



**NIHR** | Applied Research Collaboration  
East of England

## Stevenage

# Dementia Involvement Group

### What we did

The Stevenage Dementia Involvement Group aims to provide opportunities for people living with dementia, and their carers, to influence dementia research and the planning of local services. The group was launched in 2020 and meets monthly to discuss topics relating to living with dementia or health and social care services in Stevenage. At each session a guest visits the group to discuss their work and then the group have a conversation with them about the topic and share their experiences.

### Who with

People with experience of dementia, including those living with dementia and their carers. A second group with people living in a care home has also been set up. The group is hosted by [The Red Shed](#), a charity based in Stevenage providing gardening activities for people living with dementia and their carers and families. Researchers from universities across the region and providers of local health and care services have attended the group.



## What difference does this make?

- There are 25 groups members signed up who have contributed to over 15 projects (e.g., about physical activity, diagnosis, dementia friendly hospitals, technology, care homes and local service provision).
- Contributed to the development of a Dementia Friendly Activity brochure that is being shared by Stevenage Borough Council.
- Input into the development of a Dementia Urgent Care Plan that NHS England launched in February 2023.
- Collaborated with local organisations to improve dementia services, including the local council on how to make Stevenage Dementia friendly.
- Specific groups being run in collaboration with Hertfordshire Partnership NHS Foundation Trust Memory Clinic to improve their dementia services.
- Wider connections have developed, inspiring the establishment of a new local walking group.
- Currently working with Hertfordshire County Council to input into their Dementia Strategy
- Helps to develop a support network for people with dementia and their families and carers where their views and experiences are valued and listened to. Have signposted new members to other groups that they can attend in Stevenage.

***“I am so pleased to be given the opportunity to be involved with the group and know that my thoughts and feelings are being listened to and hopeful that this may lead to positive change” Group Member***

Find out more about the [group by clicking here.](#)



**NIHR** | Applied Research Collaboration  
East of England

## Stevenage

# Stevenage Playcentre Project

### What we did

Building health and wellbeing research links with children and their families living in Stevenage, the project involved holding engagement events in local Playcentres, using creative play activities, and art sessions. The research team talked to children and their families about their lives and health and wellbeing concerns.

### Who with

A collaboration between children and their families, local Playcentres, Healthwatch Hertfordshire, Stevenage Borough Council and researchers from the University of Hertfordshire.

***“At Healthwatch Hertfordshire we were delighted to build such a good relationship with the Playcentre, Stevenage Borough Council and the University of Hertfordshire” (Healthwatch Hertfordshire)***

You can watch a video about the project [by clicking here.](#)





## What difference does this make?

- Skills developed for researchers and community partners involved in the project, including learning about creative methods for engagement.
- Improvement in knowledge and experience of approaches to research engagement with children and their families.
- Engagement with underserved communities and children and young people.
- Developed relationships with local organisations who shaped the community-driven project.
- Supported engagement and collaboration through activity packs for children during Covid-19 lockdown restrictions to help support their wellbeing during difficult periods.
- Strong research partnerships developed between partner organisations that has sustained, with new projects and research collaborations as a result.

***“Those living in socio-economically challenged areas can be vulnerable to poorer health and emotional wellbeing. Public engagement and research activities often fail to engage and hear the voices of children and families in these areas about their experiences and what is important to them. The project aim[ed] to bridge this gap and create awareness and understanding of the key issues for children and their families in Stevenage.” (Professor Julia Jones, University of Hertfordshire)***

Find out more about this project by [clicking here](#).





**NIHR** | Applied Research Collaboration  
East of England

# Great Yarmouth and Waveney Carer Support Nurse Pilot Project

## What we did

We have worked with carers, health and social care professionals, voluntary organisations and national leaders in carer support, to develop a new Carer Support Nurse role. This role is designed to help carers who have their own needs, or who need extra support for their caring role, that cannot be met by their usual healthcare team. The nurse will also work with other healthcare providers to raise their awareness of carer needs and how to support them. This study explores the role's value and impact, and the feasibility of a larger study of how the role works across multiple sites.

## Who with

Carers, health and social care professionals from Norfolk and Waveney Integrated Care System, charity and voluntary organisations (e.g., Carers Voice), national organisations (e.g., Carers UK), NHS England, Adult Social Care, and Queen's Nursing Institute.



## What difference does this make

- Co-creation of a local carer asset-map for Great Yarmouth and Waveney.
- Collaboration with an engaged group of local and national stakeholders from health and social care and community and voluntary sector.
- Understanding the impact of the role on carers, as well as health and social care professionals.
- Endorsement of the role by 70+ East of England stakeholders and groups consulted across health, social care and the voluntary sector, over 100 carers and patients through Patient & Public Involvement (PPI) work, and regional and national leads in carer support.
- Regional winners of the Nursing and Midwifery NHS Parliamentary Award 2023.
- Shortlisted as a finalist in the Royal College of Nursing's Nursing Awards for the Innovations in your Speciality award (outcome due November 2023).

***“The Carer Support Nurse role is unique as it encourages cross-sector working with other healthcare professionals and third sector organisations. We are already hearing about the positive impact of the role and its very existence has been reported to have an impact on carers – it makes them feel supported.” Professor Morag Farquhar, University of East Anglia***



**NIHR** | Applied Research Collaboration  
East of England

# Great Yarmouth and Waveney

## Compassionate Communities

### What we did

Compassionate Communities supports the idea of spreading a concept known as death literacy – which is practical know-how about what to do and where to find support in a palliative or end-of-life care context. This project was evaluating a method to support communities in Great Yarmouth and Waveney to make use of their own skills and resources to support and improve the experiences of people experiencing life-limiting illness, loss or grief.

### Who with

Local GPs and hospices, community members and people experiencing life limiting illness, loss or grief, local charities, schools, voluntary groups, funeral homes, faith groups, artists and dramatists and the Town / County Councils.

***“I will be braver to discuss death with a dying friend or relative, to try and support them holistically.”*** Member of the community network





## What difference does this make

- Created a visual 'treasure map' of social support opportunities in the local area.
- Community members trained as 'compassionate companions' and 'conversation partners' to support community members with future care planning.
- Created a citizen-led community network to improve end-of-life care in Norfolk and Waveney.
- Increased public awareness and practical support.
- Launched a bereavement cookbook with stories of grief, accompanied by face-to-face cooking classes.
- Organised a community memorial event.
- Implemented a remembrance project with two local schools with support from the Men's Shed.
- Enabled someone to die at home, according to their wishes, after a hospital discharge was previously deemed unviable. This was directly attributable to the community network.
- A program of events was developed in collaboration with three hospices in the East for National Dying Matters Week 2021.
- Contributed to national ambitions to embed community-driven activity that connects with health and care services in support of people experiencing life-limiting illness, loss or grief.

***"I have learnt magical things can happen when people get together. I have discovered many organisations who are gently and lovingly supporting people experiencing difficult times."*** Member of the community network

Find out more about this work by [clicking here](#) and more about the [communities of practice by clicking here](#).



**NIHR** | Applied Research Collaboration  
East of England

## Thurrock

# Community Connections & Gypsy, Roma & Traveller Communities\*

\*Involvement and projects span across and beyond Thurrock and areas of the region

### What we did

ARC EoE researchers spent time talking and listening to those living and working in the local areas of Thurrock to understand local issues and health and social care priorities. These conversations and relationships developed led to further work, developed networks and funding bids to continue work with Gypsy, Roma and Traveller communities.

Gypsy, Roma and Traveller communities have been underserved by research and populations live within and beyond Thurrock. People in these communities continue to experience significant health needs and barriers to accessing health care. A network has been developed across the East, working with Gypsy, Roma and Traveller communities to understand difficulties in accessing health care and collaboratively developing research priorities. Building on initial community engagement work, further projects have been funded to develop a community of practice working with Traveller Communities, health practitioners and regional and national policy makers to identify barriers to accessing healthcare and to propose solutions to overcome those barriers.



## Who with

We worked with members of local Gypsy, Roma and Traveller communities, representatives and advocates such as, Gypsies and Travellers Essex, Compas and Oblique Arts Traveller Advocacy project, Public Health teams in local Councils and healthcare stakeholders across the county.

## What difference does this make

- Developed sustainable, trusting relationships between local organisations, research and Gypsy, Roma, and Traveller communities to enable co-produced approaches and outcomes that are directly addressing the barriers to access identified by the community.
- Creation of a community of practice involving Gypsy, Roma and Travellers and health care practitioners.
- Inform changes to policy and action plans to tackle ongoing issues of engagement and involvement of Traveller communities.
- Traveller Community Researchers trained to be interviewers to co-facilitate workshops to identify barriers to healthcare access and possible solutions.

Find out more about these projects here:

[Community Connections in Thurrock](#)

[Right to health for Gypsy, Roma, Travellers and Showmen families.](#)

[Building a community of practice to identify strengths, barriers and prioritise solutions to the right of access to healthcare for Travelling Communities](#)





**NIHR** | Applied Research Collaboration  
East of England

## Thurrock

# Implementing Shared Decision-Making across Mid and South Essex Integrated Care System

### What we did

Shared decision making is a key component of personalised care. It is a process by which people are supported to understand their options and given the opportunity to consider information that might influence their choice. All clinicians with a role in offering people treatments, investigations, therapies or interventions will be required to incorporate shared decision making except in life threatening situations.

In response to national plans by NHS England, to make Shared Decision-Making routine practice by 2024, the Mid and South Essex Integrated Care System (previously Thurrock Clinical Commissioning Group) worked with researchers to understand how routine Shared Decision-Making is in practice in the local area and to understand how this can be improved.



## Who with

Researchers worked with the Mid and South Essex Integrated Care Board to implement Shared Decision Making within the Integrated Care System.

## What difference does this make?

- An understanding of the extent of shared decision-making consultations across Mid and South Essex Integrated Care System (including Thurrock).
- An understanding of barriers and enablers to making this part of routine practice in consultations.
- A strategy for shared decision making was implemented.

## Peterborough

# Evaluating an intervention of bowel cancer screening in the Muslim Community

### What we did

Unequal access to healthcare and prevention services leads to significant and avoidable differences in health outcomes, particularly for ethnically diverse communities. Bowel cancer screening uptake is approximately 28% lower in people of South Asian ethnicity compared to the general population. Lower rates of screening uptake have also been reported overall among the UK Muslim population. This project evaluated a culturally adapted intervention for use in faith institutions to see if this could improve uptake of cancer screenings.

An initial British Islamic Medical Association promotion event, delivering educational cancer screening awareness talks by The Muslim Council of Britain involved 39 faith-based venues where 900 BIMA members participated has proved successful in triggering positive cancer screening awareness in the Muslim community.

The British Islamic Medical Association (BIMA) developed a “faith-placed” intervention to increase awareness of cancer screening and provide information to Muslim communities. It adapts a slide-deck used by Cancer Research UK and uses it to dispel myths, provide motivation and model positive behaviour in relation to screening.







## Who with

Researchers worked with clinicians, members of The British Islamic Medical Association, NHS professionals, public health officials and community leaders at a stakeholder event to launch the study. We worked closely with mosque leaders and volunteers (including local GPs) who spread the work about the intervention and encouraged people to attend. Peer researchers who supported data collection were also recruited from the community.

## What difference did this make?

- The intervention was delivered in local religious venues and had the support of both local community figures and religious leaders. This created trust and credibility among the Muslim community; it helped convince people to attend the intervention and to take part in the study.
- The involvement of health professionals and doctors from within the Muslim community was important as it allowed for the health message to be delivered in a way that was tailored to participants' religious and cultural background; it also allowed the participants to relate better to the clinicians and to align health promotion with the values of their community.
- Increasing awareness of bowel cancer symptoms and screening in the Muslim community through dispelling myths, providing motivation, and modelling positive behaviour in relation to screening, thus working on improving health outcomes for this target group.
- An understanding of what the barriers and facilitators are that might impact cancer screening.
- An assessment of the impact of a public health intervention tailored specifically to a Muslim community.
- Addressing health inequalities in ethnically diverse (and often marginalised) populations.
- Local evidence to inform national practice in the long-term.



**NIHR** | Applied Research Collaboration  
East of England

## Peterborough

# The Peterborough Exemplar

### What we did

The Peterborough Exemplar is a new community mental health care model, where an individuals' mental health and well-being can be supported by various professionals and service providers. It is an umbrella term referring to services ranging from early intervention psychological therapies to treatment of complex needs and crisis support.

Despite progress, gaps in service provision remain key barriers to effective community mental healthcare in England. Recent policies highlighted the need to transform service provision by developing patient-centred, joined-up community mental healthcare. In response to policy guidance and local strategy priorities, a system-wide community mental health care model was developed in Peterborough. This project evaluated a pilot of this community mental health care model in Peterborough.



## Who with

Users of local mental health services were involved to discuss how the evaluation could best assess the effectiveness of this model of community mental healthcare. Frontline workers and service managers shared their views about how services are delivered. As well as involvement of the Cambridgeshire and Peterborough NHS Foundation Trust, Peterborough County Council, Mind Charity and the Greater Peterborough Network with researchers from the Applied Research Collaboration.

## What difference did this make?

- Strengthened relationships between community mental health service provision organisations in Peterborough.
- The development of new community services to address gaps in provision in Peterborough.
- Information from the evaluation has informed local and national stakeholders about good practice, lessons learned and areas for improvement.

Find out more about this project by [clicking here](#).



### What is NIHR East of England?

The National Institute for Health and Care Research Applied Research Collaboration East of England (NIHR ARC East of England) is one of the 15 NIHR ARCs. NIHR East of England collaborates with Cambridgeshire and Peterborough NHS Foundation Trust, and the Universities of Cambridge, East Anglia, Hertfordshire and Essex along with other NHS Trusts, Local Authorities, Integrated Care Systems, patient-led organisations, charities, and industry partners.

### Get in contact with NIHR East of England

 [arc-ee.nihr.ac.uk](https://arc-ee.nihr.ac.uk)

 [ARCOffice@cpft.nhs.uk](mailto:ARCOffice@cpft.nhs.uk)

 [@ARC\\_EoE](https://twitter.com/ARC_EoE)

 [arc-ee.nihr.ac.uk/newsletter](https://arc-ee.nihr.ac.uk/newsletter)

