the UK

Data analysis is critical for understanding health gaps, and is therefore an essential aspiration for fair and inclusive health. Yet without the availability of high-quality data, we cannot monitor and address inequalities across Integrated Care Systems.

Several policy reports highlight the importance of improving the quality of data used for the identification and monitoring of health inequalities in the UK. This raises two critical questions: how can data quality be improved, and are there established methods for doing so?

To answer these questions, ARC researchers aimed to identify evidence-based mechanisms for improving data quality and suggest how best practices may be implemented. This relied on a dual approach. First, the team reviewed the literature to identify approaches taken to improve data quality. Next, they reconducted an interview-based study to gather health professionals' views on effective ways to transition best actions into practice.

A variety of methods that professionals rely on for improving data quality were identified. These tend to work across



Co-developed
case examples with
health and care
professionals

“

The more we [talk about] the importance of using data to form evidence-based...outcomes...the more they'll become... embedded in all programmes at work.”

Study participant



different points of the data-to-decision-making pathway. For example, using multidisciplinary groups to standardise data collection instruments and systems. Importantly, the work suggests that increasing awareness of the variety of employable mechanisms and supporting their delivery are two key steps for improving data quality.

The next step will be to develop and test a resource that supports improvements in the quality of health data across health settings.



Identified

mechanisms to improve data quality to address health inequalities



Led by

Dr. Louise Lafortune,
University of
Cambridge

Understanding treatment preferences among people with cystic fibrosis

Cystic fibrosis (CF) affects over 10,000 people in the UK, and the median life expectancy for a person in the UK with CF is around 49 years. ARC EoE is involved with a number of CF studies focusing on reducing treatment burden, and improving wellbeing and quality of life.



Involved in first trial

of its kind exploring safe reduction of CF treatment burden



Studies inspired

and informed by patients living with CF



Led by

Dr. Rory Cameron,
University of
East Anglia

Feedback from the CF community has identified reducing treatment burden as a key research priority. CF patients spend over 1.5 hours everyday to manage their condition, impacting their quality of life. While there is growing consensus that patient perspectives should guide the evaluation of new treatments, how best to incorporate these views remains unclear. A recent survey (conducted by ARC researchers) of over 100 adults attending a CF centre revealed that while improving life expectancy is highly valued, many patients are willing to trade some treatment benefits to lessen the burden of their treatment.

The CF STORM trial aims to determine

whether patients on a specific CF medication can safely reduce their daily treatments, specifically by discontinuing some of the nebulised medicines they use daily. If successful, this could save patients considerable time and improve their quality of life. ARC EoE is leading the health economic evaluation within this trial.

Additionally, ARC EoE researchers are working on a new trial led from Royal Brompton and Harefield Hospitals to investigate whether online yoga classes (YOGA-CF) can help CF patients with physical issues like pain and breathlessness, as well as mental health challenges such as anxiety and overall wellbeing.



One of the single biggest impacts of CF on my wellbeing is the time it takes to complete all of my treatments. Reducing this burden will have a huge impact on my overall quality of life, giving me valuable time back! So trials such as YOGA-CF and CF STORM are very exciting and of huge importance to me and many others with CF.”

Kieron Smith, Person with CF

Developing collaborations across the region and beyond



ARC East of England (ARC EoE) has built new partnerships and strengthened our collaborations with individuals and organisations across the region and nationally. These partnerships are crucial for our research because they bring diverse perspectives that enhance the quality and impact of our findings.

Within the East of England, we continue to work in our areas of focus, supporting project ideas stemming from local needs. For example, in Essex, researchers have partnered with the County Council to identify areas for resource allocation aimed at dementia prevention. In Cambridge, we are collaborating with Cambridge Children's Hospital, Cambridgeshire and Peterborough NHS Foundation Trust (CPFT) and Cambridge University Hospitals (CUH) on the Food with Care Project. Additionally, we have recently launched a project to evaluate the implementation of the Hertfordshire County Dementia Strategy 2023-2028, with a pilot set to take place in Watford and Stevenage in 2025. Furthermore, ARC EoE researchers conducted a review of Saffron Housing Trust's communication and service provision, recommending the creation of an accurate and user-friendly database to address accommodation needs.



It is fruitful and galvanising to have the opportunity to make a positive impact through the meaningful and diverse collaborations that we have across the region.”

Dr. Adam Wagner, University of East Anglia

In addition to designing and working together on specific local projects, NHS Trusts in the region have pledged co-funding in support of more general research areas, including: Hertfordshire Community NHS Trust on work to improve support for older people and those living with long-term conditions; East Suffolk and North Essex NHS Foundation Trust; and NHS England on researching the prevention and management of diabetes.

We also facilitate networking among our six regional Integrated Care Systems through the Research Engagement Network (REN) programme, which aims to increase the diversity of those who take part in research to be more representative of the local population; and our regional population health data panel

which plays a crucial role in identifying challenges of data collection and sharing for research.

Many of our initiatives are collaborative projects across multiple ARCs. Notable examples include the STOPPING study, collaborating with ARC South West Peninsula to explore care home staff perspectives on deprescribing. Additionally, we are working on the Far Away From Home project, led by ARC East Midlands, which is examining the scale and impact of mental health admissions far away from home or to adult wards for young people. We also work with ARC South London on the national Palliative and End-of-Life Care programme.



Hosted joint workshops with

Cambridge Biomedical Research Centre



Over 50 cross-ARC researchers made a 'pledge' to develop more compassionate communities



Discussed future research priorities

in a focus group with all of our formal partners

Exploring the effectiveness of working with local communities in the East of England

To enhance our outreach efforts with our communities across the East of England, we incorporated an approach that focused on four key, diverse areas across the region that each have their own unique health and care challenges. This initiative aimed to evaluate whether targeted, research-based strategies would be the most effective for engagement.



Trusting relationships
developed with
underserved communities
across the region



Building community
driven research projects
that responds to the
needs of the region



Led by
Dr. Bryony Porter,
NIHR ARC East of
England

We recently reviewed our engagement approach with communities across the region to understand if it helped develop meaningful relationships and strong links. The review, carried out between May and August 2023, involved interviews with ARC researchers and community members from the local areas we have collaborated with. The interviews explored experiences in developing relationships and projects within four local areas (Great Yarmouth, Thurrock, Stevenage, and Peterborough), focusing on the lessons learnt, outcomes achieved, challenges encountered, and factors that sustain relationships and areas for improvement.

Working specifically with these areas has supported a deeper understanding of the communities and the health and social care needs to develop research that is meaningful to the community. Both the researchers and community members reflected on the learning they gained and the career, personal, and professional development that had taken place. Several enablers and barriers to engagement were also identified and summarised in a widely shared report. Overall, the review highlighted the importance of a relationship-driven approach to engagement and impact, while also emphasising the need for researcher training and support to effectively implement this approach.



Lifestyle – a lot of it is partially reversible or does not

- Cognitive sphere influences physical sphere and vice versa
- Physical wellbeing is affected by worsening mental wellbeing

...improves your sleep

...to do it all when you are still well



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 [the local authority], as with the University and [community organisations] as well. So building that network was a great outcome.”

Community member interviewed in the review

Developing a shared data system to improve the lives of care home residents

There is currently no standardised approach in England for collecting care home residents' health and social care data that all service providers can access and use to inform care and service provision.

The DACHA Study, a cross-ARC study involving six NIHR ARCs, aimed to improve research practices in care homes and create a single source of information— a Minimum Data Set (MDS)—for care home staff and those working with them. The team reviewed evidence on what is needed to implement a MDS, analysed data on 5,600 residents to create a trial archive for future research, and surveyed care homes to know the information they already collect about their residents. They linked digital care home records for 727 residents with NHS and social care data, in three ICSs, adding measures such as quality of life assessments.

The study demonstrated the potential for a MDS to reduce data duplication and improve care. However, it also highlighted the need for capacity building to enable staff across organisations to learn together. Without this, data capture risks becoming just another administrative task. For data to



Lunchtime seminars
that shared project findings and prompted discussions around care



The introduction of quality of life measures by the DACHA study helped us to move the conversation about the future away from preferences for end of life care...and enhancing quality of life.”

Care home staff participant,
DACHA study

inform care, and be the basis for decision making, it must be part of a shared understanding used by everyone who works with and in care homes.

Overall, the findings showed what is possible when using data that reflects what matters most to older people and their carers. The study demonstrated care homes can use a MDS if it aligns with their goals. Further work is needed to formalise data-sharing pathways and ensure equal access to shared dashboards for potential cross-sector collaboration.



Impactful research

methods that have informed four new studies and a fellowship award



Led by

Professor Claire Goodman
MBE, University of
Hertfordshire



Driving knowledge mobilisation in research



Knowledge mobilisation involves researchers strategically sharing their findings with diverse communities to create new knowledge that drives meaningful change. ARC East of England (ARC EoE) remains committed to engaging communities and the health and care sectors to ensure real impact.

Our research collaborates with healthcare providers, policymakers and public contributors to help identify practical solutions through research, inform decisions and improve health services and community wellbeing. For example, the MINDS study aims to improve the outcomes and experiences for people leaving mental health hospitals including their supporters, and staff members. The project, which is co-produced with people with lived experience of mental health issues, worked closely with clinicians and health providers to develop an improved discharge planning approach that is being implemented and evaluated on wards in three NHS Trusts. Findings will inform policy and discharge planning practice in a way that ensures people with lived experience feel heard and that ultimately benefits everyone involved in the discharge. Another project is mobilising knowledge of death literacy across non-clinical communities by sharing factual,



To ensure our research leads to change, we build relationships with relevant communities from the beginning.”

Professor Kathryn Almack, University of Hertfordshire

practical and community-based knowledge through an online survey. This survey provides the user with resources for seeking support and planning for death.

By working with the communities that the project impacts, we have been able to gain an understanding of the barriers that they may face to inform future service delivery and improve patient outcomes. For example, one project worked with the Asian Women’s Cancer Group to understand how healthcare services can improve in supporting South Asian women to engage with breast cancer care. This project identified language barriers, cultural sensitivity, and uncertainty about what to expect. The findings will be used to inform recommendations to improve healthcare services and

and outcomes for South Asian communities.

Health Innovation East has led capacity building for knowledge mobilisation at ARC EoE. They have hosted an expert seminar series for the ARC fellows on co-design, knowledge mobilisation and engaging with stakeholders.

This year, we have established the East of England Carer Research Network, which brings together carers, researchers and system partners to discuss potential research areas. This network aims to promote the carer voice and be a vehicle to showcase and disseminate our research nationally.



Over 1000 responses on a survey to understand the public’s awareness of death literacy and community resources



Chaired a cross-ARC seminar sharing research on young people’s mental health with over 300 attendees



Shared our research findings in Australia regarding remote monitoring pathways

Engaging people with learning disabilities in creative research partnerships

People with learning disabilities and/or autism have worse physical and mental health than the general population. Current healthcare often does not fit the needs of this community, which has led to avoidable health inequalities.

Improving the health and wellbeing of people with learning disabilities and/or autism is a national health and social care priority. Research activities often fail to effectively engage with people with learning disability and/or autism, resulting in public services informed by research that does not meet the needs of the community.

The Creative Learning Abilities Partnerships (CLAPS) project uses creative engagement methods to innovate accessible routes for collaboration with people with learning disabilities and their carers who have not been involved in research before. These methods include drawing, colouring, music, poetry, video and playing familiar games such as bingo to explore their health and wellbeing needs and related barriers. The study will continuously learn about what is effective in terms of engaging with the MENCAP groups. The project is co-lead by a Public Involvement Contributor who is neurodiverse and provides a bridging role



In partnership;
with Lowestoft &
District and Barnet
MENCAPS

“

This project uses creative methods to enable people with learning disabilities and/or autism to become active health and social care research partners.”

Amander Wellings,
Co-Lead and Public Involvement Contributor



between academics, clinicians and the autistic learning disability community. This project has facilitated creative engagement workshops, which have allowed space and time to build confidence and familiarity with each other. The CLAPS partnership will co-produce a plan identifying beneficiaries of the new methods and they will host a stakeholder event to share their findings, promoting research in the identified areas.

This image was created during Lowestoft MENCAP art session by Amander Wellings.



Co-produced engagement

that has been shaped by people with learning disabilities



Co-led by

Professor Julia Jones, University of Hertfordshire and Amander Wellings, Public Involvement Contributor



Supporting person-centred approaches across health and care settings

Unmet support needs in managing chronic or progressive conditions can lead to decreased quality of life, mental health challenges, poor adherence to treatment, increased reliance on unpaid carers, and isolation. While health policy emphasises assessing and addressing patient needs, guidance often lacks specific strategies on how to achieve this.



Recently won
the University of East Anglia's Innovation and Impact Award



Used internationally
and translated into Swedish, Portuguese, and Traditional Chinese



Led by
Professor Morag Farquhar, University of East Anglia

The Support Needs Approach for Patients (SNAP) is a healthcare intervention that helps individuals with chronic or progressive conditions such as chronic obstructive pulmonary disease (COPD) identify their most important unmet support needs. The SNAP tool involves using the 'How are you?' booklet, which contains key questions to facilitate a focused conversation between the patient and trained healthcare professional to identify their needs. This approach helps to support conversations around their needs without patients feeling guilty or worrying about limited clinical time, thus enabling person-centred care. Individuals with lived experiences, unpaid or family carers and healthcare professionals

supported the researchers in developing SNAP. The project continues to evolve: its latest development has focused on adapting it for people with mental health conditions. This adaptation was in direct response to NHS staff requests to use the SNAP tool for facilitating holistic, person-centred conversations. The project team is currently preparing to adapt and implement SNAP in prisons. Former prisoners have provided input on the project, highlighting that person-centred conversations rarely happen in such settings. In addition, the project team is currently working with Health Innovation East to expand the rollout of SNAP in a range of clinical settings, including embedding it in healthcare services.



[It] did prompt me to ask some more questions with [the nurse]...and that was a good thing. [The appointment] went a bit deeper this time, which was what I really needed...this was something that I hadn't really understood in the past, that I should have a few more questions and now I have I feel a lot happier about everything...[the tool] did help"

COPD Patient, SNAP Study




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“It remains a great privilege to be associated with the impressive work of the ARC. 2024 has been another fantastic year, particularly when you consider the impact our work continues to have on real people and the service support they need. We continue to build on this work and are looking ahead to achieving even greater benefits for those we serve in the year ahead.”

Scott Haldane

Interim Chief Executive, Cambridgeshire and Peterborough NHS Foundation Trust

Looking ahead

We are approaching the end of the fifth year of ARC East of England and will then move into the 'reset and refresh phase', until March 2026, by which time we hope to have secured the next tranche of NIHR funding to allow our work to continue.

We will evaluate how our Public Involvement Hub has supported individuals on our Fellows Programme to inform how this model could be expanded to encompass the research we do across our themes.

We will continue to work with our Integrated Care System partners, responding to their needs and working in collaboration with the additional funding we have secured from NIHR for knowledge mobilisation. This will expand what we can achieve with Health Innovation East to turn robust research evidence into practice.

We will also continue to strengthen social care research by introducing new ARC initiatives focused on training and, crucially, providing practitioners with the time to investigate the areas where they identify the greatest need.

I look forward to sharing our progress next year.



Professor Wendy Wills,
Director of NIHR ARC East of England





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