NIHR | Applied Research Collaboration East of England

NIHR ARC East of England Research & Impact Fellowship

We are pleased to share the success of our 14th cohort and celebrate all that they have achieved during the Fellowship programme.

2025-2026

NIHR | Applied Research Collaboration
East of England

Introduction

This booklet celebrates the outstanding work of the 14th cohort of the NIHR ARC East of England (EoE) Fellowship programme.

What is the programme

The ARC EoE Fellowship is a prestigious programme aimed at people working in health, care and voluntary service settings across the East of England. It is for those who would like to work at the interface of research and practice. It aims to develop an understanding of the research environment, and develop skills in research methodology, service redesign, change management and implementing evidence-based improvements into practice.

Since the scheme's establishment in 2010, over 170 ARC Fellowships have been awarded. Our fellows have come from a wide range of clinical and non-clinical backgrounds including Clinical Psychologists, Registered Nurses, Allied Health Professionals, Pharmacists, General Practitioners, Consultant Psychiatrists, Paediatricians, Consultants in Palliative Care, and managers in health and social care services.

There are two types of Fellowships: Research and Impact.

- **Research Fellowship:** The ARC Research Fellowship is for people who are keen to understand the research environment, and to develop skills in research methodology. The focus of this fellowship is on local applied research and evaluation projects (including audits), while building local capacity for evidence-informed practice.
- **Impact Fellowship:** The ARC Impact Fellowship is for people who are interested in developing knowledge and skills to implement and disseminate for impact evidence-based improvements in health and care settings.

What is included in this booklet

This booklet celebrates the outstanding work achieved by our 14th cohort. It displays Fellow's academic posters outlining the finding of their project work. It includes, also, a blog shared by the Fellows, highlighting their experiences of, or personal development on the programme.

With thanks to

The ARC EoE network continues to thrive, ensuring and facilitating meaningful collaborations between our partner institutions and supporting organisations. We would like to extend our ongoing thanks to all of them, for their continued engagement and support of the Fellowship programme.

Research Fellows

Since 2010, over 170 fellowships have been awarded to professionals, from varying clinical and non-clinical backgrounds, social care services and third sector organisations.

Dr. Rimsha Chohan

ST5 Psychiatry Doctor
Hertfordshire Partnership NHS Foundation Trust
E: rimsha.chohan@doctors.org.uk

NHS
Hertfordshire Partnership University
NHS Foundation Trust

The Acceptability of Chronic Obstructive Pulmonary Disease (COPD) Screening in People with Severe Mental Illness (SMI)

Chronic Obstructive Pulmonary Disease (COPD), characterised by inflammation of the airways and excess mucus (bronchitis) and breakdown of the alveolar membranes/air sacs (emphysema), is one of the most prevalent respiratory illnesses in the UK. The single biggest risk factor for COPD is tobacco smoking, the prevalence of which remains significantly higher in people with severe mental illness (SMI) than in the general population (Public Health England, 2020). People with a diagnosis of severe mental illness (SMI) have a higher premature mortality rate than the general population and can have death rates that are 4.7 times higher for respiratory disease (Public Health England, 2018).

Community mental health base in Hertfordshire sees a caseload of approximately 198 patients for depot injections, clozapine clinic, and physical health clinic. Incorporating COPD screening into this clinic using a handheld device, and offering this at a mental health base that patients already attending could facilitate more timely COPD diagnoses and treatment, and possibly work towards levelling this health inequality.

Key findings or insights

Due to staffing shortages, the initial plan to train clinic staff to administer COPD screening was changed to having myself administer COPD screening by joining the clinics or running a parallel clinic. Despite approaching at least 50 patients and the project being developed with the Patient and Public Involvement (PPI),recruiting participants proved difficult. Ultimately only 4 participants signed up, and so we instead began to explore the reasons for not wanting to participate. We did this by directly asking service users and carrying out a structured interview with a member of staff. Primary themes identified include:

- Time constraints: the nature of the clinics often meant patients spent as little time as possible there. Patients also felt they required more time to consider the screening and psychologically prepare for this.
- Patient commitment: the idea that a positive screening may mean committing to further appointments and/or tests was a discouraging factor, suggesting that motivation may remain a barrier even where the screening is more easily accessible
- Mental state: in some cases, it was felt offering the screening may do more harm by leading to disengagement or may be unsafe, particularly where patients were struggling with anxiety or agitation.
- Perception of reprimand: previous experiences of patients often led to concerns that the screening would lead to them being chastised for smoking.

Impact on people in the East of England

4 patients have been referred for further investigations via their GP and will be followed up to identify if they made any lifestyle changes (including smoking cessation where applicable) and identify if they have received a formal diagnosis and/or treatment for COPD.

The project also impacted patients who were unable to partake in the screening. In one case, a patient with a medical contraindication was unable to complete the COPD screening, but after discussing their symptoms, resolved to make an appointment with their GP to discuss these further; it prompted us to think about whether psychoeducation may be more acceptable than medical device screening, and therefore more effective in diagnosing COPD earlier.
Informing future research, practice, or policy.

Next steps would involve exploring barriers and facilitators to physical health checks (including COPD screening) via health questionnaires (and where possible, structured interviews). We may need to consider if psychoeducation about the symptoms of COPD and better access to smoking cessation services may be more impactful than screening with a medical device.

Challenges and Lessons Learnt

Ordering a medical device proved to be more complicated and challenging than expected. My expectations from this project were also that the main focus would be literature searches, planning, and data analysis; however the most exercised skills concerned collaboration, organisation, and leadership. Much of my project required relying on (and often waiting for) discussion and approval from others.

I also left the project with a better understanding of the importance of approaching any work (whether academic, clinical, or otherwise) with both humility and curiosity. Future projects would also require earlier collaboration with stakeholders, including both staff and patients, to ensure they are patient-centred from conception, rather than focused purely on the researcher’s goals and expectations.

Insights for Future Applicants

One tip for future applicants; remain curious. Even if your project isn't going as expected, sit back and ask - what is the reason for this and what information can you take away from it?

NIHR | Applied Research Collaboration East of England

COPD Screening in Severe Mental Illness

R CHOHAN [1], E KAMINSKY [2] C SHAH [3]
1 Hertfordshire Partnership University NHS Foundation Trust (HPFT)
2 Anglia Ruskin University (A.R.U.)
3 Hertfordshire Partnership University NHS Foundation Trust (HPFT)

INTRODUCTION

People with a diagnosis of severe mental illness (SMI) have a higher premature mortality than the general population and can have death rates that 4.7 times higher for respiratory disease (Public Health England, 2018).

The single biggest risk factor for COPD is tobacco smoking, the prevalence of which remains significantly higher than in the general population (Public Health England, 2020).

Despite their greater need for physical healthcare interventions, people with SMI struggle more than others for a variety of factors to access good care and therefore often require personalised support from services, delivered in ways they find helpful.

AIM

The aim of this service evaluation was:

- To understand the acceptability of delivering a COPD screening intervention in a community mental health setting.
- To evaluate the outcomes from COPD screening interventions including appropriate follow up in primary or secondary care
- To understand the experience of people with SMI accessing a COPD screening intervention in a community mental health setting
- To understand the experience of nursing staff delivering a COPD screening intervention in a community mental health setting

METHOD

1. This was carried out as a service evaluation/pilot at a community mental health base where depot, clozapine clinics, and physical clinics are run
2. Participants were offered COPD screening using a handheld screener
3. If they tested positive for COPD, their GP was advised of the positive screening. Smokers were given information on accessing smoking cessation services.

Feedback was collected:

- Via questionnaires from patient participants
- Via structured interviews from staff

Follow up will be completed to identify if patients:

- Had made lifestyle changes
- Had received a formal diagnosis
- Are receiving treatment for COPD

RESULTS

The project was changed prior to roll-out due to staffing issues at the clinic. There were delays in confirming meetings with staff to discuss the project and at least 2 cancellations of training sessions due to staff shortages. Ultimately, staff expressed they would be unable to complete the COPD screening during clinics due to being inundated with clinic lists and due to the nature of drop-in clinics making certain times too busy to complete COPD screening.

The methodology was changed; rather than staff carrying out COPD screening during clinic, the main investigator would be the sole member of staff completing screening.

This change, alongside limitations in time, also meant that the attempted number of patient participants we wanted to recruit was significantly reduced from the initially planned 100.

Patients were approached for recruitment during 5 clinics (depot, clozapine, and physical health clinics) via:

- Clinic staff telling patients about the study and referring them to a parallel clinic offering the screening
- The main investigator joining physical health clinics to offer COPD screening
- Reception staff providing information on the leaflet
- Posters advertising the COPD screening in the waiting room

Despite at least 50 patients being approached, only 4 were able to and consented partake in the COPD screening. At least 1 patient had a medical contraindication to using the screener (due to being symptomatic of COPD, they were signposted to discuss their concerns with their GP).

Despite the project being developed with the Patient and Public Involvement (PPI) input, recruitment proved difficult. During this process, we were able to identify and explore reasons around why patients did not wish to take part in screening. In combination with this information and the structured interview with a member of staff, preliminary themes around health beliefs and potential barriers to screening were identified.

Participants (n=4)	
Sex	
Male	2 (50%)
Female	2 (50%)
Smoker/ex-smoker	
Yes	2 (50%)
No	2 (50%)
Occupational risk	
Yes	1 (25%)
No	3 (75%)
Lifestyle risk	
Yes	0
No	4 (100%)
FEV/FEV6	
<0.8	0
>0.8	4 (100%)
Obstructive index	
RED	1 (25%)
YELLOW	3 (75%)
GREEN	0
To be referred for further spirometry	
Yes	4 (100%)
No	0

TIME CONSTRAINTS

"People want to be in and out [of clinic]."

Staff noted that the nature of the clinics often meant patients spent as little time as possible there, and often did not plan to stay longer than 1-2 minutes within the clinic.

"I might be interested but not today."

Patients may not feel psychologically prepared to complete a COPD screening on the day and would prefer to have time to consider this. This was particular in cases where patients expressed that English was not their first language, and they required time to read information and decide whether to consent.

PATIENT COMMITMENT

"Sorry, this seems like a lot of work."

A patient who initially agreed to the screening changed their mind after finding out that she may need to be referred via her GP for further investigations if indicated by the COPD screener. This means motivation may be a barrier, even where

"Will I need to go anywhere else?"

A patient who did participate, wished to clarify if hey would be able to do the screening in the same location as their physical health clinic – being told that it would take place in the same location seemed to reassure them.

MENTAL STATE

"She didn't have blood tests for 2 years at one point."

One patient presented as very restless and anxious during their physical health appointment, this was in part linked to concerns about the results, and had led to the patient previously refusing investigations for 2 years. In this case, COPD screening was not offered as it was felt that the patient may not have capacity to consent in addition to concerns that it could increase anxiety and potentially lead to complete disengagement from the physical health clinic.

"I don't feel he's well enough today."

At least one patient was not offered the COPD screening due to being unsettled in his mental state, and concerns that it could lead to further distress.

PERCEPTION OF REPRIMAND

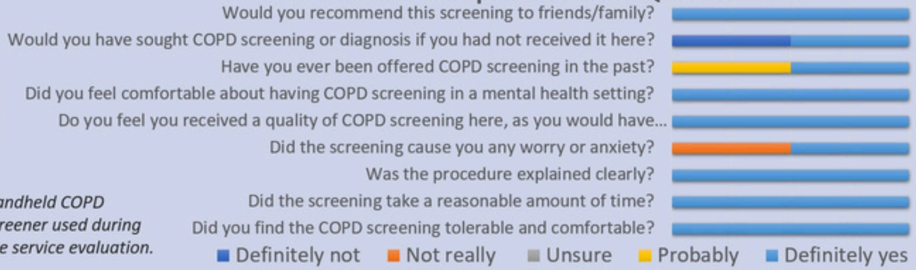
"People think they're going to be told off"

Some patients perceived the clinic as somewhere they would be chastised for smoking.

Health beliefs of patients and potential barriers to engaging with COPD screening in a community mental health setting

Handheld COPD screener used during the service evaluation.

Patient Participant Feedback Questionnaire



CONCLUSIONS

This service evaluation was able to identify health beliefs associated with COPD screening included and factors that could influence the engagement of patients with severe mental illness (SMI) with physical health checks; these included concerns about time constraints, needing to commit more time and energy later, struggles with their mental state, and perceptions that they would be reprimanded.

Next steps will involve identifying outcomes of patient participants who have been referred for spirometry.

Future work could focus on gaining further views on health beliefs via semi-structured interviews with patients to explore barriers in further detail, as well as exploring if written COPD questionnaires (that have no medical contraindications and can be completed remotely) may be more beneficial.

REFERENCES

Public health England **Severe mental illness (SMI) and physical health inequalities: briefing.** Published 27 September 2018 https://www.gov.uk/government/publications/severe-mental-illness-smi-physical-health-inequalities/severe-mental-illness-and-physical-health-inequalities-briefing

Public Health England **Health matters: smoking and mental health.** Published 26 February 2020 https://www.gov.uk/government/publications/health-matters-smoking-and-mental-health/health-matters-smoking-and-mental-health

Contact Information

rimsha.chohan@doctors.org.uk
rimsha.chohan@nhs.net

This service evaluation was sponsored by Hertfordshire Partnership University NHS Foundation Trust (HPFT) and support by National Institute for Health and Care Research (NIHR) Applied Research Collaboration East of England (NIHR ARC EoE) who are sponsoring the fellowship associated with this fellowship. This service evaluation has received ethical approval from the Faculty Research Ethics Panel (FREP) at Anglia Ruskin University (A.R.U.)

Jenny Garrett

Senior Anchor Project Manager
Mid and South Essex NHS Foundation Trust
E: jenny.garrett@nhs.net

Community Insights into Avoidance Attendances at Basildon Emergency Department

Basildon Hospital's Emergency Department continues to experience sustained pressure from high levels of avoidable or non-urgent attendances, placing strain on clinical capacity and affecting waiting times and patient experience. Local data shows that many attendances could be better supported in community, primary care, or preventative settings. This issue is particularly significant in Basildon, where communities face higher levels of deprivation, long-term conditions, and barriers to accessing timely care. The project focuses on residents living in Basildon, engaging diverse community groups to understand the real drivers behind avoidable Emergency Department use.

Addressing avoidable attendances at Basildon Emergency Department is vital for improving patient outcomes, ensuring safe and timely care, and reducing operational pressure on urgent and emergency services. Basildon serves some of the most deprived communities in the East of England, where long-standing health inequalities, barriers to accessing primary care, and social barriers such as financial stress and low health literacy contribute to higher Emergency Department use. Without understanding the real-life drivers behind these attendances, system-wide interventions risk missing the mark, leaving significant unmet need unaddressed. Nationally, reducing avoidable Emergency Department demand is a key NHS priority, yet there remains limited qualitative evidence capturing the lived experience of local people in areas like Basildon. This project helps fill that gap by amplifying community voices often overlooked in traditional data analysis. By addressing this issue, local partners across Mid and South Essex can work with communities to co-design unique, preventative, and equitable models of care that better meet the needs of underserved populations.

Key findings from the study highlight:

- A substantial proportion of attendances were avoidable, with only around a quarter clinically appropriate and up to 60% potentially divertible.
- Ongoing challenges accessing GP care, compounded by digital exclusion, limited transport options, and anxiety fuelled by alarming social media content, particularly among parents.
- High trust and confidence in Emergency Department staff, with participants consistently praising the quality of care despite long waits, which in turn encouraged continued attendance.
- Positive views of pharmacies and community health outreach, which were seen as accessible and trusted alternatives for advice and support.
- Uncertainty about appropriate care pathways, with many residents unsure what to do when a problem fell between basic first aid and a serious emergency, leading them to default to the Emergency Department.

Its Impact

This research is already informing thinking and decision-making across Mid and South Essex. By demonstrating that a significant proportion of Emergency Department attendances could be managed elsewhere, it has strengthened the case for redesigning patient pathways and improving patient flow. Insights from residents highlighting barriers such as digital exclusion, transport difficulties and challenges accessing GP care, are helping services understand why people default to the Emergency Department and where targeted support is most needed.

The findings are being shared widely with internal colleagues and external multi-agency partners to guide service development and improvement. In direct response to the digital exclusion identified through the research, a new digital inclusion project is being co-designed with South Essex College students, who will support community members to download the NHS App and navigate healthcare websites, increasing confidence and access.

Building on this momentum, ARC Impact Fellowship funding has been secured to take the work into its next phase. This will involve co-producing new health solutions with Basildon communities, focusing on the root causes of avoidable Emergency Department use and supporting preventative, community-led health interventions.

Overall, the findings provide a strong foundation for engaging communities and using lived experience to shape clearer and more effective services.

Challenges and Lessons Learnt

A key challenge was the ethics process, which took longer than expected and required, with the support of my Academic Supervisor, the need to pivot aspects of the study's design.

Recruitment to community listening sessions relied heavily on partners' strong relationships with local residents, and I was fortunate to work with three trusted community groups whose support made participation possible.

Insights for Future Applicants

·Be prepared for delays and adapt your design, if needed.
·Plan your workload, a slow start can quickly turn into very busy final stages.

NIHR | Applied Research Collaboration East of England

Community Insights into Avoidable Emergency Department Attendances at Basildon Hospital

Jenny Garrett, Mid South and Essex NHS Foundation Trust, is supported by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration East of England (NIHR ARC EoE) at Cambridgeshire and Peterborough NHS Foundation Trust. The views expressed are those of the author and not necessarily those of the NIHR or the Department of Health and Social Care.

J GARRETT[1] L SMITH[2]
1 Mid and South Esse NHS Foundation Trust, England,
2 Anglia Ruskin University

Introduction

Avoidable Emergency Department attendances place pressure on acute services and often reflect barriers to accessing timely, appropriate care. This study explores community insights into non-urgent Emergency Department use at Basildon Hospital.

Aim

To understand the behavioural, social, and system factors driving avoidable Emergency Department attendances at Basildon Hospital, in order to inform community-led preventative solutions.

Method

- Analysis of Emergency Department attendance data to identify non-urgent visits
- Community listening sessions exploring experiences, barriers, and decision-making
- Feedback of findings through stakeholder and multi-agency discussions

What the community said

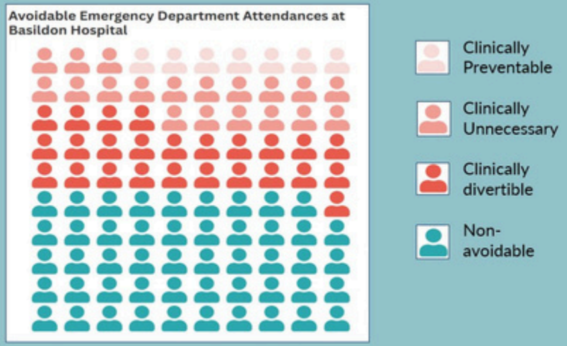
- In moments of concern, choices felt unclear and options limited
- Accessing GP or community care in time was often not possible
- The system felt difficult to navigate, especially outside normal hours
- As a result, the Emergency Department was seen as the safest and most reliable choice

"When you're worried and can't get through to anyone, A&E feels like the only safe option."

What the Data Tells Us About Avoidable Emergency Department Attendances at Basildon Hospital

We reviewed Emergency Department attendance data to identify visits that did not need emergency care. These included non-urgent problems that could have been treated safely by GPs, pharmacies, or community services, or avoided altogether with better access or information[2].

Classification was based on primary diagnosis data recorded by a health professional following consultation with the patient.



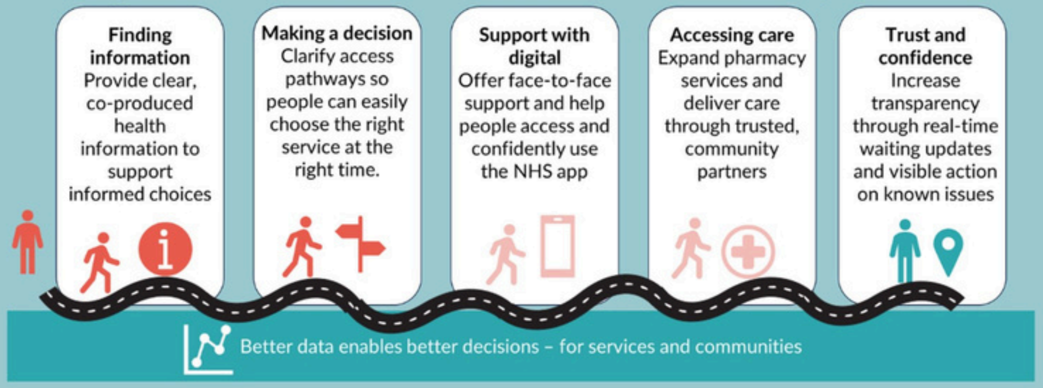
Avoidable ED attendances at Basildon Hospital are driven less by misuse and more by access barriers, system complexity, and confidence gaps, issues best addressed through community-led solutions.

If just 10% of these identified avoidable emergency department attendances were re-directed the hospital could save[3]

£1,275,000 per year

Money that could fund additional capacity for community alternatives and navigation support

Community-Led Recommendations Across the Patient Journey



Finding information
Provide clear, co-produced health information to support informed choices

Making a decision
Clarify access pathways so people can easily choose the right service at the right time.

Support with digital
Offer face-to-face support and help people access and confidently use the NHS app

Accessing care
Expand pharmacy services and deliver care through trusted, community partners

Trust and confidence
Increase transparency through real-time waiting updates and visible action on known issues

Better data enables better decisions – for services and communities

From Insight to Impact

Sharing and embedding learning

Findings will be shared with key partners through presentations and a report to stakeholders, and Anchor Institutions Group. The academic poster will be displayed on-site in Basildon.

Community Insights into Avoidable Emergency Department Attendances at Basildon Hospital

Community voices shaping better use of Emergency Departments

Building impact through the ARC Impact Fellowship

This work will move beyond research into real-world impact, co-designing a community-led health intervention that is grounded in evidence and driven by local priorities.

Acknowledgements

We thank NIHR ARC East of England for funding, Mid and South Essex NHS Foundation Trust for data access and Mayoor Sunilkumar for data analysis, and our community partners at Mother's Kitchen, Sign Post, and Trust Links for their invaluable contributions. Special thanks to Prof. Lee Smith, academic supervisor at Anglia Ruskin University.

References

[1] The King's Fund (2013) Emergency hospital admissions: managing the demand. London: The King's Fund.

[2] O'Cathain, A., Connell, J., Long, J., Coster, J., Knowles, E. and Turner, J. (2014) Clinically unnecessary use of emergency and urgent care: a systematic review of definitions and measures. Emergency Medicine Journal, 31(8), pp. 671–678.

[3] Monitor and NHS England. (2016). NHS National Tariff Payment System 2016/17. [online] GOV.UK. Available at: https://www.gov.uk/government/publications/nhs-national-tariff-payment-system-201617 [Accessed 25 Sep. 2025].

Contact Information

Jenny Garrett, jenny.garrett@nhs.net

Teresa Gibbon

Advanced Public Health Officer
Norfolk County Council, Public Health Team
E: teresa.gibbon@norfolk.gov.uk

Healthy Weight in Pregnancy: What do Women Want?

Prevalence of those living with obesity has increased over time for the general population, and thus the number of women presenting for obstetric care with a BMI outside of the healthy range, has also increased, causing additional challenges for health care providers, and increased risk of poor maternal and neonatal outcomes. High pre-pregnancy BMI and excessive gestational weight gain are known predictors for immediate obstetric risk and long-term risk for obesity and obesity-related disease, in both pregnant women and their offspring, both in childhood and later life. Data tells us that obesity in early pregnancy has continued to rise locally, with 28.9% of women in Norfolk and Waveney starting their pregnancy with a BMI in the obese range, compared to 26.5% in the East of England region, and 26.2% in England (2023/24). This figure places N&W as the 7th highest ICB in England.

Importance of addressing this issue

National data shows that rates are highest among women in the most deprived communities (32.4%) compared to those in the least deprived communities (19.8%) and higher for those in subsequent pregnancies (28.7%) compared to first pregnancies (22%). As reported in the MBRRACE-UK 2025 report, maternal obesity was present in 64% of maternal deaths, highlighting its significance as a public health challenge.

One in four pregnant women in England is now living with obesity, significantly increasing risks of gestational diabetes, pre-eclampsia and caesarean birth. Other increased risks include stillbirth or neonatal death, preterm birth, developmental issues, and a higher chance of the baby developing childhood obesity and type 2 diabetes later in life.

Despite this, the UK still has no official gestational weight gain guidelines, leaving pregnant women and healthcare professionals without a clear framework for consistent conversations around healthy weight. Historically, research has focused on midwives' perspectives of women's healthy weight needs during pregnancy, however, there has been little evidence to capture what women themselves feel that they need, especially in Norfolk and Waveney.

Key findings or insights

The strongest finding across the BMI categories was that pregnancy symptoms were the biggest barrier to maintaining a healthy lifestyle, with 56% of respondents reporting difficulties with eating a healthy diet. All but one of those reported morning sickness/hyperemesis gravidarum as the main reason.

The majority of respondents (75%) reported having difficulty engaging in regular physical activity, with pelvic girdle pain being listed by all of those respondents, as the top reason, followed by exhaustion, childcare responsibilities and fear of harming the pregnancy. Symptoms were seen to outweigh motivation, knowledge, or BMI as drivers of behaviour.

Emotional experiences varied widely. Some women felt unconcerned about weight gain due to a previously healthy BMI or severe symptoms like hyperemesis, whilst others, particularly those with higher BMI or complex health histories reported anxiety, mixed messages, conflicting advice and experiences of judgement or stigma. Many talked about just ‘getting through’ or ‘surviving’ pregnancy and worrying about health behaviours afterwards.

The majority of women (72%) felt that support regarding heathy weight management is needed throughout their pregnancy journey (before, during and after pregnancy), and that face-to-face support was the preferred method of delivery.

Impact on people in the East of England

Women who participated in the research were very open and honest with sharing their feelings, experiences and pregnancy journeys, and ensuring that their voices were heard. Hopefully, this will have helped them feel that their voices have been heard. The research informs us of what support women feel they need with healthy weight management throughout pregnancy. This insight can guide future support to help women feel more supported and, ultimately, reduce obesity.

Informing future research, practice, or policy

The findings will help inform future direction regarding policies and possible support interventions regarding healthy weight management before, during and after pregnancy, and may support the case for a scaled-up project reaching more diverse groups. Findings are currently being shared with partners, maternity researchers, universities and local authorities across the East of England to discuss implications for future work.

Challenges and Lessons Learnt

Key challenges were IT issues regarding access to required applications, a long wait for ethics approval and difficulty with partners sharing the survey.

Insights for Future Applicants

1.Start the ethics application as early as possible
2.Talk with any relevant partners and stakeholders early on to get early engagement
3.Take part in the PPI Hub; they are very helpful and informative
4.Avoid doing a survey or interviews over the Christmas period – low engagement

NIHR | Applied Research Collaboration East of England

Author, Teresa L Gibbon
1 Universityof Hertfordshire
2 Norfolk County Council, Public Health Team
3 NIHR Applied Research Collaboration,
East of England

Managing a Healthy Weight in Pregnancy… What Do Women Want?

Introduction

Who:
Norfolk and Waveney women (18+) who are, or have been pregnant in the last 2 years

What:
Amixed methods online survey and interviews

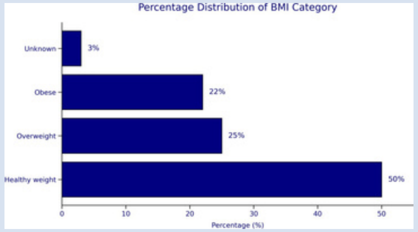
Why:
Obesity levels in early pregnancy continue to rise in Norfolk and Waveney

Aim

Tounderstand what support women need for healthy weight management in pregnancy

Sample

- 32 self selected respondents
- 2 online interviews
- Age range: 25-43 years
- 1 - 6 pregnancies
- 30 of the 32 respondents reported some awareness of current physical activity and dietary guidelines



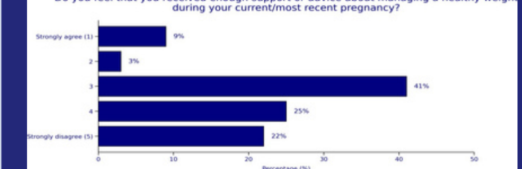
Results

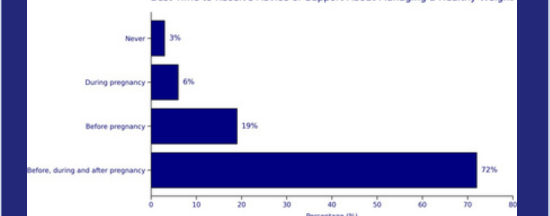
Barriers

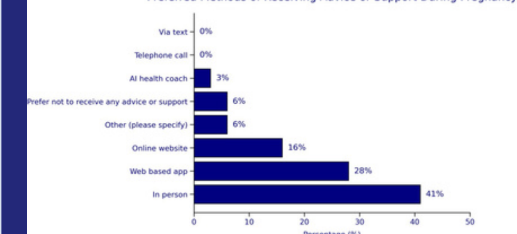
56% had difficulties eating a **healthy diet** in pregnancy, with **94%** of those stating morning sickness and food aversions/cravings as the reasons.

75% had difficulty engaging in regular **physical activity**, stating pelvic girdle pain as themain reason.

Support Needs







Women's Voices

"Hyperemesis gravidarum until 23 weeks – it was **survival mode**"

"Pelvic girdle pain left me **unable to walk**, on many occasions"

"I **stopped exercising** because I wasscared it would cause miscarriage, even though I knew it wouldn't"

"Open conversations with health professionals, **1:1 support** would have been helpful, like a specific service or practitioner, who I could 'check in' with for support"

"I gained 40kg during my pregnancy, and it was **difficult to lose it**"

"Being constantly weighed like a farm animal, including in a corridor when in active labour was **humiliating**. I'd been weighed the day before in clinic"

"When feeling **nauseous** it was hard to want to eat healthy foods"

"I feel **it's hard to lose weight when pregnant**, this should be done prior"

"I wasn't worried [about weight]. I thought pregnancy was hard enoughwithoutweight toworry about. **I'll deal with it after**"

"Pregnant people over a certain BMI are infantilised and treated poorly andwith bias by medical professionals. It actively **put me off having a future pregnancy**"

Conclusions

What Do Women Want?

1. **Stronger support across the entire pathway** (before, during and after pregnancy), that is less BMI-centric, less stigmatising and more holistic and person-centred.
2. **Personalised, non-judgemental guidance** on healthyeating,exercise andrealistic weight gain, responsive to pregnancy symptoms such as morning sickness and pelvic girdle pain.
3. **Tailored healthy lifestyle advice** recognising anindividual'scircumstance,such as health history, family circumstances, cost of living and time pressures.
4. **Accessible, affordable and baby-friendly options** forpregnancyandpostnatalexercise classes.

Acknowledgements

4I w. ould very much like to thank my Academic Supervisor, Claire Thompson, and my Public Health Principal, Katherine Attwell, for their very valuable support with this research project.

I would like to thank the NIHR ARC East of England and Norfolk County Council Public Health for the opportunity to undertake the research fellowship.

For more information

Email: teresa.gibbon@norfolk.gov.uk

or scan the QR code:

Teresa Gibbon of Norfolk County Council Public Health Team is supported by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration East of England (NIHR ARC EoE) at Cambridge and Peterborough NHS Foundation Trust. The views expressed are those of the author and not necessarily those of the NIHR or the Department of Health and Social Care

Marlene Kelly

Director
Auburn Mere Care Home
E: Marlene@auburnmere.uk

Listening to the People Who Hold Care Homes Together: What Registered Managers Say They Need for Their Wellbeing

This project explored a simple but surprisingly overlooked question: What do Registered Managers of care homes feel would genuinely support and nurture their wellbeing?

> As a Registered Manager myself for 16 years, I lived the reality of the role — long hours, heavy responsibility, pressure to "hold everything together," and the emotional weight of caring not only for residents, but for entire staff teams. I loved the work deeply, but I also knew how wellbeing can quietly erode underneath the surface.

When I moved into a role supervising Registered Managers, that pattern became even clearer. People who were fiercely committed to their homes, doing extraordinary things every day, were feeling exhausted, isolated, and unsure whether anyone truly understood the pressures they carried.
When I looked for research to help guide better support for them, I was surprised how little there was. We have studies on support workers' wellbeing, and plenty on how managers look after their teams — but almost nothing on managers themselves. The people at the centre of the service were missing from the evidence base. That gap alone told me this project was needed.

Through one-to-one interviews, Registered Managers described their job as a "labour of love," something they gave "110%." But they also spoke about the cost: constant pressure, unrealistic expectations, lack of recognition, and the loneliness of a role where "it's all on me." Some rated their wellbeing as just one out of ten. One told me they sat crying in their car every day before work, before eventually leaving their job.

Managers also suggested practical, realistic ideas — simple things that could genuinely lift their wellbeing. Flexible working. Being listened to. Protected time to reflect. More regular check-ins. Small acts of appreciation. Nothing expensive. Nothing complicated. Just meaningful attention and care.
These insights sit at the heart of this project: a human understanding of what Registered Managers are experiencing — and a clear message that improving their wellbeing doesn't require big budgets, just thoughtful action.

> Although this was a small study, the potential impact is significant

Care homes rely on the stability of their Registered Managers, and we know that stable leadership links directly to stronger CQC outcomes. When a manager leaves, whole teams destabilise. Residents feel the ripple effect. Organisations struggle to recover quickly. Supporting Registered Managers' wellbeing is not only good for them — it strengthens the entire care ecosystem.

The findings can help:

- care organisations rethink how they support their managers, even though small, low-cost changes
- registered Managers feel heard, validated, and confident raising wellbeing needs
- leaders recognise the need for system-level support, networks, and protected reflection spaces
- future research to build the missing evidence

I'm taking this forward through NIHR ASCENT (Social Care Research Development) funding to co-develop a larger project, and to create a knowledge-building network for people working in care homes who want to connect with research. This means the findings will shape ongoing work across the East of England, not sit quietly in a report —
There were, of course, some memorable hurdles along the way.

The scoping review was my first personal barrier. As a Registered Manager, I had built systems around my dyslexia without realising it. Suddenly I was navigating academic databases, referencing styles and literature-search language — and it was hard. I learned quickly that this is not my natural environment. My second challenge was ethics approval, which took four attempts. I fully support the ethics process, but the written precision it required was tough for me. If I'd been able to present it verbally, I think I would have passed first time.

But once I began the interviews, everything clicked. This was where my strengths lived — listening, connecting, and understanding the job from the inside. I absolutely loved it. Thematic analysis, too, came naturally; spotting patterns and themes felt intuitive. My confidence grew with every step...

The biggest lesson?

You don't have to be good at every part of research — you just need to find your bit. For anyone thinking about applying for the ARC East of England Fellowship, I'd say:

- Be honest about your strengths — and your challenges.
- Be realistic about what you can achieve; make a timeline early.
- Apply for ethics as soon as possible — it takes a long time.
- Ask for help. People genuinely want you to succeed.
- Choose a topic that matters to you.
- Make the most of the Active Learning Sets — they're invaluable.

And enjoy it. It's a genuine privilege.

Thank you to my supervisors, Anne Killett and Elspeth Mathie and NIHR for the opportunity.

SUPPORTED BY

NIHR | National Institute for Health and Care Research

Listening to the People Who Hold Care Homes Together: What Registered Managers Say They Need for Their Wellbeing

This project explored a simple but surprisingly overlooked question: What do Registered Managers of care homes feel would nurture their wellbeing?

Introduction

Around 10,000 Registered Managers are expected to retire in the next 15 years, with approximately 2800 vacancies already in the sector. Evidence shows that care homes with stable, long-standing managers achieve better CQC ratings — stability matters for compliance, staff, residents, and quality of care.

My motivation is both personal and professional. After spending years as a Registered Manager, I know how demanding the role is and how deeply it affects wellbeing. Now supervising Registered Managers, I want to understand — with evidence — what can make their roles healthier, more supported, and more sustainable.

Aim

The aim of the study:

To find out if Registered Managers are willing to talk about their own wellbeing and see if they can identify what would improve their wellbeing in the future.

At the end of the NIHR Applied Research Collaboration, East of England fellowship the researcher would like the findings from this research to encourage further research in this topic, on a larger scale, that could influence practice change, to support registered managers of care homes with their own wellbeing.

> “There’s more work than you can do in a day.” (RM6)

> “If you’re a good manager, you give it everything.” (RM2)

Methodology

A scoping review was conducted to identify existing evidence on the wellbeing of Registered Managers (RMs). Six registered managers then took part in semi-structured interviews (up to 90 minutes) in a location of their choice. Interviews explored their experiences, their willingness to discuss wellbeing, and ideas for improving registered managers wellbeing. All interviews were recorded, transcribed and anonymised. Data was analysed inductively using six-stage thematic analysis. The ARC East of England Public Involvement Hub and an advisory panel of two retired registered managers provided ongoing input.

Contact Information

Marlene Kelly

Email: Marlene@auburnmere.uk

The Care Home Team’s Knowledge-Building Network was recently established by Fellow Marlene Kelly, in collaboration with ARC East of England. This network is specifically designed for individuals working within care homes, rather than academic researchers. Please use this QR code to find out more.

Health Innovation East

Acknowledgements

With sincere thanks to Associate Professor Anne Killett (University of East Anglia) and Dr Elspeth Mathie (University of Hertfordshire) for their invaluable supervision and guidance throughout this fellowship.

Marlene Kelly is supported by the National Institute for Health and Care Research, Applied Research Collaboration East of England (NIHR ARC EoE) at Cambridgeshire and Peterborough NHS Foundation Trust. The views expressed are those of the author and not necessarily those of the NIHR or the Department of Health and Social Care.

> “Work from home one day would really help the balance.” (RM1)

Findings

Six key themes emerged from interviews with Registered Managers (RMs), highlighting both the rewards and intense pressures of the role. Many described their work as a “labour of love”, driven by long-term commitment to residents and pride in leading high-quality care. However, persistent challenges—including staff shortages, regulatory pressures, and unrealistic expectations—create a level of stress that is often unsustainable.

RMs frequently reported feeling undervalued by organisations and external professionals. Lack of recognition, limited career development, and experiences of disrespect all contributed to low morale. Support networks were uneven; while some managers had trusting relationships with colleagues, many felt isolated and responsible for “holding everything together.”

The scale and weight of responsibility were described as overwhelming, with RMs expected to manage every aspect of the service while remaining constantly available. This had a significant impact on wellbeing, with several describing exhaustion, burnout, or leaving previous roles due to pressure.

Despite these challenges, RMs offered clear, practical solutions. They emphasised the need for better recognition, protected time for reflection, more flexible working (including occasional home working), consistent managerial support, and realistic expectations from providers and regulators. Even small gestures—such as appreciation from senior leaders or wellbeing budgets—were seen as meaningful steps toward improving retention and wellbeing in the sector.

Six key themes

Conclusion

This fellowship shows that registered managers are deeply committed but often overstretched, isolated, and undervalued, and that simple, practical supports could make a real difference to their wellbeing and retention. These findings are already shaping next steps: through NIHR ASCENT funding I am co-developing a larger project with academic partners. The work will continue to influence practice across the East of England, ensuring the insights do not remain on the page but drive real change.

Edyta Klata

Clinical Research Assistant

East Suffolk and North Essex NHS Foundation Trust

E: edyta.klata@esneft.nhs.uk

NHS
East Suffolk and
North Essex
NHS Foundation Trust

Best
Poster
Awards

Evaluating the Early Impact of the Essex and Suffolk Elective Orthopaedic Centre on Waiting Times and Length of Stay for Hip and Knee Replacement Surgery

The New Essex and Suffolk Elective Orthopaedic Centre (ESEOC) opened in Colchester in November 2024 following a £64 million investment. The centre includes eight operating theatres and three inpatient wards, designed to increase capacity for elective orthopaedic procedures. This project evaluates whether the centre improved patient pathway outcomes during its first year of operation for hip and knee replacement surgeries.

The study focuses on patients undergoing total hip replacement (THR) or total knee replacement (TKR) at ESEOC, a regional elective hub serving populations across Essex and Suffolk. Key outcomes assessed include length of hospital stay and waiting times across the surgical pathway: GP referral to consultant appointment, consultant to surgery, and overall referral-to-treatment (RTT) time. These measures reflect service efficiency and system performance.

Long waiting times for elective surgery remain a major challenge for the NHS. The 2024 Darzi Review reported around 7.6 million people on waiting lists, with approximately 300,000 waiting over a year. Orthopaedic procedures make up a significant proportion of this demand, and delays can lead to worsening pain, reduced mobility, and poorer quality of life. Elective surgical hubs like ESEOC aim to address this by increasing capacity, improving patient flow, and reducing cancellations. National policy highlights the importance of productivity through better pathway management, infrastructure investment, and workforce innovation.

This project used a retrospective observational design following STROBE guidelines. Data were collected from two cohorts: 48 patients treated at the opening of ESEOC in 2024 and 48 patients treated one year later in 2025 (24 THR and 24 TKR in each group). Patient demographics—including age, sex, ethnicity, postcode, and medical history - were comparable between cohorts. Length of hospital stay decreased from an average of two days in 2024 to one day in 2025, suggesting improvements in recovery pathways and discharge processes. Waiting times from GP referral to consultant appointment remained largely unchanged (193 days in 2024 vs 191 days in 2025). However, the consultant-to-surgery interval improved significantly, particularly for TKR patients, who experienced a 114-day reduction. THR patients saw a smaller but meaningful reduction of 18 days. Overall, GP-to-surgery waiting time decreased by 39 days, indicating improved efficiency within the treatment phase of the pathway.

Patient Impacts

The project shows that patients are now getting surgery more quickly, reducing the chance that their condition will get worse while they wait. Waiting times have reduced a lot, including a 114-day decrease from seeing the consultant to having surgery for knee replacement patients, and a 39-day decrease in the journey from GP referral to surgery. After surgery, patients are also able to go home sooner. Improvements in recovery support and discharge planning have reduced the average hospital stay from two days to one. Importantly, the similarity in demographics between cohorts indicates that these improvements were achieved equitably, without disadvantaging specific patient groups.

Organisational Impacts

Shorter hospital stays and more efficient scheduling of operations mean the service can use its resources more effectively. This can lead to cost savings because fewer inpatient days are needed, and it allows more operations to be carried out with the same resources. These improvements also help staff plan better and keep the whole elective pathway running smoothly.

Service-Level Impacts

The findings suggest that the elective surgical hub model is effective and becoming increasingly streamlined. Improvements in pathway efficiency support the case for expanding high-volume, low-complexity surgical centres. The consistency in patient characteristics across cohorts strengthens confidence that gains have not been achieved at the expense of fairness or access. This study contributes early evidence to broader NHS efforts to improve elective care delivery. Future research should explore the drivers behind reduced consultant-to-surgery waiting times, such as theatre utilisation, preoperative optimisation, and multidisciplinary team coordination. Additionally, qualitative work examining patient and staff experiences would provide valuable insights into how these changes affect recovery, service delivery, and workforce wellbeing. Sharing these findings may help inform service improvements across the Trust and beyond.

Challenges and Lessons Learnt

One of the main challenges was the time needed to collect and check the data, particularly for the first cohort, with records crosschecked before use. For the second cohort, lessons were learned to complete these checks more systematically. Another challenge was realizing the project is only a snapshot, one piece of the puzzle and a starting point for further projects.

Insights for Future Applicants

Stay curious, work hard, ask questions, learn from mistakes, support others, and accept feedback. It is hard work, but this is your project—enjoy it.

NIHR | Applied Research Collaboration East of England

East Suffolk and North Essex NHS Foundation Trust

Wind of Change? Evaluation of the waiting time for hip and knee replacement surgeries in Essex and Suffolk Elective Orthopaedic Centre (ESEOC)

Edyta Klata – Clinical Research Assistant, East Suffolk and North Essex Foundation Trust (ESNEFT)

a.r.u. Anglia Ruskin University

Background

- NHS Waiting List Context (Darzi Review, June 2024)
- 7.6 million patients waiting in England
- 300,000 patients waiting >12 months Service Response
- Essex and Suffolk Elective Orthopaedic Centre
- Opened November 2004 in Colchester
- Capital investment: £64 million
- Infrastructure: 8 operating theatres and 3 large inpatient wards

Aim

- To determine the standard that ESEOC achieved with regards to length of hospital stay and waiting times for total hip replacement (THR)and total knee replacement (TKR) surgery by comparing these outcomes on opening of ESEOC to one year later.
- To evaluate the contribution of ESEOC to meeting national NHS waiting-list targets
- To explore whether ESEOC reduces pressure on NHS finances

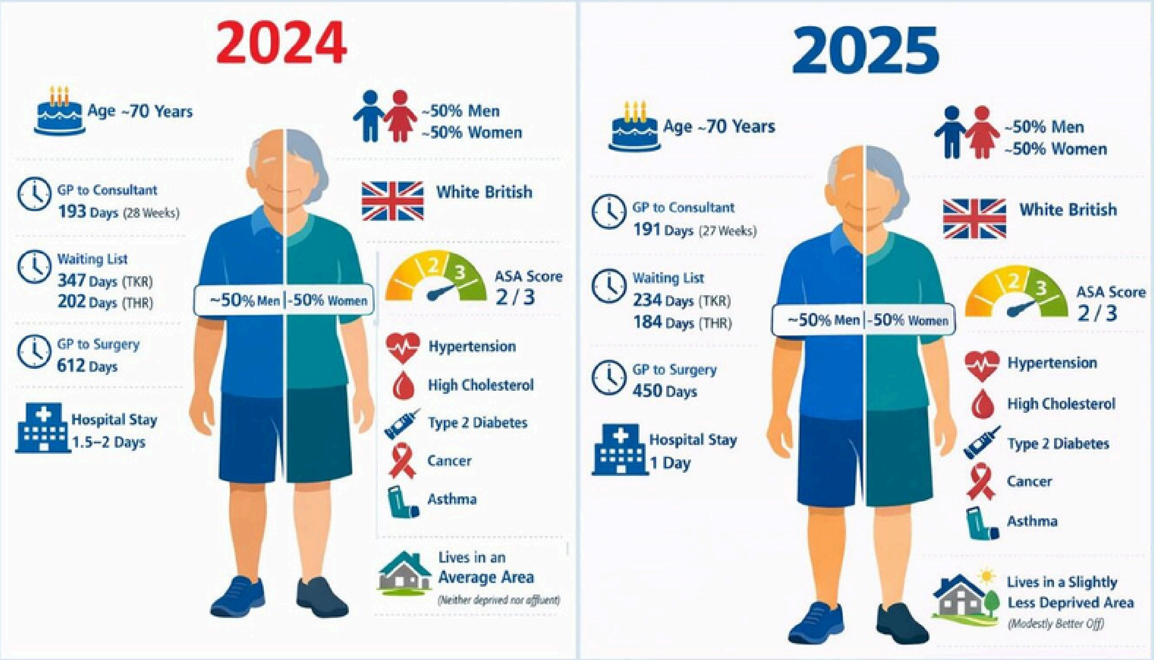
Methods

Conducted according to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guideline (von Elm et al., 2008)

Data collection:

- 48 randomly selected patients (24 TKR and 24 THR) on opening of ESEOC and 48 randomly selected patients (24 TKR and 24 THR) one year later.
- Demographics: Sex, age, post code, ethnicity, medical history
- Outcomes: Length of hospital stay and waiting times – from GP referral to consultant, consultant to surgery and GP referral to surgery.
- Descriptive statistics and inferential statistics used as appropriate (T-test, Mann Whitney U test and Chi^2.

RESULTS



- No significant differences between 2024 and 2025 cohorts in: Sex, Age, Ethnicity, Medical History
- Hospital stay reduced from 2 days (2024) to 1 day (2025)
- 2025, THR patients were from slightly less deprived areas compared with 2024
- Referral-to-Treatment (RTT) Target 18 weeks/126 days:
  - ✓ 2024: Met for 2 patients (TKR) and 6 patients (THR)
  - ✓ 2025: Met for 4 patients (TKR) and 6 patients (THR)
- Waiting times:
  - ✓ GP referral to Consultant – similar
  - ✓ Consultant to Surgery TKR – reduced by 114 days ↓ Significant
  - ✓ Consultant to Surgery THR – reduced by 18 days ↓ Moderate
  - ✓ GP to Surgery – reduced by 39 days in total ↓ Meaningful

* (T = - 1.95, P = ≤0.05)

Conclusions

- Shorter hospital stay suggests:
  - ✓ better recovery pathways
  - ✓ potential cost savings
  - ✓ increased bed availability
- Reduced waiting time means:
  - ✓ surgical scheduling, theatre capacity, or pathway efficiency improvement,
  - ✓ less time in pain, lower risk for deterioration while waiting, improved quality of life sooner.
- Equity of access requires monitoring.

Acknowledgements

- **I would like to sincerely thank Dr Leica Claydon-Mueller, my academic supervisor, for her invaluable guidance and support throughout this project.**
- With appreciation to Cathleen Chabo for inspiring me and believing in my potential.
- Special thanks to Merry Philip and Jonathan Poulteney for providing the essential data spreadsheets.
- A heartfelt thank you to my colleagues and family for their support and patience.

References

- Darzi, A. (2024). Independent Investigation of the National Health Service in England. Department of Health and Social Care. ISBN 978-1-916594-05-0.Available at: https://www.gov.uk/government/publications/independent-investigation-of-the-nhs-in-england.
- NHS ESNEFT (2024) Public Consultation for the elective orthopaedic centre. Available at: https://www.esneft.nhs.uk/your-visit/building-work-information-for-visitors/building-work-at-colchester-hospital/elective-orthopaedic-centre-eoc/publicconsultation/ [Accessed 2 February 2026].
- NHS England (2024) Referral to treatment. Available at: https://www.england.nhs.uk/rtt/ [Accessed 15 January 2026].
- von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP; STROBE Initiative. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE)statement: guidelines for reporting observational studies. J Clin Epidemiol. 2008 Apr;61(4):344-9. PMID: 18313558

Contact Information

edyta.klata@esneft.nhs.uk

Edyta Klata (ESNEFT) is supported by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration East of England (NIHR ARC EoE) at Cambridge and Peterborough NHS Foundation Trust. The views expressed are those of the author[s] and not necessarily those of the NIHR or the Department of Health and Social Care.

Danielle Leek

Environmental Public Health Scientist
UK Health Security Agency
E: danielle.leek2@ukhsa.gov.uk

More Questions Than Answers: Investigating Low Detection of Childhood Lead Poisoning Cases in the East of England

My public health career has taken me through microbiology, epidemiology, and health improvement, before pivoting in 2023 into environmental public health, where responding to chemical incidents and environmental hazards became part of daily work.

When I joined UKHSA, I was surprised to learn that lead poisoning remains a real issue, with the tragic death of a child from extremely elevated blood lead levels recorded as recently as 2015. I was even more struck to discover that the East of England had some of the lowest detection of childhood lead poisoning, despite having similar risk factors to regions reporting higher case numbers.

Given the well-documented lifelong consequences of childhood lead exposure, I wanted to understand whether the East of England genuinely had fewer cases, or whether cases were simply being missed within the wider health system. That question became the starting point for my fellowship.

How it went?

Like many roles in health settings, most of my time is absorbed by urgent incident response and statutory responsibilities. This leaves little free time to analyse the data we collect and explore wider patterns that might improve future response.

The research fellowship enabled me to have protected time to explore data, and access to expert academic support. Guidance received from my supervisor Dr Adam Wagner was invaluable. Supporting with my ethics application, keeping my timescales realistic, and shaping pragmatic research questions.

This support gave me the space and confidence to become familiar with RStudio, something which had previously felt like a lofty goal having largely been an Excel user! It also deepened my understanding of how to approach data, choosing appropriate tests, thinking critically about what the data could and could not tell me, and shaping results into a coherent narrative. All of which enabled me to successfully carry out a descriptive analysis of my case data.

How it's going?

My results showed that there were similarities between cases in the East of England (EoE) and the rest of England (RoE), such as a comparable number of cases were male (EoE = 51.7%; RoE = 52.0%). We also found some unexpected differences. For example, over half of EoE cases lived in private rented housing (52.6%), whereas more RoE cases lived in social housing (25.4%).
The insights generated through my fellowship have been invaluable in understanding our local context and will support development of incident response and intervention development moving forward.

Its Impact

Presenting this work to a public patient involvement and engagement (PPIE) group, and to health professionals has already helped raise awareness of the issue in the region. The PPIE group explained that they would prefer information on lead exposure to come from clinicians, so we are now considering co-producing materials with clinical teams to support diagnosis and management. As part of future work, we are considering providing similar resources to local authorities to raise awareness, support environmental sampling in local authority housing, and highlight the importance of good housing quality and condition. Our overall aim is to prevent cases where possible by removing sources of lead from the home environment and creating safer homes for children in the East of England. Earlier detection of existing cases will enable faster intervention and quicker reductions in blood lead levels to minimise harm.

Feedback from the PPIE group has been shared with senior managers and is already informing planning for the next stages of our internal lead-related work. The project has highlighted important gaps, including the lack of reporting from a regional laboratory to LEICSS, which we are now considering how to address to strengthen regional detection of elevated BLCs. We will also look at refining the enhanced questionnaire to target missing data and improve future assessments. These developments, alongside targeted work to raise awareness among clinicians, will support better practice. Ultimately, this work aims to inform policy and demonstrate the need for a consistent, active national surveillance system.

Challenges and Lessons Learnt

A key challenge was discovering at short notice that a data impact assessment was required; I have learned to consider this at the start of any project. I also found it difficult to switch off from my usual role, so I managed this by limiting email access, setting an out-of-office message, and removing access to Teams to maintain focus.

Insights for Future Applicants

Allow more time than expected for each milestone and begin planning your presentation and poster as early as possible.

Victorian-era villain, or modern-day menace?

Exploring reporting of paediatric lead poisoning cases in the East of England

D. Leek [1] and A.P. Wagner [2,3]

1 UK Health Security Agency ; 2 University of East Anglia ; 3 Applied Research Collaboration East of England

[D.Leek, UKHSA is supported by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration East of England (NIHR ARC EoE) at Cambridgeshire and Peterborough NHS Foundation Trust.
The views expressed are those of the author[s] and not necessarily those of the NIHR or the Department of Health and Social Care]

SCAN ME

Introduction

Exposure to environmental lead is still a significant public health concern.[1,2] Children are more susceptible to toxic lead effects and having elevated blood lead concentrations (BLCs). Prolonged exposure results in intellectual disability, behavioural disorders, renal disease, and can lead to death.[1,2]

Existing data from the UK Health Security Agency (UKHSA) lead exposure in children surveillance system (LEICSS)[3] shows that the East of England (EoE) has some of the lowest average detection rates of elevated BLC in children compared to other regions. Reasons for these lower rates are unknown – it is possible cases are going undetected and so not receiving appropriate interventions.

Aim and Methods

Aim

To understand factors influencing case reporting and detection, by exploring differences between cases in the EoE & Rest of England (RoE)

Methods

Exploratory statistical analysis of UKHSA lead case data for children (≤16 years). Data consist of:

- 251 cases across all UKHSA regions, 2017-2022
- 19 (8%) in the EoE
- All cases had one or more BLC at levels known to cause adverse health effects[2]
- Some cases involve multiple children (e.g siblings) – these are treated as individual cases

Lead sources include[3]:

- Paint in homes
- Old plumbing – and therefore drinking water
- Imported spices & cookware
- Soil
- Makeup such as kohl or surma
- Old toys decorated with lead paint

Risk factors[1,2]:

- Living in housing built-in/before 1970's –more likely to have lead pipes or lead paint
- Eating disorders (e.g pica – where children repeatedly eat non-food items like paint)
- Iron deficiency – which can cause/worsen pica; more lead absorbed than usual when iron deficient

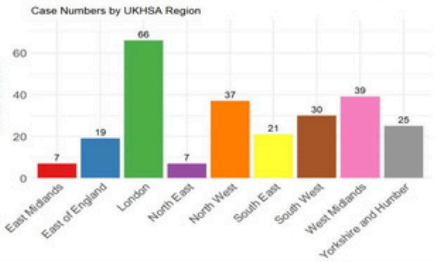


Figure 1. Number of cases per UKHSA region in the study period.

Findings

- Similar case age (years) between EoE & RoE – mean age: **4.5 vs 4.7**
- Similar sex split – % male: **EoE 47% vs RoE 52%**
- Similar percentage of cases recorded pica: **EoE 74% vs RoE 69%**
- More cases in EoE recorded other health (**42% vs 22%**) and behavioural (**26% vs 13%**) issues
- Index of multiple deprivation (IMD) mean quintile scores similar (EoE, 3; RoE, 2), but distributions differed – see **Figure 2**
- Housing ages were similar between EoE & RoE, but more EoE cases lived in privately rented accommodation (**53% vs 22%**)
- EoE cases had higher mean BLCs and greater distribution over higher concentrations.– see **Figure 3**

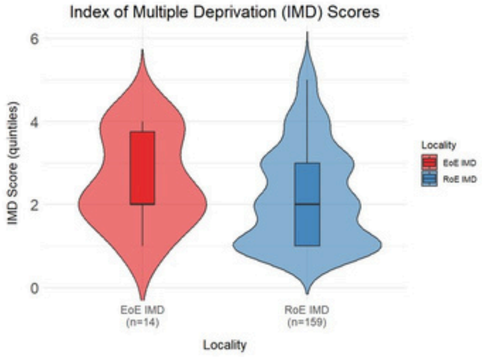


Figure 2. Distribution of index of multiple deprivation (IMD) quintile scores for the East of England (EoE) & Rest of England (RoE): more EoE cases relate to areas of higher deprivation. Quintile 1 = most deprived

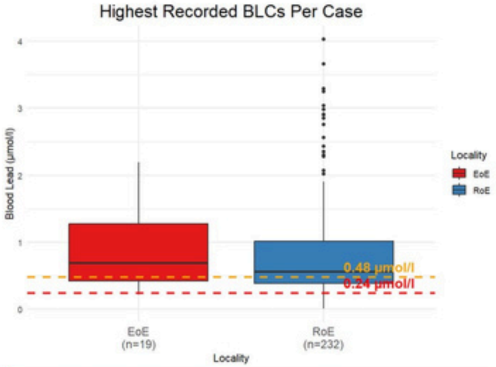


Figure 3. Distribution of highest recorded blood lead concentrations for the East of England (EoE) compared to the Rest of England (RoE). Similar median BLCs but the distribution high lead concentrations differs

Conclusions

- More EoE cases in less deprived areas, most at quintile 2. May not qualify for targeted support and could be 'slipping through the cracks'
- Higher BLC more common in EoE, but extreme BLC more common in RoE
- Potentially harder to impact EoE cases, as proportionately more cases in privately rented housing
- Similar risk factor profile between EoE and RoE
- Further internal and external work needed to improve reporting and detection of lead cases – e.g. awareness raising with clinicians

Acknowledgements

- Dr Adam Wagner (Project supervisor) - University of East Anglia; ARC EoE
- Dr Naomi Earl – UKHSA
- Sarah Dack – UKHSA
- James Stewart-Evans - UKHSA

References

1. Crabbe H, Verlander NQ, Iqbal N, Close R, White G, Leonardi GS, et al. 'As safe as houses; the risk of childhood lead exposure from housing in England and implications for public health'. BMC Public Health. 2022;22(1):2052.
2. Dave M, Busby A, Shammari LA, Iqbal N, Coole L, Bagnall H, et al. Lead exposure sources and public health investigations for children with elevated blood lead in England, 2014 to 2022. PLoS One. 2024;19(7):e0304866.
3 Agency UHS. Lead exposure in children 2025 [17/07/2025]..

Contact: Danielle Leek, UKHSA – Danielle.Leek2@ukhsa.gov.uk ;

Iuliia Marenina

Divisional Analyst
East Suffolk and North Essex NHS Foundation Trust
E: Iuliia.Marenina@esneft.nhs.uk

Early Cancer Risk Prediction Modelling: Machine Learning Approach

Cancer diagnosis at early stages (1 and 2) remains one of the key priorities for NHS as it improves survival outcomes and reduces treatment burdens. According to the "Annual Public Health Report 2023"[1], cancer diagnosis at stage 1 and 2 did not change between 2013 and 2019 and remained at ~54%. At the same time, the Cancer Delivery Plan 2025/2026 aims to achieve 75% of cancer cases diagnosed at stage 1 or 2 by 2028.

To address this issue, we proposed to utilise routinely collected medical data such as sociodemographic, lifestyle, diagnosis and medication information to predict the risk of cancer. This project focuses on three cancer types with the lowest early diagnosis rates in the East of England: pancreatic with 23% early diagnosis rate (ICD10 - C25), oesophageal with 17% early diagnosis rate (ICD10 - C15), and lung with 32% early diagnosis rate (ICD10 - C34).

Multiple academic papers about early cancer risk prediction modelling were identified. We used these papers as examples to replicate in healthcare settings.
To do this, the plan was to:

1. Assess the availability and suitability of data for cancer risk classification modelling.
2. Replicate and evaluate approaches described in published research studies on cancer risk prediction.
3. Assess model performance for both general risk and high-risk patient prediction.

- General risk – Evaluate how accurately the models predict overall cancer risk
- High-risk – Evaluate how accurately the models predict cancer risk among people with a risk score greater than 80%

Relevant datasets were identified and datasets for machine learning modelling were prepared.
For machine learning modelling, gradient boosting (XGBoost, LGBM) and Random Forest algorithms were used due to their ability to capture complex non-linear relationships and robustness to overfitting and missing values. The modelling approach is a binary classification task, where the positive class represents cancer and the negative class represents non-cancer.

The general risk prediction model did not achieve an acceptable level of predictive performance for further implementation, although its performance was comparable to or exceeded that reported in the reference studies.

For the high-risk modelling evaluation, we identified cases classified as having an ≥80% risk of cancer and assessed how many were confirmed cancer cases. Overall, high-risk prediction modelling identified 65%-83% high-risk patients with cancer correctly:

- Oesophagus – 71%
- Pancreas – 65%
- Lung – 83%

However, the proportion of patients classified as high risk is relatively low for pancreatic and oesophageal cancers (9%-27%), and slightly higher for the lung model (41%). This indicates that although the model performs reasonably well among those identified as high risk, it captures only a small share of all patients, limiting its overall impact for early detection and intervention.

Its Impact

The developed models demonstrated performance comparable to that reported in previously published studies. This suggests that data available in local healthcare settings can support targeted risk assessment at a level comparable to that reported in leading academic research. However, the overall predictive performance remains insufficient for implementation, as the proportion of false negatives is high and the models' discriminatory ability is limited.

This project represents the first step for our organisation toward a more proactive approach to early cancer diagnosis. Although it did not lead to immediate implementation, it provided valuable insight into available data and established a pathway for data aggregation to support risk modelling.
The models could be improved in the future by incorporating additional potentially important variables, such as medication information, longitudinal trends, and health-related activity data.

Challenges and Lessons Learnt

Data-oriented projects in healthcare face several challenges. The primary challenge relates to the use of the data itself, as access, sharing, and permitted uses are tightly regulated. A second challenge lies in understanding how the data are collected and structured. Considerable time is often required to identify the correct data sources, interpret the datasets and prepare them in a format suitable for modelling. Data quality presents a further issue, as healthcare data are typically collected routinely for administrative and commissioning purposes (e.g. activity reporting) by multiple providers, limiting the ability to control and validate them at the academic research level. Finally, clinical expertise is essential. While this project focused on replicating existing studies, further model development would benefit from close collaboration with clinical experts.

Insights for Future Applicants

For data-oriented projects, I recommend engaging with your organisation's information governance leads at an early stage and ideally before proposing a project to discuss the intended data use, data-sharing permissions, and project objectives. This will help establish realistic expectations and appropriate methodologies.

[1] Healthy Suffolk. Earlier cancer diagnosis (routes and screening), Suffolk, 2023. Cancer profile (Chapter 7)

NIHR | Applied Research Collaboration East of England

Early Cancer Risk Prediction: Machine Learning Approach

Authors: I. MARENINA [1], H. CHICHGER [2] and N. GHAVAMI [1]
1 East Suffolk and North Essex NHS Foundation Trust, UK
2 Anglia Ruskin University, UK

a.r.u. | Anglia Ruskin University

NHS East Suffolk and North Essex NHS Foundation Trust

Introduction

Between 2013 and 2019, cancer diagnosis at stage 1 and 2 has remained similar at 54.5% nationally.[1]

Recent research has demonstrated that medical records can serves as a valuable source of data for cancer risk predication. Routinely collected sociodemographic, lifestyle, diagnosis and medication data can be used for risk modelling.[2]

This research project focuses on three cancer types with the lowest early diagnosis rates in the East of England: pancreatic (C25), oesophageal (C15), and lung (C34).

Aims

1. Assess the availability and suitability of data for cancer risk modelling
2. Replicate and evaluate approaches described in published research studies on cancer risk prediction
3. Assess model performance for both general risk and high-risk patient prediction (risk score > 80%)

Methods

Model selection:
Gradient boosting (XGBoost, LGBM) and Random Forest algorithms were chosen due to their ability to capture complex non-linear relationships and robustness to overfitting and missing values. These models demonstrated the best performance in a similar study.[3]

Model performance evaluation:

1. Sensitivity – proportion of actual positives correctly identified
2. Specificity – proportion of actual negatives correctly identified
3. Precision – proportion of predicted positives that are true positives
4. Area Under the Precision-Recall Curve (AUC-PR) – overall model performance measure for imbalanced datasets
5. Confusion matrix

Metrics 1–4 range from 0 to 1; the closer to 1, the better the model performance.

Results

Data:

	Cancer	Non-cancer
Number of patients	7,653	8,000
Age, average in years	73	72
Sex (Female/Male)	2738 F / 3402 M	4330 F / 3598 M

General criteria: age > 40 y.o., no cancer history for non-cancer group, no prior cancer history before the target cancer diagnosis for cancer group.

Explanatory variables were extracted from records dated before the cancer diagnosis date for the cancer group and before January 1, 2023, for the non-cancer group.

Cancer group includes patients diagnosed between 02/01/2018 and 30/09/2025.

Missing values are retained in the dataset for all explanatory variables.

Explanatory variables:

Socio-demographic data	Age, sex, ethnicity category, area of living (urban/rural), index of multiple deprivation quantile
Lifestyle data	Weight, height, BMI, smoking status, cholesterol, cholesterol low density, alcohol intake, glucose level (plasma fasting and regular, blood fasting and regular glucose), haemoglobin
Diagnosis data (ICD10)	E10, E11, E13, E14, F17, I73, H36.0, K05.3, K20, K21, K22, K25, K26, K29, K30, K31, K59.0, J18, J41, J42, J43, J44, J45, Z72, Z80, Z81, Z82, Z96

For primary care data, corresponding SNOMED codes were identified using a code-description similarity check.

General model performance:

Oesophageal - XGBoost

	Predicted Negative	Predicted Positive
Actually Negative	1532	62
Actually Positive	190	83

- ➢ Sensitivity – 0.57
- ➢ Specificity – 0.88
- ➢ Precision – 0.30
- ➢ AUC PR – 0.44

Pancreatic - XGBoost

	Predicted Negative	Predicted Positive
Actually Negative	1538	55
Actually Positive	241	34

- ➢ Sensitivity – 0.38
- ➢ Specificity – 0.86
- ➢ Precision – 0.12
- ➢ AUC PR – 0.30

Lung – LightGBM

	Predicted Negative	Predicted Positive
Actually Negative	1367	245
Actually Positive	380	605

- ➢ Sensitivity – 0.71
- ➢ Specificity – 0.78
- ➢ Precision – 0.61
- ➢ AUC PR – 0.74

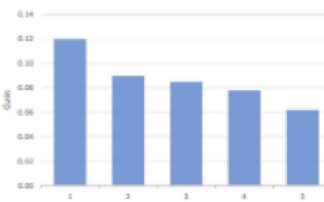
High-risk classification performance:

Cancer	Number of patients with cancer (test set)	Number of predicted high-risk cases	Number of correctly identified cancer cases
Oesophagus	273	74 (27%)	53 (71%)
Pancreas	275	26 (9%)	17 (65%)
Lung	985	402 (41%)	336 (83%)

65% of pancreas, 71% of oesophagus and 83% of lung cancer high-risk patients were identified correctly.

However, the proportion of high-risk patients is low in the pancreas and oesophagus groups, but slightly higher in the lung group.

Best performing model - Lung: feature importance, top 5 factors



1. F17 (Mental and behavioural disorders due to use of tobacco)
2. Age
3. Haemoglobin
4. J44 (Other chronic obstructive pulmonary disease)
5. Height

Conclusions

The developed models demonstrated performance comparable to previously published studies. The lung cancer model outperformed other published models.
However, overall predictive performance remains insufficient for implementation, as the proportion of false negatives remains high and discrimination ability is limited. Further research is required.

Potential areas for improvement and future research are:

1. **Health-related activity data**: Incorporating information on healthcare activity such as frequency of primary and secondary care visits, emergency department visits and level of disease control may improve predictive accuracy.
2. **Medication data**: Although not all medications are prescribed through NHS providers, analysing routinely collected prescribing data could help identify specific drugs or combinations of drugs associated with increased or decreased cancer risk.
3. **Longitudinal trends**: Some factors, such as lifestyle data and medication use, change over time. Analysing longitudinal trends rather than relying on single time-point measurements may improve predictive performance and allow earlier detection of risk patterns. For diagnosis data, incorporating the duration of chronic conditions (e.g., in months or years) may provide additional predictive value.
4. **Risk threshold calibration modelling and survival analysis** for high-risk patients to determine when the disease occurs.

References

1. Healthy Suffolk. Earlier cancer diagnosis (routes and screening), Suffolk, 2023. Cancer profile (Chapter 7)
2. Abdullah Alfayez A, Kunz H, Grace Lai A. Predicting the risk of cancer in adults using supervised machine learning: a scoping review. BMJ Open 2021;11:e047755. doi: 10.1136/bmjopen-2020-047755
3. Lee E, Jung SY, Hwang HJ, Jung J. Patient-Level Cancer Prediction Models From a Nationwide Patient Cohort: Model Development and Validation. JMIR Med Inform. 2021 Aug 30;9(8):e29807. doi: 10.2196/29807. PMID: 34459743; PMCID: PMC8438609.

Contact Information

Email: Iuliia.Marenina@esneft.nhs.uk

Iuliia Marenina and East Suffolk and North Essex NHS Foundation Trust are supported by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration East of England (NIHR ARC EoE) at

Bethany Pittuck

Research Officer
Healthwatch Essex
E: bethany.pittuck@healthwatchessex.org.uk

Best
Poster
Awards

Exploring Adolescents And Emerging Adults' Experiences Engaging With And Responding To Local Physical Activity Programmes

My name is Beth Pittuck, and I am a Research Officer at Healthwatch Essex. Since finishing my Psychology degree in 2021, my passion for research, statistics and using evidence to create meaningful change has continued to grow. So, when I came across the ARC Fellowship programme, I was excited by the idea to enhance my research skills and lead a project on something I've cared about for a long time.

My own experience

When I was around 9 or 10 years old, I was told that I was 'morbidly obese'. At that age, I didn't really understand what that meant. I was left with a lot of unanswered questions including "What does that term even mean?" and "How can I change this?" I was then part of a weight-loss programme that encouraged some quite intense behaviours such as walking around Sainsbury's with a magnifying glass reading calorie labels. Those experiences have stuck with me and looking back, I felt like my voice wasn't really part of the conversation around what a healthy lifestyle should look like.

This experience shaped the focus of my fellowship project. We often see in the media that young people are spending more time indoors and becoming less active. Which has huge implications for both physical and mental health. At the same time, there are local initiatives such as running, karate and dance clubs that encourage young people to be more active, whilst fostering social connections and wellbeing. However, when looking at the creation of these programmes, they are usually designed for young people, rather than with them. This made me question how much we understand about what young people want. This became the focus of my project, speaking directly to young people to hear their perspectives.

My project

To do this, I sent surveys to young people aged 13-23 and ran 2 focus groups. Young people shared common barriers to getting involved in local programmes which included cost, lack of confidence and limited awareness of programmes available locally. When we discussed what would encourage their involvement, social connection was often repeated. Young people wanted to do something with friends or meet new people. They also mentioned the importance of accessible locations, beginner-friendly options and clearer, more engaging advertising.

One of the best parts of this project was seeing how eager young people were about designing their own activities. The ideas they came up with were creative and centred on social connection. One participant said that they “really enjoyed the focus group” as it gave them “the opportunity to do something creative”. When speaking with young people about their designs, one individual highlighted that they’d “really like to do my activity” but that they “would probably need some sort of help with that”. Highlighting that motivation from young people exists, but we need to create more opportunities and support young people to get involved.

As I continue to share my findings, I will highlight how important it is for organisations and services to involve young people in the design and delivery these programmes. Their insights are valuable in creating accessible and engaging physical activity programmes locally. Moving forward, I’d really like to see some co-designed physical activity programmes piloted with young people. This would give us the chance to explore what works in practice, whether more young people get involved in physical activity, and what still needs improving.

My reflections...

I often look back on my fellowship journey as though I was travelling down a path (one that changed directions many times!) There were challenges along the way, especially with recruiting young people, which meant changes to ethics and my methods. In December, I didn’t think I was going to collect any data at all! However, with some adaptations to my methodology (and additional work in the evenings and weekends) I overcame this.

When I reflect on this journey, I realise how much I have learnt about my capabilities as a researcher, which is something I struggled with at first. Now I feel proud of what I have achieved, and I look forward to continuing my journey as a researcher.

I will leave you with a piece of advice my supervisor shared with me early on, which turned out to be very true of research:

“Whatever you think will take one month, triple it”.

“They’re not really targeting my sort of audience”

Young people’s experiences of local physical activity programmes

Beth Pittuck | Healthwatch Essex | Bethany.pittuck@healthwatchessex.org.uk

Introduction

- Physical **inactivity** in young people is on the rise (Manic et al., 2021).

- Local programmes promote physical activity → positive relationships between **mental** and **physical wellbeing**.

- BUT often overlooked by young people as they are **not included** in programme design (Ostermeier et al., 2024).

Research Questions

- What **motivates** young people to participate?
- What **barriers** do they face?
- How can initiatives be **improved** and **promoted?**

Methods

Young People’s Perspective

- Provided feedback on methods and documents.

Surveys

- 13-17-year-olds (7)
- 18-23-year-olds (21)

Focus Groups

- 2 meetings (3 young people).

Creative Task

- Young people designed their own local physical activity programme.

Results - Key Themes

Accessibility

- Local activities.
- Affordable.
- Flexible timing.

“easy to get to with public transport”

Social Factors

- Having friends there.
- Beginner friendly sessions.
- Women’s only spaces.

“friendly faces each week”

Advertising

- Real young people in adverts.
- Posters on social media, in schools & bars.

Conclusion

- **Accessible**, **affordable**, **diverse** and social activities are key for engaging young people.

- **Creativity** when designing posters.

- **Co-produce** posters and programmes with young people.

Acknowledgements

BethPittuck andHealthwatch Essex is supported bytheNational Institute for Health and Care Research (NIHR) Applied Research Collaboration East of England (NIHR ARC EoE) at Cambridgeshire and Peterborough NHS Foundation Trust. The views expressed are those of the author and not necessarily those of the NIHR or the Department of Health and Social Care.

I would also like to thank my supervisor Prof Kristy Sanderson for her wonderful support throughout the project.

NIHR | Applied Research Collaboration East of England

healthwatch Essex

What Young People Said...

“A video of someone doing the activity”

“Safe spaces for less experienced people”

Dr. Olajide Popoola

NHS
Norfolk and Waveney
Integrated Care Board

Locum General Practitioner
Norfolk and Waveney Integrated Care Board
E: olajide.popoola@nhs.net

Best
Poster
Awards

Healthcare Research Delivery in Correctional Facilities: Barriers and Solutions

Current data show that the health outcomes of people in correctional facilities - prisons and young offender institutions- are poor compared to the general population. There is a significantly higher burden of physical and mental ill-health among people in secure settings. The mortality figures, as expected, follow the morbidity pattern. A person in prison is likely to die from natural causes 20 years earlier than someone in the general population.

Despite these profound healthcare needs, people in correctional facilities remain underserved by healthcare research. Historically, the prison population has been excluded from healthcare research for several reasons, including response to past exploitation and abuse, ethical concerns about consent and vulnerability, and the logistical difficulties of accessing the population. However, we know that for an evidence base to be applicable to a group of people, the evidence must have been generated from research that included participation from that group. Therefore, without access to research, the healthcare provided to people in prison risks being informed by evidence generated in mainstream populations with different social contexts and health profiles. This approach, aside from limiting the quality of healthcare provided to incarcerated patients, has wider implications for public health and services, since most people in custody are eventually released to the community.

A significant implication of the above approach is that it ultimately undermines the principle of equivalence, the internationally agreed standard that people in custody are entitled to the same standard of care as those in the community. However, it is increasingly clear, given the disparities in health outcomes, that without equivalent evidence, equivalence of care remains aspirational. The aim of the project was to identify barriers and facilitators to the delivery of healthcare research within correctional facilities. The findings are relevant to correctional institutions in the East of England as well as to the rest of the nation. The work package consisted of a narrative literature review and a series of stakeholder workshops.

The central finding from this project is that the underrepresentation of people in secure settings in healthcare research is a multi-layered problem reflecting a complex interaction of barriers across multiple levels. A socio-ecological framework was adapted to map the barriers identified in a literature review across policy, institutional, interpersonal, and individual levels. The overall learning is that the evidence points towards the need for a systemic paradigm shift in the approach to research delivery in secure settings. The delivery of healthcare research within correctional facilities is feasible but requires purposeful adaptation at every level of the system, including modified approaches to informed consent and methodological flexibility.

This work, directly and indirectly through its related projects, has contributed to strengthening research capacity and capability across the local research ecosystem through active collaboration with the NIHR East of England Research Delivery Network and the NHS Norfolk and Waveney ICB Research and Innovation team. It has also facilitated engagement with the staff at a local prison, creating potential inroads for future delivery of healthcare research.

An early impact has been achieved through the acceptance of the abstract for this project at the 54th Annual Scientific Meeting of the Society of Academic Primary Care (SAPC) in June 2026. Additionally, a related abstract for a prison stakeholder engagement event has been accepted at the Research and Development Forum Conference in May 2026. These represent a valuable opportunity to disseminate findings to national audiences of research and healthcare leaders, highlighting the importance and priority of correctional health research.

The socio-ecological model of barriers articulated in this work provides a structured, evidence-based framework for researchers and policymakers to understand and navigate the correctional healthcare research landscape. The concept of prison-ready research (i.e., methodologically flexible, operationally sensitive, and co-designed with institutional stakeholders) can offer a standard against which future studies can be evaluated. Instead of approaching the prison environment as a uniquely impenetrable setting, future research can draw on the framework to anticipate challenges, devise appropriate methodology, and build the institutional relationships necessary to sustain research activity over time.

It is anticipated that this foundational work will ultimately contribute to increased access to healthcare research for incarcerated populations.

The major challenges encountered during this project were time constraints and delays in obtaining ethical approval. The implication was that the data analysis of the stakeholder workshops could not be completed within the fellowship year.

Insights for Future Applicants

- Embrace the fellowship as a learning opportunity.
- Be pragmatic about what you can feasibly deliver within the year.

NIHR | Applied Research Collaboration East of England

UNLOCK: Breaking Barriers to Prison Health Research

O. POPOOLA[1], M. FARQUHAR[2], C. GARDENER[2], C. SYMMS[1] and S. ENGAMBA[3]
1. NHS Norfolk and Waveney Integrated Care Board; 2. University of East Anglia; 3. Oak Street Medical Practice
Contact: olajide.popoola@nhs.net

Introduction

Despite facing complex illnesses and poorer health outcomes, people in prison are vastly underrepresented in clinical research, creating a critical gap in evidence-based healthcare.[1,2]

Strict security environments and protective regulations unintentionally exclude this vulnerable population from beneficial research.[2,3]

This synthesis identifies multi-level barriers to prison research and extracts actionable strategies.

Aims

Identify barriers to healthcare research delivery in correctional settings.

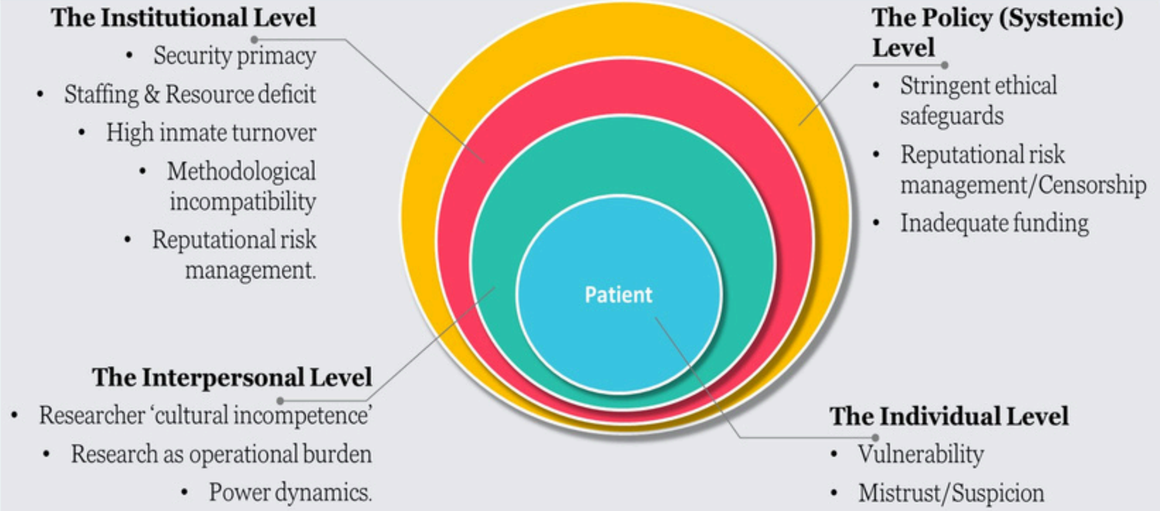
Identify potential solutions to address these barriers.

Method

Systematic Search:
- Reviewed six major databases (2000–2025)
- Identified 16 key studies for inclusion.
- Evaluated the reliability of each study using the Mixed Methods Appraisal Tool.
-10% sample of screening and appraisal independently verified by a second researcher.

Data Extraction: Identified specific barriers and solutions within the studies.

Thematic Analysis: Mapped the barriers and solutions across four levels of a socio-ecological framework: Individual, Interpersonal, Institutional, and Policy.



The Institutional Level
- Security primacy
- Staffing & Resource deficit
- High inmate turnover
- Methodological incompatibility
- Reputational risk management.

The Policy (Systemic) Level
- Stringent ethical safeguards
- Reputational risk management/Censorship
- Inadequate funding

The Interpersonal Level
- Researcher ‘cultural incompetence’
- Research as operational burden
- Power dynamics.

The Individual Level
- Vulnerability
- Mistrust/Suspicion

Fig 1. Barriers: a socio-ecological model

BARRIER CATEGORIES	FEASIBLE STRATEGIES
1. Policy Level	- Paradigm shift: ‘protection by research’ - Review of prison research regulations - Accessible regulatory guidelines
2. Institutional Level	- Methodological flexibility; prison-ready research - Co-design; prioritise institutional needs
3. Interpersonal level	- Stakeholder collaboration; build a team of experts - Identified contact person(s) + communication plan - Development of correctional cultural competence - Promotion of research awareness among correction staff
4. Individual level	- Co-delivery - Consent adaptation i.e. verbal consent, ‘teach-to-goal’

References

1. Ahalt C, Haney C, Kinner S, Williams B. Balancing the Rights to Protection and Participation: A Call for Expanded Access to Ethically Conducted Correctional Health Research. J Gen Intern Med. 2018;33(5):764-8.
2. Wakai S, Shelton D, Trestman RL, Kesten K. Conducting Research in Corrections: Challenges and Solutions. Behav Sci Law. 2009;27(5):743-52.
3. Apa ZL, Bai R, Mukherejee DV, et al. Challenges and Strategies for Research in Prisons. Public Health Nurs. 2012;29(5):467-72.

Acknowledgements

Olajide Popoola and the NHS Norfolk and Waveney Integrated Care Board are supported by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration East of England (NIHR ARC EoE) at Cambridgeshire and Peterborough NHS Foundation Trust. The views expressed are those of the author and not necessarily those of the NIHR or the Department of Health and Social Care.

Adapted Approaches and **Purposeful Partnerships** are feasible strategies for opening doors to life-saving health research within prison settings.

Anu Shaikh

Head of Public Health Evidence and Intelligence
Bedford Borough Council
E: anu.shaikh@bedford.gov.uk

Optimising Data Management & Use To Improve Population Health In Local Authorities: Understanding Public Health Intelligence Leads' Experience And Perspectives In The East Of England

Local authorities in England play a crucial role in improving and protecting health. Public health teams support this by advising social care services and NHS partners and by shaping local strategies. Within these teams, public health intelligence teams provide the evidence needed to understand population health, monitor risks and inequalities, and design and review services.
By understanding the experience of Public Health Intelligence Leads on how data infrastructure and access currently vary across public health intelligence functions in the East of England, the research sets out a clear case for change. It recommends a more joined-up approach, aligned with access to data, secured data platforms, shared data standards, and training on modern analytical tools. Strengthening regional intelligence and analytical quality.

This research explored the real-world experiences of East of England Public Health Intelligence Leads to understand what helps and hinders using data and analytics effectively. Discussions were structured using the Gartner Analytics Maturity Model1, a way of thinking about how close a team is to making the most of its data.

This research matters because good data and intelligence are essential for making fair and effective decisions about people's health and care. Currently, there is very little practical evidence or tested guidance on what 'good' looks like for public health intelligence teams, especially around data systems, data access, data governance and ways of working. By highlighting these gaps, this research builds the case for investment and improvement of public health data infrastructure, so that local and national priorities can be tackled using robust and timely evidence.

Key findings or insights

Public health analysts in local authorities currently work with multiple, often disconnected, data sources; however, the overall data landscape is slowly improving. Teams mainly produce descriptive and diagnostic analyses, reflecting constraints around analytical capacity, skills, and data quality, but there is clear evolution towards more advanced methods and greater data maturity. New data platforms and analytical tools are beginning to strengthen data access and capability in some areas, demonstrating more sophisticated analytics is feasible where the right infrastructure exists.

However, persistent challenges around information governance, data quality, data ownership, workforce upskilling, and technical limitations continue to hinder routine data integration and the wider acceptability and adoption of advanced analytics in everyday public health practice.

The anticipated impacts of this research, if its learnings and recommendations are acted upon, extend across residents, professionals, and organisations, reflecting the system-wide value of improved public health analytics in East of England.

Timely access to data will enable earlier identification of health needs, better targeting prevention initiatives, and more coordinated delivery of care. As duplication of effort is reduced and data flows become more integrated, decision-making will be faster and more consistent across organisations, leading to improved outcomes and greater equity for local populations.
For health and care professionals, strengthened analytical processes will increase confidence in using evidence to inform decisions, foster collaboration across teams, and encourage a culture of continuous learning.

Local Authorities and Integrated Care Boards will benefit from shared infrastructure to access data, standardised reporting, and resource efficiencies achieved through joint working. Collectively, these developments will create more resilient, data-driven systems capable of responding effectively to emerging public health priorities and sustaining improvements in population health outcomes.

The research highlights significant opportunities to strengthen public health analytics in East of England, particularly through improving information governance processes, data access procedures and analytical workforce development.

Further work is required to develop a framework that enables timely and secure access to public health data across organisations. Collaboration between public health intelligence teams, Integrated Care Boards, NHS England, and the Department of Health and Social Care will be essential to refine guidance, streamline approval routes, and reduce barriers to data sharing. Strengthening these processes will enhance analytical capacity, support better decision-making, and ultimately improve population health outcomes.

Challenges and Lessons Learnt

One challenge I faced was having limited time to deliver a project I deeply cared about. It taught me to focus and prioritise the most important parts of my research.
Overall, it was a positive experience, and I am looking forward to the next steps in my research career.

Insights for Future Applicants

Treat the process as a learning journey and be realistic about what you can do within given time.

NIHR | Applied Research Collaboration East of England

The ‘Peak’ of Analytics

Optimising local authority data management and use to improve population health

Anu Shaikh [1], Prof Katherine Brown [2] and Dr Adam P Wagner[3,4]
1 Bedford Borough Council, 2 University of Hertfordshire, 3 University of East Anglia, and 4 NIHR ARC East of England

Introduction

Local authorities in England hold a vital responsibility for improving and protecting public health. Public health teams advise social care services, NHS boards and support development of local strategies (1,2). Within these teams, public health analytics provides the evidence base that informs decisions, monitors risk, tracks health outcomes and inequalities, and shapes services (3).

Amounts of data available and associated stakeholder expectations about its use, are growing rapidly. However, variability in data access, its governance, and infrastructure hinders progress (4).

This research explored Public Health Intelligence Leads’ experiences and perspectives to understand barriers to, and enablers of, better use of data and analytics. Discussions were framed using the Gartner Analytics Maturity Model (3), which provides a structure for understanding how close teams are to utilising data to its full potential.

Aim

To understand experience and perspectives of Public Health Intelligence Leads on barriers to, and enablers of, improving analytics to boost evidence-based decision making in public health.

Method

Qualitative study

Semi-structured interviews
(Conducted online)
Framework: Gartner’s Maturity Model

Public Health Intelligence Leads from local authorities across East of England
(6/10 teams represented)

Thematic Analysis: Braun and Clarke (2006)

Findings

Each barrier removed takes teams closer to analytics excellence!

Barriers

- **Inconsistent data management and poor data quality** "The biggest challenge... is the data, data quality and coding inconsistencies... data quality is probably a priority... some of the local data sets are just not good enough... big barrier... is the data quality."
- **Information governance ambiguity creates delays** "NHS data governance... really difficult to navigate.”
- **Technological fragmentation forces inefficient workarounds** “The local authority, they don’t really have a like a big data platform... there’s no big data platform or anything."
- **Skills shortages demand constant upskilling amid cultural and financial resistance** "There’s sometimes a little bit of resistance ... because... there’s a lot of expectation that we will learn all of these systems and all of this different type of coding."
- **Disconnect in leadership and systems impact data flow** “There’s a whole heap of changes coming up both nationally and locally... For anybody that was ... around in 2012 in public health world when we moved over from NHS, we ...lost all access to data for quite a considerable time and it’s taken us till now to set up those PHM [Population Health Management] solutions.”

Analytics maturity of public health teams

1 Descriptive
What happened?
All teams show strong capabilities in descriptive analytics, including developing dashboards, data visualisation, and reporting

2 Diagnostic
Why did it happen?
Some teams are advancing into diagnostic analytics by using regression models and seasonal variation analysis to understand why and how events occur

3 Predictive
What might happen?
Efforts emerging towards predictive work; machine learning experimentation and forecasting

4 Prescriptive
What should we do?
Teams use minimal prescriptive analytics; limited segmentation/cohort recommendations

Enablers

- **Networks enables knowledge sharing** “Collaboration group, ...Office of Data Analytics ... analysts from the police... lower tier local authorities, from health... meet every couple of months... share knowledge.”
- **Right roles and tools turn barriers into assets** “Not every team gets to have a Data Engineer, and we are in a massively, privileged position to have someone who essentially makes a lot of our access and processing and things like that really efficient.”
- **Raising the value of data and analytics** “Data culture... with our latest chief exec... we’ve definitely come on leaps and bounds... invest some money in infrastructure.” “ Happy that Fingertips [Public health data platform] is getting an upgrade...we rely heavily on that...continued investment in that is important, especially for the API [Application Programme Interface].”
- **Systems integration that offers unified access and promotes joint working** “When they do merge the ICBs [Integrated Care Boards] in April... we will finally access to all this data in one system.”
- **Leadership and management focus on evidence base** “Having strong management support for how we are using data... having people that provide you that clarity on what’s needed.”

Recommendations

1. **Ensure analytical teams are adequately resourced**, with sufficient posts & appropriate skills mix to meet current and future analytical demand.
2. Establish an **Integrated Care System (ICS)-wide analytical collaboration** to create a shared analytics function, standardise tools and methods, and coordinate system-wide insight generation and efficiency savings.
3. **Implement a standardised analyst training** programme to upskill the public health analytical workforce and consistently strengthen analytical maturity across the system.
4. **Create a dedicated data stewardship function** responsible for access & quality assurance of data at source, under a standardised framework.
5. **Standardise processes to address data access and Information Governance (IG)** policy gaps in public health to access & use health data.
6. Create consistent **access to shared data platforms, with standardised permissions and processes**, to enable integration, reduce duplication, and minimise costs.

Acknowledgements

Supervisors:
Prof Katherine Brown, University of Hertfordshire
Dr Adam P Wagner, University of East Anglia and NIHR ARC East of England

Line Manager:
Dr Ian Brown, Bedford Borough Council

NIHR ARC East of England & ARC Fellow colleagues
Bedford Borough Council and Public Health colleagues
East of England Local Knowledge & Intelligence Service (LKIS)
Public Health Intelligence Leads from East of England

References

1. Local Government Association (2025). *Councillors’ guide to local authority public health responsibilities.* [online] Available at: https://www.local.gov.uk/publications/councillors-guide-local-authority-public-health-responsibilities-0.
2. Heath, S. (2014). Local authorities’ public health responsibilities (England). *commonslibrary.parliament.uk.* [online] Available at: https://commonslibrary.parliament.uk/research-briefings/sn06844/
3. Data for Everyone’s Health (2025). *Optimising public health intelligence: challenges, opportunities and ways forward.* Available at: https://www.fph.org.uk/media/evifcwvv/fph-data-for-everyones-health-2025.pdf.
4. Global Institute. (2021). *Building Real-Time Data Infrastructure Into the Heart of Public Health.* [online] Available at: https://institute.global/insights/public-services/building-real-time-data-infrastructure-heart-public-health

Contact Information

Anu Shaikh, Bedford Borough Council (anu.shaikh@bedford.gov.uk)

Disclaimer: Anu Shaikh and Bedford Borough Council is supported by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration East of England (NIHR ARC EoE) at Cambridgeshire and Peterborough NHS Foundation Trust.
The views expressed are those of the author[s] and not necessarily those of the NIHR or the Department of Health and Social Care.

Dr. Anastasia Tew

CPsychiatry Trainee
Hertfordshire Partnership University NHS Trust
E: anastasia.tew1@nhs.net

Best Poster Awards

Eating Disorder Clinicians Perspectives on the Potential Misuse of Glucagon-Like Peptide-1 Receptor Agonists in Adults with Eating Disorders: A Mixed Method Exploration

GLP-1 receptor agonists (GLP-1s) commonly known as Wegovy and Mounjaro have been licensed in the UK for weight loss purposes since 2023. The National Institute for Health and Care Excellence (NICE) recommend their use for weight loss purposes alongside specific BMI eligibility criteria: (i) 35.0 kg/m2 or (ii) 30.0-34.9 kg/m2 and meeting the criteria for a referral to specialist overweight and obesity management services (NICE, 2023). However, individuals not meeting such criteria may be obtaining these drugs and self-medicating inappropriately, especially so in individuals with eating disorders.

Previous research has shown people with eating disorders are known to abuse medication and illicit substances to promote weight loss and in 2023 the Royal College of Psychiatrists Eating Disorder Faculty raised concerns about their abuse potential. However, no published research has yet explored this issue. These concerns come at a time when hospital admissions for eating disorders have increased at an alarming rate. In 2021-2022 there were 29,024 hospital admissions, a 38% increase from the previous year (Ayton, 2024). It is estimated that 1.25 million people in the UK currently have an eating disorder (NICE, 2025). Widespread media coverage involving headlines such as “Ozempic can supercharge weight loss” (The Independent, 2024) and “The miracle weight-loss drug” (The Guardian, 2023) has propagated the popularity of GLP-1 agonists and promoted the belief that anyone can use these medications to obtain their desired body shape and weight. Hence, the rise in both popularity of these drugs and people with eating disorders emphasises the need for research into the extent of their potential misuse.

The research project aimed to assess the frequency, patterns, and risk factors associated with misuse, and to explore the motivations and behaviours behind it. In addition, the study examined eating disorder clinician’s awareness, perceptions and clinical responses to suspected misuse. Questionnaires were sent to eating disorder clinicians across the UK and 10 semi-structured interviews were conducted to explore their perspectives in greater depth. All clinicians had observed eating disorder patients misusing GLP-1s: 6/11 clinicians reported 1-5% patients; 4/11 clinicians reported 6-10% of patients and 1/11 clinicians reported 11-25% of patients. Misuse was observed across broad range of different eating disorder diagnoses. Clinicians reported unregulated access online enabling misuse as patients were able to bypass safeguards by falsifying information such as weights and photos. The misuse of GLP-1s was seen to be an emerging and rapidly increasing issue in the eating disorder population impacting patients treatment and recovery, as well as clinicians feeling a sense of uncertainty with no clear management pathways or national guidelines.

I am aiming to publish this paper by the end of the year. The insights generated from this research could play an important role in raising awareness of emerging concerns surrounding the misuse of GLP-1s among adults with eating disorders, while also contributing to improved clinical understanding of this complex issue. The findings are expected to provide valuable information to better inform the assessment and management of patients with eating disorders, particularly highlighting the potential need for more robust and systematic screening protocols to detect GLP-1s misuse.

Furthermore, the study may offer important insight into whether current eating disorder services feel adequately equipped to identify and manage this growing concern. It could help determine whether there is a need for enhanced clinical guidance, additional support systems, or further training for healthcare professionals working in this area. As the first published study to specifically investigate the misuse of GLP-1s in adults with eating disorders, this research has the potential to make a meaningful contribution to the field. It may also help inform future policy decisions regarding these medications, including considerations around their regulation and supply. During my research fellowship, I also published an opinion piece in The Pharmaceutical Journal titled “The dark side of the ‘miracle jab’: why eating disorder safety cannot be an afterthought” (Anastasia Tew, Chetan Shah, 2026). This article highlighted the importance of thorough eating disorder screening, multidisciplinary oversight, and careful monitoring of GLP-1s to minimise the risk of harm to vulnerable populations.

Challenges and Lessons Learnt

Challenges emerged in recruiting pharmacists to explore perspectives, including cases where patients ineligible for GLP-1s attempted access. Despite sharing study links through professional networks, a published opinion piece, and LinkedIn, only two pharmacists participated. The protocol has been amended to include vouchers, aiming to improve recruitment and encourage more pharmacists to contribute their valuable insights. My advice is “Do not put too much pressure on yourself to complete the project by the end of the fellowship year -my project is still ongoing! “

NIHR | Applied Research Collaboration East of England

Eating Disorder Clinicians' and Pharmacists' Perspectives on the potential misuse of GLP-1 receptor agonists in adults with eating disorders: A Mixed Methods Exploratory Study

Authors, A.TEW [1], C. SHAH [1], S. KUCUKTERZI [1], S. NEUFELD[2]
1 Hertfordshire Partnership University NHS Foundation Trust
2 Department of Psychiatry, University of Cambridge

Introduction

GLP-1 receptor agonists commonly known as Wegovy and Mounjaro, have been licensed in the UK for weight loss purposes since 2023. NICE guidelines recommend their use for weight loss purposes if fulfilling a specific BMI criteria (1).

Concerns have emerged regarding inappropriate access and potential misuse, particularly among individuals with eating disorders, a population already known to misuse weight-loss medications and substances (2-5). Despite warnings from the Royal College of Psychiatrists' (6), research on GLP-1 receptor agonist misuse in eating disorders remains extremely limited, with only a recent case report documenting semaglutide misuse in Atypical Anorexia Nervosa (7). Given rising eating disorder prevalence (8) and increasing media promotion of these drugs, investigation into their potential misuse is urgently needed.

Aim

This study aims to investigate the misuse of newly licensed GLP-1 receptor agonists for weight loss among adults with eating disorders.

The primary objectives are to assess the prevalence, patterns, and risk factors associated with misuse, and to explore the motivations and behaviours behind it. In addition, the study examines health care providers' awareness, perceptions and clinical responses to suspected misuse.

Method

The study adopts a **mixed methods design**, combining quantitative and qualitative items in a **questionnaire** and **semi-structured interviews.**

Participants have been recruited through existing clinical contacts, professional networks and LinkedIn.

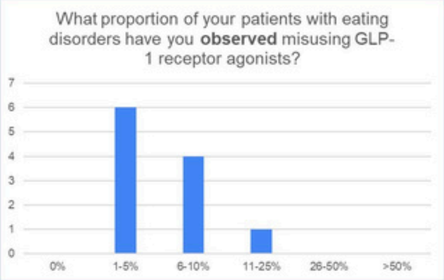
Results

Sample characteristics:

- 11 eating disorder clinicians responded to the questionnaire (4 psychiatrists, 4 psychologists, 1 therapist, 1 GP, 1 specialist nurse)
- 9/11 clinicians worked predominantly in an NHS outpatient ED service, 2/11 clinicians worked predominantly in an NHS inpatient service.
- 1 clinician in London, 3 clinicians in South West of England, 3 clinicians in South East of England, 2 clinicians in East of England, 1 clinician in North East and Yorkshire

Estimated frequency of GLP-1 RA misuse:

- 6/11 clinicians: 1–5% of patients
- 4/11 clinicians: 6–10% of patients
- 1/11 clinician: 11–25% of patients



Clinical Characteristics of Misuse:

Misuse was observed across Anorexia Nervosa, Bulimia Nervosa, Binge Eating Disorder, OFSED and Type 1 diabetes with disordered eating but not in ARFID. Patients were predominantly female and across all age groups 18yrs ->65 yrs. Multiple routes of access observed but frequently brought online and forging medical information.

Clinical Impact:

3/11 clinicians reported patient cases requiring medical admission who were misusing GLP-1 RAs, frequent psychological fixation on GLP-1RAs, unwillingness to stop medications and barrier to accessing eating disorder treatment.


the PHARMACEUTICAL JOURNAL

Monthly edition | News | CPD & Learning | Research | PJ Jobs

Home / Opinion

Mental health

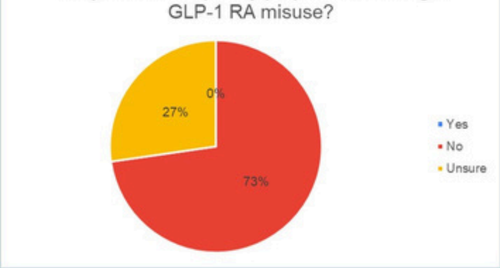
09 February 2026

By Anastasia Tew & Chetan Shah

The dark side of the 'miracle jab': why eating disorder safety cannot be an afterthought

As the use of glucagon-like peptide-1 receptor agonists increases, so must our awareness of patients who have an eating disorder or who are at risk of developing one.

The Pharmaceutical Journal, 9th February 2026, Dr Anastasia Tew and Dr Chetan Shah



Screening and preparedness:

- Routine screening: 8/11 'Yes', 2/11 'No', 1/11 'Sometimes'
- 8/11 clinicians did not feel prepared to manage GLP-1 RA misuse
- 1/11 were unsure about their level of preparedness

Future requirements:

- 100% of clinicians believed national guidelines for managing GLP-1 RA misuse in eating disorders is required
- >70% reported the requirement for training workshops, patient information resources and clinician training was required

Conclusions

- Misuse of GLP-1 RAs is occurring across ED services nationally
- Ease of online access lowers prescribing safeguards
- Drivers include desire for rapid weight loss, medial and societal pressures, "magic pill" narrative, limited understanding of medical risks
- GLP-1 RAs are impacting patients psychologically, physically and their ability to access treatment.
- Clinicians report feeling "unprepared", "unsupported" and "unsure how to manage"
- Lack of clear national guidance and structured screening approaches
- What is needed: national guidelines, clinician training, standard screening, patient education materials on risks and safe use

Acknowledgements

Anastasia Tew, Hertfordshire Partnership University NHS Foundation Trust is supported by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration East of England (NIHR ARC EoE) at Cambridgeshire and Peterborough NHS Foundation Trust. The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

References

1. National Institute for Health and Care Excellence. (2023). Semaglutide for managing overweight and obesity (NICE technology appraisal guidance No. 875). https://www.nice.org.uk/guidance/ta875
2.Geer, B., Gibson, D., Grayeb, D., Benabe, J., Victory, S., Mehler, S., & Mehler, P. (2019). Metformin abuse: A novel and dangerous purging behavior in anorexia nervosa. The International Journal of Eating Disorders, 52(3), 319–321. https://doi.org/10.1002/eat.23010
3.Herzog, D. B., Franko, D. L., Dorer, D. J., Keel, P. K., Jackson, S., & Manzo, M. P. (2006). Drug abuse in women with eating disorders. The International Journal of Eating Disorders, 39(5), 364–368. https://doi.org/10.1002/eat.20257
4. Kontić, O., Vasiljević, N., Jorga, J., Jašović-Gašić, M., Lakić, A., & Arsić, A. (2010). Presence of different forms of compensatory behaviours among eating disordered patients. Srpski Arhiv za Celokupno Lekarstvo, 138(5–6), 328–332. https://doi.org/10.2298/SARH1006328K
5. Sharma, M. P., & Kar, S. K. (2015). Surreptitious metformin abuse in anorexia nervosa presenting as periodic hypoglycaemia. The Australian and New Zealand Journal of Psychiatry, 49(9), 851–852. https://doi.org/10.1177/0004867415584642
6. Royal College of Psychiatrists (2023) 'RCPsych response to the availability of semaglutide treatment in England', *Royal College of Psychiatrists*. Available at: https://www.rcpsych.ac.uk/news-and-features/latest-news/detail/2023/03/09/rcpsych-response-to-the-availability-of-semaglutide-treatment-in-england (Accessed: 18 November 2025).
7. Guerdjikova, A. I., Ward, A., Ontiveros, M., & McElroy, S. L. (2024). Semaglutide misuse in atypical anorexia nervosa—A case report. Journal of Clinical Psychopharmacology, 44(2), 179–180. https://doi.org/10.1097/JCP.0000000000001820
8.National Institute for Health and Care Excellence. (2024). Eating disorders. NICE Clinical Knowledge Summaries. https://cks.nice.org.uk/topics/eating-disorders/

Contact Information

Lead Researcher: Anastasia.tew1@nhs.net

Sarah Thompson

Clinical Lead Specialist Palliative and End of Life Care
Hertfordshire Community NHS Trust
E: sarah.thompson47@nhs.net

Community Nurses’ Experience Of Using An Anticipatory Medication Decision Aid Tool

The emphasis to die at home has never been stronger in policy narratives. Yet often the experience of home deaths is fraught with difficulties and high levels of stress for the patient, their informal carers and health care professionals alike.

Community nurses are autonomous practitioners, often faced with uncertainty when called to administer injectable medication to relieve distressing symptoms during last days of life care. Co-produced with nurses as part of a Masters, I devised a twofold decision aid tool consisting of screening questions to ask the patient ahead of need, seeking permission to involve family members to be more involved in the decision-making process during last days of life care, and an algorithm to support their clinical decision making. My research fellowship explored nurses’ experience of using this tool.

Despite a growing body of national recommendations to recognise and include informal carers more in last days of life care in the home setting, there remains scant empirical research or evidence-based tools that support clinicians to make shared decisions during this crucial period of life. This is pertinent to symptom control, as patients are often too unwell to convey their own wishes and needs, relying on family members to act as advocates, sometimes with limited success. This is burdensome for all involved and can contribute to significant detrimental experiences such as the patient dying with uncontrolled symptoms, leaving loved ones unsatisfied with the care given which in turn negatively affects their bereavement. Complaints made against staff can adversely affect their confidence levels and future willingness to embrace end-of-life care. As a clinical leader, I have faced all aspects of such poor experiences and felt compelled to better the situation for everyone involved.

A fundamental determinant as to the willingness of nurses to administer anticipatory medicines related to the associated perceived risk. There were multiple references to the scariness of giving subcutaneous injections, balanced with a strong desire to “do the right thing.” Influencing factors that shaped nurses’ ability to hold risk were the level of trust they had with family members, together with their own confidence and comfort zones. This correlated to the amount of exposure they had (or hadn’t) experienced giving last days of life care, compounded by the pressures of work and the nurses’ autonomy in the community.

All nurses reported that the tool was useful, both for providing reassuring guidance to aid their confidence but also permission to administer medications. The algorithm provided rationale and was used more than the screening questions.

Its Impact

Most nurses reported they felt better supported to administer anticipatory medications by using the decision aid tool. This could have several potential positive impacts; increased patient empowerment, as the offer to tell staff and family what is important to them during their dying phase regarding symptom control and medication, ahead of need. Community nurses feeling more confident making shared decisions regarding medication administration with informal carers and the patient (if able), contributing to job satisfaction. Informal carers may feel more involved in the decision-making process for their loved one. Repeated call outs to administer medication are also likely to be reduced if anticipatory medications are administered when requested and required, a more cost-efficient way of working to reduce unplanned work pressures. Admissions to the acute setting could be reduced if more patients receive the appropriate symptom management in their preferred place of care, a national priority.

My research was a small, preliminary study. Next steps, already in motion are to replicate the study in other areas to understand its feasibility and to explore the patient and family experience of using the tool. If the results are reproduced and impactful, there is potential to consider validating the tool with a view to embedding it into everyday practice during last days of life care whatever the setting. This could inform future policy, training and ongoing research as it is such a nuanced, understudied area of care.

Challenges and Lessons Learnt

IRAS for ethical approval was a time consuming, repetitive process, however the Health Research Authority staff were extremely helpful, as was my supervisor.

Having previously run focus groups with community nurses to develop the tool, I was not prepared for the difficulty I had during my Fellowship to repeat this, only achieving minimal numbers. Sometimes good is good enough!

Insights for Future Applicants...

Write your application with conviction. Plan well in advance and be prepared for potential curveballs! Take up the offer of meeting the Patient and Public Involvement Panel, they are fab!

NIHR | Applied Research Collaboration East of England

NHS Hertfordshire Community NHS Trust

Community nurses' experience of using an anticipatory medication decision aid tool

Sarah Thompson
Clinical Lead for Specialist Palliative and End of Life Care

Introduction

The emphasis to die at home, away from the acute sector has never been stronger in policy narratives. Yet often the experience of a home death is fraught with difficulties and high levels of stress for the patient, their informal carers and health care professionals alike.

Community nurses are autonomous practitioners and are often faced with uncertainty when called to administer injectable medication to relieve distressing symptoms during last days of life care. A decision aid tool was co-produced with nurses to see if it supported their clinical decision making and foster a more shared decision-making approach, with informal cares during last days of life care.

Aims

1) To understand community nurses' views and experiences of using the decision aid tool.
2) To explore whether the tool fosters a shared decision-making approach when using anticipatory medication.

Method

Using purposive sampling, 24 qualified community nurses with a wide range of nursing experience were recruited to attend a Focus Group, according to their Band.

Semi-structured interviews lasting up to 1 hour explored nurses' experience of using the tool and whether they felt it supported decision making to administer anticipatory medication.

In total,15 Band 5 nurses attended 3 Focus Groups and 9 Band 6's attended a further 3 Focus Groups.

Data was coded using NVIVO, then compared and analysed using Braun and Clarke's reflective thematic analysis.

Results

Data captures nurses from 5 out of the trusts 6 localities.

- All nurses felt the tool was useful and supported their ability to administer anticipatory medicines, even if they were sure/unsure
- The ability to hold risk was an overarching theme and central to decision making
- The tool provides reassurance, guidance, direction and permission
- Trust and building relationships with informal carers was an important factor in nurses' decision making
- Level of experience did not necessarily correlate to the ease/uncertainty of administering anticipatory medicines
- Junior nurses in particular liked the screening questions
- Not all nurses felt comfortable to include/take into consideration the views of informal carers
- A plan ahead of need was deemed agreeable and beneficial to all
- Organisational context is an important factor to consider
- The tool has a role in future education to support nurses


Symptom control plan for last days of life care

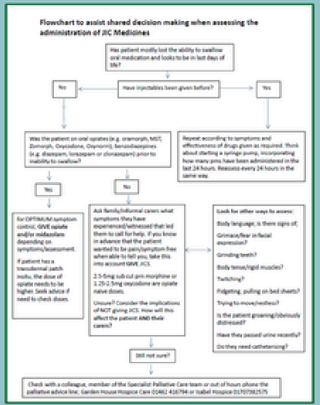
What choices are important to me at the end of life and after my death?

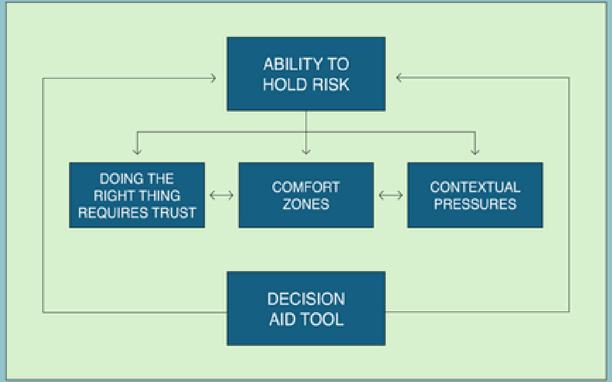
The Choice in End-of-Life Care Programme Board 2015

What worries, concerns do you have (if any) about symptoms such as pain or anxiety at the end of your life?

When that time comes, you might not be able to tell us about your symptoms. Would you like to receive medications we call "just in case" drugs that relieve pain, anxiety, sickness, and respiratory secretions?

If you should become unable to let us know directly about how you are feeling, is there anyone you would like us to involve in making decisions about giving you medication to control your symptoms and help you to be comfortable?


Flowchart to assist shared decision making when assessing the administration of JIC Medicines


ABILITY TO HOLD RISK

DOING THE RIGHT THING REQUIRES TRUST

COMFORT ZONES

CONTEXTUAL PRESSURES

DECISION AID TOOL

Contact Information

Sarah.thompson47@nhs.net

Conclusions

This study has contributed to a deeper understanding of a small number of community nurses' experiences, not only of using the decision aid tool in their practice but also the context within which they need to reach decisions that often do not feel comfortable for them for a variety of reasons.

The ability to hold risk was the overarching theme that determined the ease of clinical decision making and warrants further investigation.

Ongoing education needs to include the decision aid tool to ensure it gets embedded into routine practice and to promote shared decision making with informal carers.

The tool was a helpful resource to use both ahead of need and when called to administer anticipatory medication and fosters shared decision making.

The findings went beyond the decision aid tool. Organisational constraints need to be considered to better support nurses' ability to make informed decisions about whether or not to administer anticipatory medicines.

Next steps

To repeat the research, with further refinement of the tool using a larger cohort of nurses from different organisations to see whether this decision aid can potentially become a validated tool and be implemented more widely into last days of life care.

To also seek to understand the viewpoint and experience of patients and their families when using the tool.

Acknowledgements

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

Huge thanks to Dr Ben Bowers my Supervisor and Hertfordshire Community NHS Trust for sponsoring and supporting my research.

Sarah Turner

Commissioning Manager
Thurrock Council
E: saturner@thurrock.gov.uk

Ageing Without Children (AWoC): No One to Care?

Across England, more older people are ageing without children. This is framed in the context that people who AWoC will require more formal social care to replace the informal support that children often provide. This would result in increased costs for top-tier local authorities.
My fellowship started with an acceptance of this assumption. I had planned to model future demand for Thurrock (eventually enabling this to be replicated across the East of England) by updating the evidence via a scoping review, carrying out a demographic impact assessment on Thurrock's population and projecting the likely cost impact of this change.

Early on, my scoping review suggested that core assumptions might be unstable: health outcomes for older people without children are not consistently worse; the definition of "childlessness" changes the size of the population; and other factors, especially partner status and wealth appear to influence outcomes more than parental status alone.

Some international research suggested that those AWoC may have accumulated more wealth than ageing parents. This forced me to rethink my research proposal.

In England, adult social care is means-tested. If a person has resources, they are free to purchase more hours of home care, enter residential care earlier, and generally choose services that suit them. This means higher usage of formal care may reflect ability to pay, not unmet need.
If we treat parental status as a proxy for need without considering whether this is simply a reflection that they have greater wealth and therefore experience greater autonomy as 'self-funders', we risk incorrect demand models and shaping markets on the wrong assumptions.
For commissioners, we may need to plan for market-shaping and information/advice, rather than assuming a uniform increase in state-funded spend. This reframing is particularly relevant to all top-tier local authorities making medium-term market decisions including regions like the East of England.

Key findings

- Health outcomes: no consistent evidence that older adults AWoC have poorer health; however, bereavement (child predeceases the parent) and involuntary childlessness in men does appear to impact negatively.
- Definitions matter - different definitions of "childlessness" produce very different prevalence estimates, challenging any projections based solely on biological definitions of childlessness (ONS model).
- Heterogeneity: partner status, culture, gender and socio-economics influence outcomes more than parental status alone.
- Wealth & resource exchange: international evidence suggests older adults AWoC may accumulate assets and use property/inheritance strategically for support. In England's means-tested context, this could drive consumer choice and higher usage among self-funders.
- Widely repeated claims around AWoC (e.g., earlier residential entry "by 25%") should be treated cautiously until verification of source.

Impact on people in the East of England

This work helps reframe ageing without children from deficit to sufficiency and challenges stigma. For commissioners and market-shaping leads in the East of England, it encourages modelling that separates need from ability-to-pay. For providers, it signals growth in demand (earlier admission by preference, different home-care patterns) driven by resources rather than lack of family.
For researchers, it highlights the risk of definition error and negative framing. Together, these changes can support more accurate medium-term planning across top-tier local authorities in the region and beyond.

Informing future research, practice, or policy

I propose that ELSA date is reviewed (national data on parental status, wealth/tenure, health and care usage) to see if there is a link between wealth/income/tenure and parental status. If so, Thurrock is well-placed to test the hypothesis: is higher usage primarily need, ability-to-pay or a lack of information and advice to self-funders?

Thurrock is unusual because self-funders access adult social care and council-commissioned markets on an equitable basis to those receiving state funded care. This would reduce biases related to access, advice and gatekeeping. Findings could guide demand models, market-shaping, and Care Act information/advice duties locally and nationally. For this to be explored further I would need to seek collaboration with a social care/health economist and experienced research supervisor to examine the effects of wealth/tenure on outcomes/usage.

Challenges and Lessons Learnt

The main challenge was recognising that my original plan rested on potentially unstable assumptions. I chose to pause modelling to avoid drawing confident, but wrong, conclusions.

> Don't be afraid to change course. Follow the findings, not your original application!

NIHR | Applied Research Collaboration East of England

Ageing Without Children: No One to Care?

Older adults without children may use formal care not because they lack support — but because they can afford to.

S. Turner, NIHR Research Fellowship, ARC East of England (Employer: Thurrock Council)
Supervisor: Dr Aaron Wyllie, University of Essex

Introduction

Rising numbers of people in England are Ageing Without Children (AWoC). The prevailing assumption is that this will create additional demand for state-funded social care (ONS 2020). My fellowship began with the expectation that childless older adults would require more formal care, increasing costs to local authorities. However, early findings challenged this assumption and prompted a re-examination of this as the 'starting point'

Aim

Revised aim: To better understand the relationship between childlessness and formal care utilisation, through identifying current evidence gaps and identify whether suitable data exists to test the hypothesis that increased formal care usage among AWoC reflects primarily an ability to pay rather than parental status.

Method

- Reviewed ONS 2020 findings on AWoC and care use.
- Conducted a scoping review of 40 peer-reviewed articles (2010-2025).
- Thematically analysed evidence on definitions of childlessness, health, wealth/resource-exchange, care usage, and policy context.
- Assessed implications for demand modelling within England's means-tested adult social care system.
- Identified data sources to test hypotheses: ELSA (national) and Thurrock (local).

Results

1. Health Outcomes

No consistent evidence that AWoC have worse health outcomes than parents, except in cases where children had predeceased them.

2. Definitions Matter

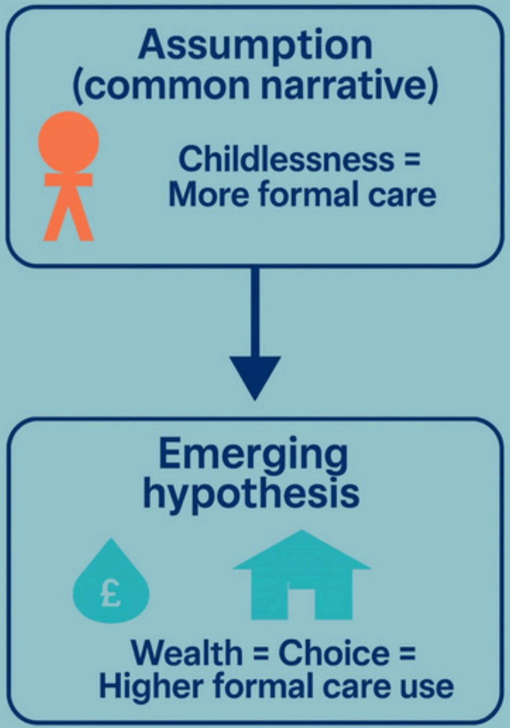
Definitions of childlessness vary widely, significantly altering estimated population size and interpretation of findings or potential demand.

3. Wealth and Resource Exchange

Wealth emerged (alongside partner status) as a protective factor. International research suggests AWoC may accumulate more assets and leverage these for support (resource-exchange strategies).

4. English Policy Context

In England, self-funders can purchase more care, enter residential care earlier, and bypass local authority gatekeeping — meaning higher usage may reflect choice or sufficiency rather than a lack of informal support options. This may indicate that increased usage of formal support is an autonomous choice.



Assumption (common narrative)

Childlessness = More formal care

Emerging hypothesis

Wealth = Choice = Higher formal care use

Conclusions

- AWoC = higher future demand does not necessarily imply higher state-funded costs.
- Higher formal care use among AWoC could be driven by ability to pay, not parental status.
- Demand-modelling risks relying on untested assumptions and should incorporate wealth, tenure, and partner status.

Next Steps

- Combine ELSA (national) and Thurrock (local) datasets to test whether higher usage reflects need or ability to pay.
- Collaborate with a health economist to model net effects and sensitivity to wealth/tenure.

Possible Policy Implications (English Upper Tier Authorities)

- Prioritise market-shaping for self-funders alongside statutory provision.
- Strengthen information, advice, and brokerage to enable informed consumer choice.
- Develop models that distinguish need versus ability-to-pay effects on usage.
- Reframe public communications: from 'burden' to 'active consumer'.

Acknowledgements

Sarah Turner (Thurrock Council) is supported by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration East of England (NIHR ARC EoE) at Cambridgeshire and Peterborough NHS Foundation Trust. The views expressed are those of the author and not necessarily those of the NIHR or the Department of Health and Social Care.

References

A reference list is available upon request.

Contact Information

SAturner@thurrock.gov.uk

Impact Fellows

> **The fellowship has upskilled professionals from over 70 organisations across the region, enabling them to apply research knowledge in their roles and organisations.**

Nancy Burridge

Clinical Nurse specialist, Palliative Care Team.
Cambridge University Hospital Trust.
E: nancy.burridge2@nhs.net

NHS
Cambridge
University Hospitals
NHS Foundation Trust

Making Virtual Reality, Reality At Cambridge University Hospital Trust
A Knowledge Mobilisation Research Project To Support The Implementation Of Virtual Reality (VR) At CUH For Patient And Service Benefit

Why Virtual Reality in Healthcare Matters

Through first-hand experience, I recognise benefits Virtual Reality (VR) can offer in healthcare. My journey began in 2020, when I led a service evaluation for the palliative care team at CUH, exploring the impact of a short VR experience on pain and anxiety. Results were compelling: Mean pain reduced by 29% and anxiety by 40%.

With support from my supervisor, Dr Simon Etkind, I presented the findings at the Palliative Care Congress in 2023. This led to a short report in the BMJ Supportive & Palliative Care and opportunities to present locally and nationally. These experiences strengthened my understanding of how VR can improve patient experience and yet despite growing evidence, VR remains underused in practice.

Raising the question: why does such a simple, proven intervention face significant adoption barriers in healthcare? Having introduced VR into clinical services myself, I am acutely aware of practical start-up and sustainability challenges and am passionate about sharing knowledge to support wider implementation of VR at CUH.

Fellowship Motivation and Training

This motivation led me to pursue the ARC East of England Research and Impact fellowship, to understand more about impact science and knowledge mobilisation research. The training was invaluable, connecting me with peer fellows, expert speakers, and my second supervisor from Health Innovation East, Ben Jackson. It provided a strong foundation for my project, introducing principles and tools such as logic models, Gantt charts and stakeholder maps. Learning theories and models helped me understand facilitators and barriers, essential for sustainable integration of evidence into practice.

My overarching aim was to gauge interest in VR use at CUH and co-develop learning resources to support uptake in other clinical specialties.

Survey and Stakeholder Engagement

I began by designing and distributing an information-gathering survey across CUH using the JISC platform. With guidance from my supervisors, Nursing, Midwifery and Allied Health Professional (NMAP) research lead, Alex Malyon and CUH communications team, it was successfully launched in June last year.

Survey responses showed enthusiasm for VR use and highlighted a need for accessible educational resources. Building on this, I held stakeholder meetings and connected with the ARC Public Involvement Hub. Discussions were insightful and instrumental in shaping the direction and content of learning materials. There was clear excitement about VR— What it looks like, how it works, and where it could be used in hospital and community settings. Barriers were also raised, including time, cost, safety, and accessibility of equipment.

Development of Learning Resources

Feedback suggested learning pages hosted on the hospital intranet, CUH CONNECT would be the most accessible and sustainable approach.

I am now developing CUH CONNECT pages entitled:
"Have you thought about how VR can support your service?"
Planning to go live in Spring, they include:

- An overview of VR
- A summary of supporting evidence
- Case studies
- A practical guide to getting started

Content was designed to be easy to navigate, using images, links and key points, whilst avoiding dense text and over-long instructions. Each page is supported by a short video, produced with the help of Nardine and Katie in the CUH communications team, to enhance engagement.

Building a Community of Practice

I have learned through collaboration and shared experience we can achieve more. I have now established a community of practice around VR at CUH and am working with colleagues on specialty-specific projects. I am particularly proud of this and hope it will help ensure the longevity of the work from the fellowship. As one colleague reflected:

> *"The community of practice makes me feel hopeful that we can move towards integrating technologies more easily for our patients to improve their symptoms and experience."*
> *- Dr Rebecca Rous, Psychologist*

Future Directions

Next steps are to create a trust wide Standard Operating Procedure (SOP) and secure organisational support. Discussions with my divisional lead and the Digital team have been positive, with clear interest in exploring how VR can be supported at scale.
Questions remain about equipment and providers with no quick fix. However, I am optimistic that ongoing dialogue will enable CUH to pioneer digital technology for patient and service benefit.

> *I am proud of achievements during the 12-month ARC fellowship. It's difficult to capture everything I have learned, but it has been a truly rewarding and enriching experience both personally and professionally. I am hugely grateful to NIHR ARC East of England for this amazing opportunity, my supervisors, Ben Jackson and Simon Etkind; Support from CUH; the Palliative Care team and PeliCam.*
> *This has been an incredible journey and as it ends, I feel another is just beginning - Thankyou!*

NIHR | Applied Research Collaboration East of England

Health Innovation East

Making Virtual Reality, Reality at Cambridge University Hospital!
A knowledge mobilisation research project to support the uptake of Virtual Reality, for patient and service benefit

Author: Clinical Nurse Specialist Nancy Burridge, Palliative Care Team, Cambridge University Hospital Trust
(nancy.burridge2@nhs.net)
Supervised by Palliative Care consultant, Dr Simon Etkind, CUH and Senior Advisor, Ben Jackson, Health Innovation East.

Key Message

Evidence shows VR is effective in health care, so now is an optimal time to mobilise knowledge for implementation in practice

Introduction and Background

Virtual Reality

Virtual Reality is a computer-generated audio, visual simulation of a 3-dimensional environment, which is immersive and responsive to an individual's movement.

How it works

It is a simple non-invasive alternative therapy option for symptom management, that works by means of distraction and immersion.

What we know

Evidence has shown VR has had consistent positive outcomes for patients resulting in reduced pain and anxiety scores(1,2,3)

Why is it important

Despite evidence VR is not widely used or accepted. Implementation into practice has proved challenging and difficult.

Aims

- Explore interest for expanding VR use at CUH
- Learn about existing knowledge
- Address barriers preventing implementation in practice
- Create useful learning resources to encourage uptake of VR at CUH

Methods

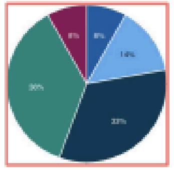
Jisc

- **Phase 1:** Information gathering survey, distributed across CUH Trust, via communications team, NMAP research group & professional contacts
- **Phase 2:** Stakeholder workshops and development of a community of practice
- **Phase 3:** design and production of educational resources

Phase 1: Survey Findings

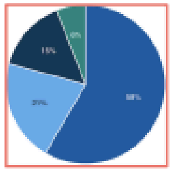
- Comprised of 8 questions (examples below)
- Total of 36 responses
- 15 people provided personal contact details.
- 77% highlighted limited knowledge of VR use in health care
- 86% wanted to learn more
- 79% Highlighted educational resources would be helpful

Q. How would you rate your understanding of VR use for symptom management in health care?



- Excellent - 8%
- Good – 14%
- Average - 33%
- Poor – 36%
- Nothing – 8%

Q. Would a pack of educational resources be helpful to support use of VR in your clinical service?



- Very helpful - 58%
- Quite helpful - 21%
- Not very helpful – 15%
- Not helpful at all – 6%

Phase 2: Activities and Community of Practice

- Stakeholder meetings revealed strong interest in VR, clinical opportunities, inclusivity needs, and enthusiasm for structured learning and a Community of Practice.
- Professional discussions provided insights into VR use in other Trusts and clinical settings.
- Public Involvement Hub meeting offered valuable perspectives and new ideas.
- Association for Palliative Medicine Technology and Digital Innovation forum aligned with the knowledge mobilisation project.

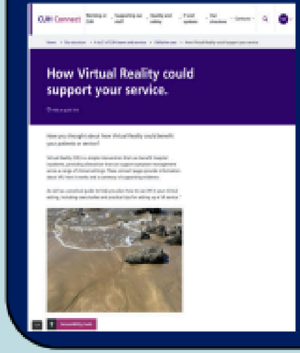
Community of Practice

"The community of practice makes me feel hopeful that we can move towards integrating technologies more easily for our patients to improve their symptoms and experience"

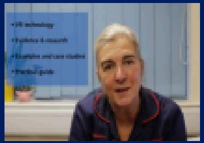
Phase 3: Resources

Connect Pages content:

1. How VR could support your service
2. What is VR
3. Why does VR work - Evidence and Impact
4. VR equipment and potential providers
5. How to implement VR – A guide!
6. Opportunities to support VR innovation
7. A community of Practice in VR



How Virtual Reality could support your service.



To watch one of our videos scan QR code.

Future steps

- Finalise & launch CONNECT pages
- Monitor & evaluate user feedback
- Continue quarterly VR Community of Practice meetings
- Complete SOP to ensure governance & safety
- Strengthen engagement with department leads to secure Trust "buy-in" and long-term sustainability

References:
1. Burridge N, Sillence A, Teape L, *et al*
Virtual reality reduces anxiety and pain in acute hospital palliative care: service evaluation
MJ Supportive & Palliative Care 2025;**15**:387-390.
2. Teh, J.J., Pascoe, D.J., Hafeji, S. *et al.* Efficacy of virtual reality for pain relief in medical procedures: a systematic review and meta-analysis. *BMC Med* **22**, 64 (2024). https://doi.org/10.1186/s12916-024-03266-61.
3. Viderman D, Tapinova K, Dossov M, Seitenov S and Abdildin YG (2023) Virtual reality for pain management: an umbrella review. *Front. Med.* 10:1203670. doi: 10.3389/fmed.2023.1203670R

NHS Cambridge University Hospitals NHS Foundation Trust

UNIVERSITY OF CAMBRIDGE

PELiCam Palliative & End of Life Care in Cambridge

Nancy Burridge and Cambridge University Hospital have been supported by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration East of England (NIHR ARC EoE) at Cambridgeshire and Peterborough NHS Foundation Trust. The views expressed are those of the author and not necessarily those of the NIHR or the Department of Health and Social Care.

Joanne Clark

Advanced Occupational Therapist, Critical Care
Cambridge University Hospitals NHS Foundation Trust
E: joanne.clark22@nhs.net

Co-Designing Training And Support Materials To Increase Use Of Structured Sensory Stimulation Programmes Following Brain Injury

Moderate-to-severe brain injury commonly leads to a disorder of consciousness (DoC), reducing awareness of the external environment for weeks or months and requiring prolonged rehabilitation. Structured sensory stimulation programmes (SSSPs) can support recovery, particularly when delivered early and involving family members. However, use of SSSPs in acute settings is inconsistent, and family engagement is limited. Families report wanting to participate in care, while staff highlight a lack of knowledge, confidence and accessible resources to guide safe delivery and support family involvement. This variability in SSSP use and family participation is seen across the East of England and contributes to inequitable care. A structured, accessible training programme is therefore needed to support staff and enable consistent, family-inclusive stimulation.

Improving consistenc in sensory stimulation is important because emerging evidence shows that structured, emotionanlly meaningful sensory stimulation can improve levels of consciousness after brain injury, particuly when delivered by family members. However, staff often lack training, time, or suitable materials, and the absence of prescribed programmes detailing dosage and format undermines routine use. A COM-B analysis identified key barriers: limited capability (knowledge, skill, confidence), restricted opportunity (time, resources, enabling materials), and fluctuating motivation (competing priorities and limited reinforcement). Addressing these barriers is essential for improving care quality, patient outcomes, and family wellbeing. Families involved in co-design emphasised that having a clear role reduced helplessness and enhanced emotional connection.

Ensuring that sensory stimulation is implemented consistently across the East of England directly supports national priorities for early rehabilitation, personalised care, and meaningful family involvement. Creating co-produced, accessible training and technique materials provides a realistic and impactful way to embed evidence-informed practice into acute neuro-critical care settings.

Key findings or insights

The co-design work revealed strong enthusiasm from both staff and family members to improve consistency of SSSP delivery. Nine staff members and ten family members joined the co-design activities, representing a wide range of experiences. Participants highlighted practical needs such as simple documentation tools, sensory kits, bedside signs, visual technique sheets, and a clear training structure. Co-design produced a four-tier staff training framework—ranging from general awareness to advanced, role-specific competencies—and a two-level family training offer, including one-to-one instruction and safety guidance. Materials were iteratively refined through testing in clinical practice, with improvements such as colour-coding and simplified language. Early feedback indicated high acceptability: family members described feeling empowered, while staff reported that the materials were accessible and ready for implementation.

Impact on people in the East of England

The project provides a practical, evidence-informed route to improving care for patients with a DoC across the East of England. The new multi-tier training structure enhances staff capability and confidence, addressing previously identified barriers and supporting more consistent delivery of SSSPs. Family members now have invitation and structured opportunities to participate, supported through clear technique sheets, sensory kits, bedside signage, and straightforward documentation forms. This involvement has the potential to reduce feelings of helplessness, increase emotional connection, and enhance wellbeing during a difficult experience.

For patients, increased consistency of sensory stimulation may support earlier improvements in consciousness and reduce the duration of DoC. Staff and families who trialed materials expressed enthusiasm and readiness for implementation. The outputs are already informing a phased roll-out at Addenbrooke’s Hospital, with the potential for wider dissemination regionally. This work improves alignment with national guidelines and strengthens the early neuro-rehabilitation pathway.

Informing future research, practice, or policy

The co-designed resources form a strong foundation for future implementation research. Planned next steps include evaluating the impact of training on staff behaviour, assessing consistency of SSSP delivery, and exploring effects on patient outcomes and family wellbeing. The structured training levels, competency documents, sensory kits, and documentation tools also provide a replicable framework for other acute services. The project enhances organisational readiness for a future PhD study investigating SSSP effectiveness. The methods and outputs may inform wider policy discussions about embedding family involvement and early rehabilitation in acute neurological care across the region.

Challenges and Lessons Learnt

Recruiting diverse family members required flexibility and emotional sensitivity. Wide geographic spread and differing preferences meant using varied communication methods rather than a single workshop. Co-design emphasised iterative testing, accessible language and adaptable formats. Staff time pressures highlighted the need for simple, ready-to-use materials, while structured, phased training proved essential for embedding new practices sustainably.

Insights for Future Applicants

Make full use of training seminars, allow extra time for each stage, keep the project small and achievable, and build gradually.

CO-DESIGN TO INCREASE CONSISTENT USE OF SENSORY STIMULATION AFTER BRAIN INJURY

Joanne Clark [a]
Dr Katherine Deane [b], Dr Jyothika Kumar [c], Dr Virginia Newcombe[a,d]
[a] Cambridge University Hospitals NHS Foundation Trust (CUH) [b] University of East Anglia [c] Health Innovation East [d] University of Cambridge

Background

- Moderate-to-severe brain injury can cause a disorder of consciousness [1]
- Structured sensory stimulation programmes (SSSP) can improve recovery, especially with family involvement [2,3]
- Current practice inconsistently uses SSSP and rarely involves family members [4]
- Barriers and enablers to use of SSSP analysed using COM-B and Behaviour Change Wheel model [5]

Co-Design Group Participants

- 9 staff members with experience of patients with a disorder of consciousness (DoC) were recruited via posters/email
- Staff represented therapy and nursing staff and registered/non-registered staff
- 10 family members were recruited via email to relevant PPIE groups - all self-identified as having had a family member with a DoC

Co-Design Process

Preparation

- Stakeholder analysis
- Recruit co-design group members

Gather experiences

- Informal discussions with family members
- Survey of staff members

Generate ideas

- Staff workshop
- Family members discussions online, emailed and posted information

Test and amend

- Iterative changes by group members
- Family materials tested in clinical practice with minor amendments
- Staff training tested & amended

Key Outputs

Family training

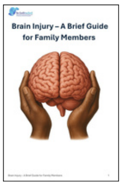
Level 1 -

General information and invitation for training in SSSP


Inviting You to Take Part in Training to Help with Rehabilitation

If you would like to:
- Take part in the rehabilitation of your loved one
- Receive one-to-one training
- Learn how to use a simple structured sensory stimulation programme

Ask to speak with an Occupational Therapist


Brain Injury – A Brief Guide for Family Members

Level 2 -

One-to-one instruction;

- techniques
- health & safety
- challenging behaviours
- documentation

Staff training

Level 1 -
General awareness training

Level 2 -
How to carry out a SSSP and support others with this

Level 3 -
How to carry out standardised assessment

Level 4 -
How to devise an individualised SSSP and teach levels 1/2

Technique Sheets

Step-by step guides:

Colour-coded for sensory area

Simple colour pictures

Brief descriptions


Visual Stimulation – Static Objects/Images

Step 1 Hold the object/image arm's length in front of their face for a count of 3.

Step 2 Stop. Slowly count to 10.

Step 3 Move the object/image to the upper left side for a count of 3.

Step 4 Stop. Slowly count to 10.

Step 5 Move the object/image to the lower left side for a count of 3.

Step 6 Stop. Slowly count to 10.

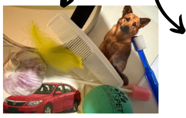
Step 7 Move the object/image to the upper right side for a count of 3.

Step 8 Stop. Slowly count to 10.

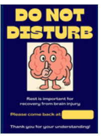
Sensory Kit

Items foreachsensory area:

e.g. personalised visual cards, bell, comb, feather, crushed garlic



Bedside signs:


DO NOT DISTURB

Rest is important for recovery from brain injury

Please come back at:

Thank you for your understanding!

Documentation forms

Simple form to record what stimulation was used and what responses were seen


Record of behaviours observed during Structured Sensory Stimulation Session

Feedback so far...

Family member:
"It's so good to have something I can do to help. The technique sheets are really easy to follow".

Staff member:
"I really look forward to putting this into practice - it's going to be so useful"

Next Steps

Phased implementation plan for 2026 underway.

Future plans for research looking at
- Effectiveness of training programmes in increasing use of SSSP
- Impact on family members of participating in delivery of SSSP

Thanks go to the Co-design Working Group, NIHR ARC EoE PPIE Hub, and NIHR HealthTech Research Centre - Brain Injury

Joanne Clark is supported by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration East of England (NIHR ARC EoE) at Cambridgeshire and Peterborough NHS Foundation Trust. The views expressed are those of the of the author(s) and not necessarily this of the NIHR or the Departmetn of Health and Social Care.

References

[1] Edlow BL et al. Recovery from DoC: mechanisms, prognosis and emerging therapies. 2021. DOI:10.1038/s41582-020-00428-x
[2] Weaver JA et al. Interventions facilitation recovery of consciousness post-TBI: systematic review. 2023. DOI:10.1177/15394492221117779
[3] Zuo J et al. The effect of family-centred sensory and affective stimulation on comatose patients with traumatic brain injury: a systematic review and meta-analysis. 2021. DOI:10.1016/j.ijnurstu.2020.103846
[4] Clark J. Brain injury rehabilitation in acute care - are we stimulating enough? 2025. Unpublished manuscript. https://www.researchgate.net/publication/389154633
[5] Michie S, van Stralen MM, West R.. The behaviour change wheel: a new method for characterising and designing behaviour change interventions.2011, 23:6:42. Doi:10.1186/1748-5908-6-42

Laura Cottrell

Advanced Practice Physiotherapist
Cambridgeshire Community Services NHS Trust
E: *laura.cottrell2@nhs.net*

NHS
Cambridgeshire
Community Services
NHS Trust

Working Collaboratively To Manage Complexity In Musculoskeletal Care: Implementing Musculoskeletal Community Appointment Days Within Cambridgeshire

Musculoskeletal (MSK) conditions frequently exist alongside other co-morbidities including poor cardiovascular health and mental health conditions. These conditions can both cause or exacerbate each other. Risk factors such as high body mass index (BMI), mental health conditions and low levels of physical activity also exacerbate the impact of both MSK pain and coexisting chronic conditions [1]. This leads to increased treatment burden for patients and more frequent use of health services [2].

Community appointment days are an innovation first trialed by MSK services in Sussex in 2023[3]. The initiative integrates local healthcare (MSK physiotherapy services, mental health support services, blood pressure and BMI checks) and local, relevant charity sector organisations (e.g. Active Fenland, Cambridge active lifestyles, healthy you, talking therapies) in one place giving patients and clinicians the opportunity to address complex coexisting issues holistically. A ‘what matters to you’ conversation with an MSK clinician on arrival helps guide which areas of the CAD could help address patient’s individual needs. A printed patient passport is provided to all attendees, as a personal record of advice, information and actions following attendance at the CAD.

My project aim was to co-design, implement and evaluate community appointment days in Cambridgeshire. In total 3 community appointment days have now been delivered by Dynamic Health MSK service in 3 different locations (Peterborough, March and Cambridge).

> *My advice is to...*
>
> *Give it a go and apply! The ARC East of England Impact Fellowship has provided an excellent opportunity for developing skills and knowledge in stakeholder engagement, coproduction, knowledge mobilisation and behavioural change. It provides time and space to implement this learning within a real world setting alongside access to a strong support network of academic and innovation expertise.*

Its Impact

A total of 378 patients who were on the physiotherapy waiting list have now attended a Community Appointment Day across 3 venues in Cambridgeshire. Locations of each CAD have been selected carefully considering the following factors:

- Areas of high deprivation index
- High incidence of MSK conditions
- High incidence of co-existing long term conditions[4]
- High local waiting times for MSK services

Attendees have had support from MSK physiotherapists, rehab instructors, MSK advanced practice clinicians, weight management services, talking therapies, local exercises professionals and other charity partners. Early evaluation of patient satisfaction with CADs has been high (>96%). There has also been positive feedback from service delivery leaders, staff and community partners.

A focus group of 8 participants on the MSK physiotherapy waiting list was held after the first CAD to co-produce and refine the patient passport and identify which local services could be invited to the event. A post attendance survey was given to all attendees with 2 further in-depth interviews carried out with attendees from the second CAD which aimed to gain more insight into how acceptable the CAD was to users and whether it had any impact on their broader health needs or utility of local services.

CADs provide excellent potential to address comorbidities and complexity with presence of community services, but further research and evaluation is needed to explore longer term impact of this on patient outcomes on both MSK and coexisting conditions and service utilisation. The CAD model has excellent potential for scalability and further reach. I have taken opportunities to share learning with MSK clinical leaders from other MSK services in the East of England and also clinical leaders in other specialties. This was met with enthusiasm and discussion about potential for applying an adaptation of the CAD model to other clinical areas.

Challenges and Lessons Learnt

The year goes very quickly and it is a challenging time frame in which to implement, evaluate and measure impact of a new practice. Engaging stakeholders, obtaining and evaluating feedback, coordinating meaningful patient and public involvement, all while also balancing clinic work has been challenging. It has been important to remain organised, motivated and persistent as well as keep clear boundaries between clinical and fellowship time. The regular action learning sets embedded throughout the fellowship proved invaluable in helping overcome obstacles and develop strong peer support. All in all, the fellowship has been extremely rewarding and a brilliant opportunity for professional development.

References

[1]Tushingham, S., et al. (2024). The prevalence and pattern of comorbid long-term conditions with low back pain and osteoarthritis in low-and middle-income countries: a systematic review and meta-analysis. International Journal of Health Promotion and Education, 1-25.
[2] Duffield, S. J., et al. (2017). The contribution of musculoskeletal disorders in multimorbidity: implications for practice and policy. Best practice & research clinical rheumatology, 31(2), 129-144.
[3] https://fingertips.phe.org.uk/profile/msk/data#page/1/gid/1938133186/pat/15/par/E92000001/ati/501/are/E07000010/iid/94210/age/164/sex/4/cat/-1/ctp/-1/yrr/1/cid/4/tbm/1
[4] https://hereweare.org.uk/app/uploads/2024/10/20240808-Sussex-MSK-Partnership-Community-Appointment-Days_Evidence-review-evaluation-FINAL3.pdf

NIHR | Applied Research Collaboration East of England

Health Innovation East

DynamicHealth

Implementing a musculoskeletal community appointment day in Cambridgeshire

Laura Cottrell, Advanced Practice Physiotherapist, Dynamic Health MSK service, Cambridgeshire Community Services NHS trust (CCS)
Impact Supervisor: Jyothika Kumar, Health Innovation East
Academic Supervisor: Kathryn Mares, University of East Anglia

Background

- Musculoskeletal (MSK) conditions frequently coexist with chronic health conditions including poor cardiovascular health and mental health conditions. These conditions can both cause or exacerbate each other. Risk factors such as high body mass index (BMI) and low levels of physical activity also exacerbate the impact of both MSK pain and coexisting chronic conditions (Tushington et al., 2024).

- Community appointment days are an innovation first trialled by MSK services in Sussex in 2023. The initiative integrates local healthcare (MSK physiotherapy services, mental health support services, blood pressure and BMI checks) and local charity sector organisations (local opportunities to engage in physical activity, social support) in one place giving patients and clinicians the opportunity to address complex coexisting issues holistically.

- A 'what matters to you' conversation with an MSK clinician on arrival helps guide which areas of the CAD could help address patient's individual needs. A printed patient passport is provided to all attendees, this is the record kept in their patient notes but is also theirs to keep, acting as a personal record of advice, information and actions following attendance at the CAD.

- CCS' MSK service hosted it's first CAD in March 2025 in Peterborough, funded by additional waiting list initiative funding.

Project aims

- To implement further CADs in Cambridgeshire so that those on the MSK physiotherapy waiting list can be offered this model of care as an alternative to routine 1:1 physiotherapy appointments

- To work with local communities and local organisations to tailor CADs to the needs of local population.

Methods

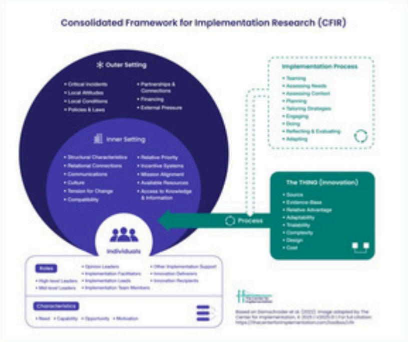
Guided by Consolidated framework for implementation of research

- *Assessing need:* Careful selection of location for CAD based on area with high deprivation index and high levels of coexisting MSK and long-term conditions.

- *Engaging*: Training delivered to MSK team on CAD model and delivering 'What matters to you' conversation.

- *Adapting*: Focus group of 8 participants held in local community to codesign the patient passport and ascertain which services would be beneficial to local community.

- *Evaluating*: Survey feedback from 49 attendees and 2 x 1:1 post attendance interviews conducted.



Implementation and outcomes

- CAD delivered in Fenland area on 22nd October 2025
- 93 attendees
- Attendees could access MSK healthcare alongside advice and support from community partners: *Age UK, Active Fenland, Healthy You, Workwell, Talking therapies*

Survey feedback (49 responses)

96% of respondents rated the day as **good or very good**

98% strongly agreed or agreed that they had been **treated with dignity and respect**

"Everyone helpful and loved the fact you could see specialists straight away"

"Great conversations and polite staff"

"Smoothly run, no issues. Got to see everyone needed in one go and leave fully sorted."

"Great communication and very welcoming. Great help and advice"

"Excellent idea"

Next steps

- Next CAD is taking place next week in Cambridge

- Potential for further and more in-depth research – does this model aiming to provide collaborative care delivery, truly help people understand, address and manage their coexisting MSK and chronic conditions?

References

https://hereweare.org.uk/app/uploads/2024/10/20240808-Sussex-MSK-Partnership-Community-Appointment-Days_Evidence-review-evaluation-FINAL3-1.pdf

Tushingham, S., Cottle, J., Adesokan, M., Ogwumike, O. O., Ojagbemi, A., Stubbs, B., ... & Babatunde, O. O. (2024). The prevalence and pattern of comorbid long-term conditions with low back pain and osteoarthritis in low-and middle-income countries: a systematic review and meta-analysis. *International Journal of Health Promotion and Education*, 1-25.

Acknowledgements

Laura Cottrell and her project on behalf of Cambridgeshire Community NHS Trust is supported by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration East of England (NIHR ARC EoE) at Cambridgeshire and Peterborough NHS Foundation Trust. The views expressed are those of the author and not necessarily those of the NIHR or the Department of Health and Social Care

Molly Garfoot

Specialist Speech and Language Therapist
Cambridge University Hospitals NHS Foundation Trust
E: molly.garfoot2@nhs.net

NHS
Cambridge University Hospitals
NHS Foundation Trust

Best Poster Awards

Mouthcare Matters: A Service Improvement Project To Investigate & Improve Oral Care Practice For Older Adult Inpatients At Addenbrookes Hospital

Research in the UK indicates that patients in hospitals and care facilities often do not receive consistent or adequate support with oral care. Admission to hospital can lead to a decline in oral hygiene, particularly among older adults, those nearing end of life, and individuals who rely on others for assistance. Previous studies suggest that nursing staff may not prioritise oral care due to competing demands. There are also reported gaps in knowledge, limited access to training, and inconsistent availability of appropriate equipment. These factors contribute to variability in mouthcare practices experienced by patients.

Poor oral hygiene in hospital inpatients can result in serious health complications, including hospital-acquired pneumonia, dehydration, and weight loss. It may also reduce patients' willingness to communicate with others or participate in social activities such as mealtimes, negatively affecting mood and overall quality of life. These issues can lead to increased mortality rates, longer hospital stays, physical deconditioning, and extended rehabilitation periods. Patients may also experience increased anxiety and stress. From an organisational perspective, poor oral hygiene contributes to higher financial burden, reduced patient flow, and limited bed availability.

Key findings or insights

A survey of 80 registered and non-registered nursing staff working on care of the elderly and stroke wards at Addenbrooke's Hospital corroborated findings from existing research. Key barriers to providing mouthcare included lack of time and insufficient training, with 59% of staff reporting they had never received formal training. Inconsistencies were also found in the use of appropriate mouthcare tools and in documentation practices. Staff reported the lowest confidence when assisting patients who were confused or agitated.

Initial bedside audit and survey of 83 inpatients identified several areas for improvement, including limited availability of mouthcare tools, inconsistent documentation, and challenges with denture care. These findings informed the development of a targeted training intervention.
In-person training was delivered to 21 staff members from 2 care of the elderly wards, alongside a visual, ward-based training package to increase awareness among wider staff. All staff who attended the training reported improved confidence in providing mouthcare, most notably with confused patients ("very confident": pre-training - 4.8%; post-training - 47.6%) and end of life patients ("very confident": pre-training – 9.5%; post-training – 66.7%).

Follow-up audit and survey of 40 inpatients demonstrated overall improvements in practise and patient experience. There was better availability of appropriate equipment, and patients reported receiving assistance with mouthcare more frequently. Fewer patients reported a decline in their oral health during their hospital stay.

Overall, the project demonstrated that targeted mouthcare training can improve staff confidence, enhance care practices, and positively impact patient experience.

Measured impact

Staff: Increased confidence and knowledge among nursing staff, contributing to a more skilled workforce.
Patients: Improved mouthcare practices and inpatient experience for older inpatients, with fewer patients experiencing high-risk oral hygiene or deterioration during admission. There was also a reduction in negative effects such as difficulty eating and drinking or communicating with others due to poor oral hygiene.

Anticipated impact

Organisation: Improved oral hygiene may reduce health complications and length of stay, improving patient flow, bed availability, and reducing financial pressures.
Community: Reduced inpatient deconditioning may lower the need for home rehabilitation services, easing pressure on community care. Reduced deterioration in oral hygiene may also reduce demand for follow-up dental and orthodontic services.

Informing future research, practice, or policy

Findings from this project will support the development of a Trust-wide Mouthcare Policy at Addenbrooke’s Hospital, providing a consistent framework for oral care across adult wards. Future research could explore the broader impact of oral hygiene on patient and service outcomes, including rates of hospital-acquired pneumonia, mortality, length of hospital stay, and financial implications.

Challenges and Lessons Learnt

The main challenge was engaging stakeholders & staff in an already busy and resource-constrained NHS environment. While the project initially targeted both care of the elderly and stroke wards, it was later narrowed to focus solely on care of the elderly wards to ensure maximised engagement and effectiveness at the implementation stage. Additionally, planned in-person ward-based training was reduced to a visual package due to competing priorities among stakeholders who had initially committed to supporting the initiative.

> Tip 1: Persevere through challenges. Seek support from supervisors for expertise and peers for encouragement. Action learning sets can be particularly valuable for problem-solving.
> Tip 2: Scale it back! There is not as much time as you think there is.

Mouthcare Matters!

Molly Garfoot
Impact Fellow

Cambridge University Hospitals NHS Foundation Trust

ImprovingoralcareforolderinpatientsatAddenbrookes Hospital

- Poor oral hygiene is associated with health issues including pneumonia, heart disease, stroke, and diabetes.
- Admission to hospital can lead to a deterioration in oral health, particularly for older patients or those in the last stages of life. This can contribute to negative health consequences, longer admissions or rehabilitation periods, and increased financial burden for the hospital.
- Assisting with oral care is an essential part of basic patient care, important for upholding quality of life, dignity and comfort for patients.

The Issues:

1.*Sub-optimal patient care & experience*

83inpatientson4wardsin3monthsexperienced:

£5k **denture loss** during admissions

44% having **difficulty eating and drinking** due to oral hygiene

50% **medium** or **high** risk oral hygiene

72% **oral health deteriorated** in hospital

2.*Inconsistent nursing knowledge & confidence*

***80 nurses & HCAs** working on the 4 wards reported:*

Lack of Time: the **biggest barrier** to assisting with mouthcare

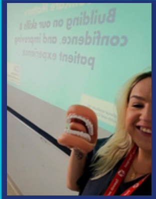
No formal training: in mouthcare for **59%** of nurses

Lowest confidence: with patients who are **confused** or **refusing care**

Documentation: about oral health **never completed** by **1 /4** of staff

The Intervention:

Raising awareness and knowledge



In-person **practical training** in oral care delivered to 21 nursing staff across 2 wards (nearly **25% of workforce**)

Ward-based educ ation: Posters, discussions at nursing handovers, family advice, "spot checks"

Mouthcare Matters!

Tools matter

Dentures matter

Documenting matters

EVERYONE matters

Areas of focus:

Documentation Matters

Dentures Matter

Tools Matter

All Patients Matter

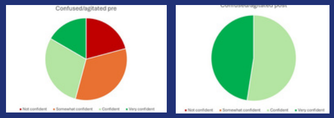
This project is supported by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration East of England (NIHR ARC EoE) at Cambridgeshire and Peterborough NHS Foundation Trust. The views expressed are those of the author and not necessarily those of the NIHR or the Department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

The Improvements:

> "It's a really helpful session. I understand the significance of mouthcare"

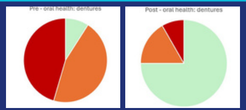
1.*Staffknowledge&confidence*

Improved confidence for **all staff** following training
Biggest improvement seen with **confused** patients



2.*Care quality & patient experience*

Improved oral health, most notably for **dentures**



20% → 63%

More mouthcare **tools available** and **reduced** use of **unsafetools**

More patientsbeingassisted with **daily mouthcare**

17% → 36%

72% → 43%

Less patients experiencing a
ioration in oral health

Next Steps:

- **Standardise training** and provide to nursing staff across all hospital wards
- More **research** into how poor oral health impacts **health outcomes** & **length of admission**

NIHR | Applied Research Collaboration East of England

Health Innovation East

Daisy Jacobs

Advanced Clinical Practitioner in Specialist Palliative Care
St Nicholas Hospice Care
E: daisy.jacobs@stnh.org.uk

Embedding Education Innovation In Families Administering Medications: Improving End Of Life Care

The project focused on improving how clinical staff are trained and supported to deliver the Families Administering Medications (FAM) model, enabling family carers to administer anticipatory medications at home at the end of life. While governance and safety evidence for FAM is strong, little was known about how to ensure clinicians felt confident and equipped to train families safely and sustainably. With more than 100 FAM champions previously trained by only two clinicians, scalable and sustainable educational infrastructure was urgently needed. FAM promotes timely symptom control, patient autonomy and the ability for people to remain at home, yet inconsistent training, gaps in confidence, variation in governance and limited support structures created risks. The literature highlights how emotional labour, inconsistent documentation and uneven organisational support affect staff readiness and family experience. Strengthening educational foundations was essential to reduce variation, enhance safety and support equitable access across the region.

A mixed-methods evaluation identified four themes shaping FAM implementation. Risk was affected by variation in governance, documentation and access to advice, creating safety concerns where confidence and competence were closely linked and risk was experienced contextually. Clinical staff education was critical, as single training sessions were insufficient; clinicians needed accessible refreshers, clear expectations, consistent resources and peer reassurance. Improved patient outcomes occurred when FAM was delivered effectively, enabling timely symptom management, reduced distress and better continuity of care at home. Sustainability required ongoing educational, organisational and cultural support, with peer networks, standardised tools and defined responsibilities enabling long-term integration.

The project strengthens the infrastructure clinicians rely on to support patients and families confidently and consistently through their end-of-life care. This contributes to safer medication administration at home, more equitable access to FAM, and improved patient experience across community, hospice and acute settings. As a result of my project, clinicians working across the Integrated Care System now have tools that reduce uncertainty in practice, enabling earlier identification of suitable patients, supporting families to manage symptoms rapidly and help prevent unnecessary hospital admissions.

The fellowship has already generated a suite of coproduced, scalable outputs, including:

- A FAM quick reference guide for clinicians
- A staff training video for refresher learning
- A family carer video providing consistent, reassuring education
- Medication information leaflet co-designed with public contributors
- A FAM awareness poster to normalise practice across settings

These resources are now being used regionally, improving confidence, consistency and visibility of FAM. They reduce dependence on a small number of trainers and embed accessible learning into everyday practice.

The findings highlight the need to prioritise educational infrastructure in interventions supporting family administration of injectable medication. The importance of establishing sustainable peer networks and relational implementation apply to other areas of end-of-life care requiring shared decision making and delegation. The project provides a foundation for future evaluations of family experiences, equity of access and long-term sustainability across Integrated Care Systems. As a transition from this project, I am supporting a national survey analysis exploring the wider picture of healthcare professionals' experiences of this topic. This leads into my literature review which i will write for publication.

Several challenges informed my learning. Variation in practice—particularly in documentation systems, out-of-hours support and local governance—hindered the development of a uniform training model, prompting the creation of co-produced and adaptable tools. Workforce pressures and the emotional labour involved in end-of-life care limited clinicians' capacity for training, leading to self-directed video materials and concise reference resources that supported learning without removing staff from practice. Confidence gaps also emerged, with clinicians reporting that their ability to train family carers diminished over time; this shaped the development of layered learning approaches that enabled timely refresher support. Finally, navigating tensions between national policy aims and local operational realities required sustained reflexivity and engagement with national communities of practice.

My insights for future learners would be to stay close to the realities of practice, where impact comes from understanding context, relationships and culture rather than simply delivering outputs. Coproducing with the people who will use the work—clinicians, patients and carers. These offered insights that genuinely improved the design of resources. The confidence, more than competence of clinicians, often proved the biggest challenge, making it essential to build tools that can be accessed repeatedly and flexibly. Engaging widely and nationally provided external validation that helped distinguish local issues from systemic ones.
Above all, the fellowship was a chance to think differently rather than just do more, with reflexivity, action learning and honest challenge driving meaningful change.

because you matter
St Nicholas Hospice Care
A Registered Charity No. 287773

NIHR | Applied Research Collaboration East of England

UNIVERSITY OF CAMBRIDGE Public Health and Primary Care

Health Innovation East

Embedding education innovation in Families Administering Medications: Improving end of life care

Daisy Jacobs
daisy.jacobs@stnh.org.uk

Introduction

This project has explored the impact of the provision of education to clinical staff across SNEE ICB who train and upskill family carers to administer medications under the Families Administering Medications (FAM) policy.

Prior to this fellowship training, over 100 FAM clinical champions had been trained by just two clinicians. This project sought to identify a sustainable method for effective training delivery, in addition to the development of accessible resources. These were designed for both clinical staff to use in the moment as training aids, and supplemental written information and support for families and carers following their initial training.

The project has identified the education, support and system enablers for clinicians to embed safe, sustainable practice in FAM across community palliative care services.

Method

The Mixed-methods service evaluation integrates three workstreams through collaboration with key stakeholders and has supported the learning and understanding of the impact of the process of FAM.

- **Stage One: National Community of Practice Discussion**

A guided discussion designed to offer a safe space in which to understand current practice and identify existing barriers, with the aim of informing future learning.

- **Stage Two: FAM Champion Survey**

12 question semi-structured questionnaire to all FAM Champions

- **Stage Three: 121 Discussions**

Participants of the survey were offered the opportunity to engage in a 121 discussion, during which we explored the survey questions and discussed their personal experiences of FAM, allowing for expansion upon their original responses.

- **Stage Four: Literature Review**

Fifteen articles were reviewed to identify and understand the experiences and impact of training and supporting family carers to administer medications for those dying at home on clinical staff. These included several articles where the title did not explicitly relate to the impact on clinical staff, but were included because they included insights into staff experiences within their findings.

- **Stage Five: Data Analysis**

Critical analysis was applied to verify the relevance of proposed actions, identify key themes requiring attention, and ensure alignment between data outputs and project objectives. The organisation of the data directly informed the project's central questions and outcomes. Maintaining an overarching analytical view supported reflexivity and enabled a more nuanced and rigorous interpretation of the findings.

Data were thematically analysed and triangulated to identify barriers, facilitators, risks and implementation of learning, thus informing practical outputs and future service development.

Results

Theme One: Risk

This theme explores the multifaceted risks associated with implementing Family Administration of Medication (FAM) in palliative care. Key issues include staff preparedness, governance challenges, inconsistent training, and lack of support systems. Variability in local policies and documentation increases the risk of errors, while ethical considerations and resource constraints influence strategic adoption. The review emphasizes the need for robust oversight, clear clinical justification, and mechanisms for continuous support to mitigate patient safety risks.

Theme Two: Clinical Staff Education

This theme highlights the critical role of structured education for clinical staff in sustaining FAM practice. It addresses gaps in training provision, time allocation, and consistency of learning outcomes. Emphasis is placed on confidence-building, role clarity, and peer support through champions and collaborative models. The need for ongoing updates, reflective practice, and accessible resources is underscored to ensure competence and adaptability in diverse care settings.

Theme Three: Improved Patient Outcomes

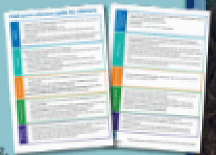
This theme focuses on the patient-centered benefits of FAM, including timely symptom control, enhanced autonomy, and reduced hospital admissions. It emphasizes the importance of consistent training for family carers, supportive debriefing, and clear communication to sustain confidence. The integration of case studies and real-world examples in training fosters understanding of FAM's impact. Challenges such as inclusion criteria, safeguarding, and equitable access are acknowledged, with recommendations for shared care and ongoing monitoring.

Theme Four: Sustainability in Practice

This theme examines the long-term viability of FAM within palliative care frameworks and addresses challenges related to resource allocation, governance, and capacity fluctuations. Sustainability requires robust audit processes, transparent communication, and co-production with stakeholders. While FAM is not a substitute for comprehensive palliative care, its integration demands ongoing training updates, shared learning platforms, and strategic planning to maintain quality and equity in service delivery.

Outputs

These outputs will be transferable across multiple care settings including community, hospice and acute services. They provide a scalable and sustainable delivery method where previously there was a reliance on a few key individuals to deliver the training.



- Staff FAM quick-reference guide

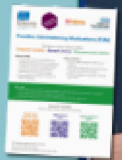
Supports clinician confidence, safe decision-making and consistent FAM use at the point of care.

- FAM Staff training video

Supports accessible refresher learning, role clarity and sustainable implementation across teams.

- Family carer FAM training video

Supports consistent education, safety, confidence and reassurance for carers administering medications.



- Medication information leaflet (PPI-informed)

The leaflet aims to be accessible and provide information which is clear and consistent about medication uses in palliative care. It invites conversation but is also providing clear facts. There are no other regional leaflets that support this information. There is a drive from the literature review to ensure that patients and their family carers are provided specific information about the medication they are given. This is particularly important when there is a variation from the norm such as in palliative care where the route, dose or indications for use vary from the original medicines licence.

- FAM awareness poster for clinical practice

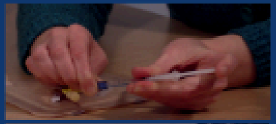
Supports visibility, proactive consideration of FAM and normalisation across clinical settings

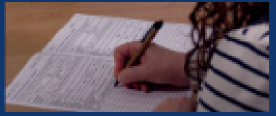
Conclusions

The fellowship demonstrates that FAM is not a single intervention but a practice change requiring ongoing clinical, educational and organisational support.

- Normalisation of refresher learning for clinicians
- Provision of accessible, practical implementation tools
- Support for peer learning and leadership
- Integration of FAM into routine palliative care pathways

This work moves FAM from a "champion-led initiative" towards a scalable, sustainable model of community end-of-life care.





Acknowledgements

St Nicholas Hospice Care and all my colleagues

Sharon Basson
St Nicholas Hospice Care
Director of Care

Dr Sarah Mollart
St Nicholas Hospice Care
Consultant in Palliative Medicine and author of FAM

Ben Jackson
NIHR Impact Supervisor
Health Innovation East

Dr Ben Bowers
Academic Supervisor - University of Cambridge
Department of Public Health and Primary Care

Dr Louisa Polak
University of Cambridge
Department of Public Health and Primary Care

Dr Marlise Poolman
University of Bangor
National Community of Practice:
Lay Carers Administration of Medications

Charlie Gienke Immersive Technology Specialist
West Suffolk Hospital to the list

NIHR Applied Research Collaborative – East of England

Patient and Public Involvement Hub

Authors, D. JACOBS
1 St Nicholas Hospice Care
2 NIHR ARC Impact Fellow

Georgina Jones

Senior Care Adviser
Parkinson's UK
E: gejones@parkinsons.org.uk

“Attempt to Escape Alcatraz” Empowering People with Parkinson’s in Hospital to Prevent Deconditioning

My project addresses the significant issue of deconditioning for people with Parkinson’s in hospital, focusing on its causes and, crucially, practical solutions to overcome them. Deconditioning is the physical and psychological decline associated with prolonged bed rest and muscle loss. This is a considerable risk for older adults in hospital; those aged over 80 can lose 10% of their muscle mass, the equivalent of 10 years of aging, for every 10 days in hospital.
For people with Parkinson's these risks are even higher. They are more likely to be hospitalised and whilst in hospital 20% of patients with Parkinson’s experience worsening motor symptoms with 44% never returning to their pre-hospitilisation functional status (Sine et al, 2024). 63.9 %Are more likely to be discharged to a care facility than their counterparts (Gerlach et al 2013). Physical exercise is a vital component of symptom management for people with Parkinson's, therefore any mobility loss due to deconditioning in hospital will have a lasting negative impact on their ability to manage their condition throughout their lives.

A study looking at people with Parkinson's experience in hospital likened it to being in Alcatraz “They had me in lockdown mode... I would just attempt to escape from Alcatraz.” (Schurer et al 2023). A quote that inspired my project title.

My research journey began with a Literature Review, where I researched existing interventions, known barriers, and potential solutions by analysing academic and industry sources, relevant websites, and local care protocols. This ensured my subsequent work was built on established knowledge.

Next, I established Professional Connections by strategically mapping and engaging with key stakeholders, including consultants, therapists, and Parkinson's nurses. As well as crucial insights from staff within Parkinson's UK, to understand their professional perspective on barriers to effective hospital mobilisation.

I then engaged with people with Parkinson's and their family members. Their personal insight was integral to shaping the future solutions. I arranged a Focus Group, where I brought professionals and people with lived experience ideas together, to collaboratively discuss the findings, refine potential solutions, and determine what was achievable within the available resources.

Its Impact

Through my research I found that most of the information provided and campaigns in place were focused primarily on professional awareness and structured multi-disciplinary programmes rather than patients. And there was a noticeable lack of focus on people with Parkinson's in this area. I therefore felt that there was a gap in educating and providing information for people with Parkinson's and their families to be able to prepare and take action themselves for when these issues arise in hospital.

When looking at the impact I could make with my project I needed to consider what I was able to achieve in my role, with my skills and within the timeframe that the fellowship would allow. Following feedback from focus groups that dismissed the idea of a leaflet, I developed a 'Hospital Mobilisation Toolkit,' staff at Parkinson’s UK can use to discuss these issues with people with Parkinson’s and their loved ones. Providing practical support to advocate their needs in hospital and to maintain their mobility. The plan is to cascade this information and provide training to advisers across the East of England, with the aim of national rollout.

Challenges and Lessons Learnt

A major challenge was recognising the limits of my influence over systemic issues. The focus group highlighted massive external barriers, such as hospital staff shortages, continued use of paper notes, and disjointed database systems between hospitals and the community. I overcame this by applying behavioral change models to focus on what I could influence, empowering the patients themselves. Additionally, I initially planned to create an information leaflet, but the focus group feedback warned me that "no one looks at them." I therefore had to change my strategy and instead develop a way of disseminating information to empower people with Parkinson's that was going to be accessible for them and I began to design my Hospital Mobilisation toolkit.

Insights for Future Applicants

Initially, I worried that the project's success depended on a single, final output within the year. I had been worried about not producing something at the end of it and that my time would be wasted. However, I now realise this work is ongoing and evolving, opening up further research and personal opportunities. I have realised this is just the start of the project leading to continued work, including designing the hospital mobilisation kit, training advisers, and helping shape Parkinson’s UK future resources and support.

NIHR | Applied Research Collaboration East of England

Health Innovation East

Parkinson's UK

"Attempt to Escape Alcatraz" Empowering People with Parkinson's in Hospital to Prevent Deconditioning

Author, G. JONES Parkinsons UK (gejones@parkinsons.org.uk); **Advisers,** B. JACKSON, Health Innovation East, DR K. DEANE, UEA; **Contributor,** H, HOLLOWAY

Background

Deconditioning syndrome is "the physiological, psychological & functional decline that occurs as a result of complex physical changes, which happens with prolonged bed rest & associated loss of muscle strength." It is a significant risk for older people contributing to 47% of delayed discharges from the hospital.

However for People with Parkinson's (PwP) who rely on physical exercise to manage & even reduce their symptoms, what are the particular risks, & how can they be overcome to create better outcomes & prevent deconditioning in hospital.

My Research Journey

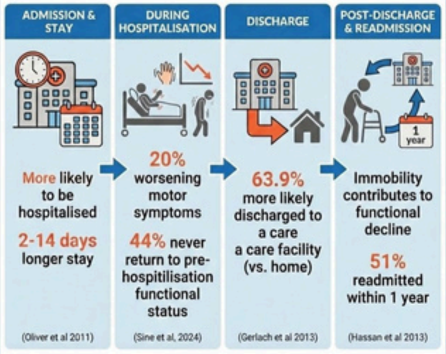
1. Literature Review: Examining barriers, solutions & existing interventions.

2. Professional Connections: Interviews with Parkinsons nurses, nurses, OT's physiotherapists, Parkinson's consultants & rehabilitation teams.

3.Lived Experience: Set up a working group with PwP & carers to gain their insights & experience.

4. Focus Group: A focus group with professionals & PwP to share research & test solutions.

The impact of Deconditioning on People with Parkinson's



Findings

People's experience of being in hospital with Parkinson's

> "They had me in lockdown mode because I was the fall risk… I would just attempt to escape from Alcatraz." Shurer et al 2023[1]

> "It was kind of funny that as soon as I said 'Parkinson's' they put a tag on my h& saying that I have fall risk. So, after that, they would not let me get off the bed by myself, even though I was able to walk.
> Shurer et al 2023[1]

Barriers to mobilisation in hospital

Clinical & Medical Related	Staffing	Patient & Environmental
Medication mismanagement	Staffing & Time Constraints	Lack of motivation & confidence
Restrictive Falls Protocol	Knowledge Gaps	Hospital Environment
Acute illness	Fear of Injury	Mobility Equipment

Existing Deconditioning Interventions & the Parkinson's Gap

Current Interventions:

- Focus primarily on raising professional awareness (e.g., 'end PJ paralysis,' 'Sit up, get dressed, keep moving' campaigns).
- Structured, multidisciplinary programmes (e.g., John Hopkins scale for daily assessment & goal setting) promote MDT-led daily discussion & goal-setting, for mobilisation in general hospital populations.

Limitations:

- Existing interventions are generic & lack specific focus for people with Parkinson's (PWP).
- The primary approach remains professional-centric.

PWP-Specific Recommendation & Impact:

- Parkinson's Foundation (US) recommends PWP mobilise at least 3 times a day during hospitalisation.
- This recommendation (introduced 2023) has been associated with reduced hospital stays & a higher likelihood of discharge home (Gunzler, 2025).

Identified Research Gap:

A need exists for educational resources & information empowering PWP & their families to proactively prepare & take action themselves to mitigate deconditioning risks in the hospital setting.

Outcome

Feedback from my focus groups was that a leaflet would not be useful or used. I therefore felt the best way to support people with Parkinson's & their families was to provide an Information toolkit for advisers in Parkinsons UK. This toolkit can be used by advisers to support PwP & their loved ones to advocate in hospital.

Toolkit for advisers containing information on:

- Preparing for a Hospital Stay
- Rights in Hospital
- Carers' passports
- Practical tips for communicating with staff & advocating
- Equipment & Daily Routines
- Safety - Green & Red light to movement in hospital
- Chair & Bed Exercises
- Underst&ing professionals in Hospital
- How to Complain

Cascaded to-

- Advisers
- Local groups
- Information sessions
- Health staff

Acknowledgements

With thanks to my advisers Ben Jackson & Dr Katherine Dean, & contributor Helen Holloway.

G Jones, Parkinson's UK, is supported by the National Institute for Health & Care Research (NIHR) Applied Research Collaboration East of Engl& (NIHR ARC EoE) at Cambridgeshire & Peterborough NHS Foundation Trust. The views expressed are those of the author & not necessarily those of the NIHR or the Department of Health & Social Care.

References

- Gerlach, Oliver H.H. et al. (2011). Clinical problems in the hospitalized Parkinson's disease patient: Systematic review. Parkinsonism & Related Disorders, Volume 19, Issue 8, 737 - 741.
- Gerlach, Oliver H.H. et al. (2013). Motor outcomes during hospitalization in Parkinson's disease patients: A prospective study. Parkinsonism & Related Disorders, Volume 19, Issue 8, 737 - 741.
- Gunzler SA, Muisyo J, Pérez JA, Brooks A, Rosenfeld S, Skarbinski J, Bitzer K, George N, Murphy J, Shea S, Pronovost P. Impact of inpatient mobility on outcomes in Parkinson's disease. Parkinsonism Relat Disord. 2025 Jun;135:107834. doi:
- Hassan A K, Wu SS, Schmidt P, et al. High rates & the risk factors for emergency room visits & hospitalization in Parkinson's disease. Parkinsonism Relat Disord. 2013; 19:949–954.
- Shurer J, Golden SLS, Mihas P, Browner N. (2023). More than medications: a patient-centered assessment of Parkinson's disease care needs during hospitalization. Frontiers in Aging Neuroscience

NHS
East London
NHS Foundation Trust

Dr. Sen Kallumpuram

Consultant Psychiatrist & Training Programme Director, East London NHS Foundation Trust
E: sen.kallumpuram1@nhs.net

Best Poster Awards

Bridging The Dementia Diagnosis Gap: Evaluating A Training & Supervision Package for GPs & Nurses In Central Bedfordshire and Its Impact On Dementia Diagnosis Rates

Background

Dementia presents an increasing challenge in Central Bedfordshire, a large rural area where the diagnosis rate was 63.8% in April 2025, below the national target of 66.7%. With nearly 40% of cases remaining undiagnosed, particularly among housebound and frail populations, patients experienced delays in accessing essential medication, social care, and post-diagnostic support. This not only impacted well-being but also increased the risk of unnecessary hospital admissions and higher system costs.

Engaging time-pressured GPs in diagnostic work often proves difficult, as clinicians question the tangible benefits. However, after engagement at an Integrated Care Board frailty meeting, a GP frailty lead joined, sparking broader interest. The project aimed to equip primary care clinicians with structured training and supervision to diagnose advanced dementia in the community—shifting from a deficit model to a proactive, patient-centred approach.

Intervention

I developed a training and supervision package based on standardised frameworks, including the Diagnosing Advanced Dementia Mandate (DiADeM) tool and the 6-item Cognitive Impairment Test (6CiT). In collaboration with the local GP frailty lead and the Tibbs Dementia Foundation, we co-created a pro forma to assist clinicians in gathering the essential diagnostic information. After obtaining ethics approval, I delivered training sessions supported by bi-weekly mentoring. A frailty nurse facilitated implementation by integrating the work into routine assessments for patients with a Clinical Frailty Score >6.

Impact

Post-training questionnaires indicated that the package enhanced clinicians' confidence in using diagnostic tools and incorporating assessments into busy practice. A focus group showed that, despite initial worries, GPs found that with appropriate support, diagnosing and organising care in primary care was both achievable and more fulfilling for patients.

Over four months, the pilot led to 10 new diagnoses of advanced dementia within the community, enabling individuals to access medication, social care, and support. The local dementia diagnosis rate increased from 63.8% in April 2025 to 66.1% in January 2026, narrowing the gap to the national target significantly. The success of this initiative secured a place in the NHS Dementia Innovators Programme 2026. I am now developing the model further as Diagnosing Advanced Dementia in Primary Care (DAD-PC)- a framework with strong potential to enhance early diagnosis for vulnerable, housebound residents while reducing reliance on traditional memory clinic referrals and associated costs.

Challenges and Lessons Learnt

My initial ethics application was returned with a request for clearer, measurable goals. Facing a tight deadline, I was worried, but the Trust's research department arranged a dedicated session to explain expectations. The guidance helped me improve the application and gain approval—a reminder that institutional support is available for those who seek it.

Insights for Future Applicants

> This journey will bring challenges, ambiguity, and time pressures. Help and support are always at hand—do not hesitate to ask, seek, and knock.

Acknowledgements

I am deeply grateful to my guides, Dr Jyotika Kumar, Professor Michael Hornberger, Professor Liz Wiggins, and my Learning Set colleagues; my ELFT colleagues, Dr Aneeba Anwar and Dr Angharad Ruttley; the ELFT Research Department; and GP colleagues Dr Geoff White and Dr Roy Boodhun, without whom this work would not have been possible.

NIHR | Applied Research Collaboration East of England

Health Innovation East

Evaluating a training and supervision package for GPs and Nurses in Central Bedfordshire and its impact on dementia diagnosis rates

Authors: Dr Sen Kallumpuram[1], Dr Jyothikakumar[2], Prof. Michael Hornberger[3]
1 Consultant Psychiatrist & Training Programme Director, East London NHS Foundation Trust
2 Senior Advisor (Consulting) - Health Innovation East, Knowledge Mobilisation Advisor - NIHR ARC East of England
3 Professor of Applied Dementia Research, University of Southampton

Introduction

Getting a new diagnosis through Memory Services for a person with suspected advanced dementia may take several months. Dementia Diagnosis Rates (DDR) are lower in Central Bedfordshire.

A timely diagnosis: will enable patients and their caregivers to plan for their future, receive medication, reduce behavioural and psychological symptoms, and reduce the need for care home placements.

Aim:

This Project aims to evaluate the training and supervision provided to GPs & Senior Nurses to diagnose Advanced Dementia in Primary Care. This Project will upskill GPs to ensure that their patients receive timely diagnosis, care and medication.

Impact:

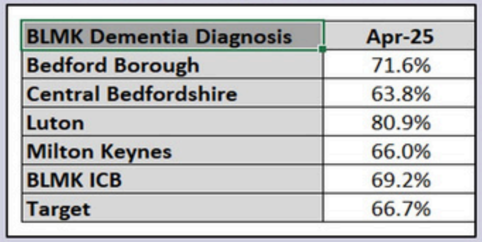
a meaningful change in clinical practice and improved DDR in Central Bedfordshire.

Methods:

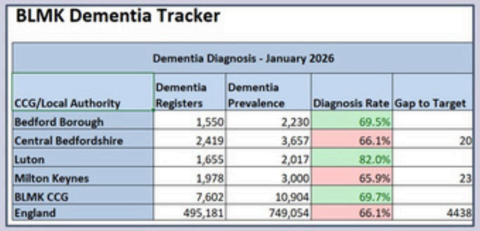
Find: GP Practices interested in joining the project
Create a semi-structured proforma to assess patients
Administer: the pre-training questionnaire
Deliver F2F Training: on diagnosing advanced dementia in Primary Care
Await: dementia assessments by GPs & Nurses.
Provide Supervision: to make a dementia diagnosis and care plan.
Enable communication: of the diagnosis & plan to patients/relatives
Ensure appropriate documentation: in Primary and Secondary Care.
Post Diagnostic Support to GPs: through Tibbs, CMHT & DISS teams.
Evaluation: through the post-training questionnaire & Focus Group.

Results

DDR in Central Beds in April 2025 and in Jan 2026



BLMK Dementia Diagnosis	Apr-25
Bedford Borough	71.6%
Central Bedfordshire	63.8%
Luton	80.9%
Milton Keynes	66.0%
BLMK ICB	69.2%
Target	66.7%



BLMK Dementia Tracker

Dementia Diagnosis - January 2026				
CCG/Local Authority	Dementia Registers	Dementia Prevalence	Diagnosis Rate	Gap to Target
Bedford Borough	1,550	2,230	69.5%	
Central Bedfordshire	2,419	3,657	66.1%	20
Luton	1,655	2,017	82.0%	
Milton Keynes	1,978	3,000	65.9%	23
BLMK CCG	7,602	10,904	69.7%	
England	495,181	749,054	66.1%	4438

West Street Surgery: Dunstable, Beds

(Dr Geoff White & Jo Lauder).

Dementia Training delivered

Pre and Post Training Questionnaire completed

Focus Group conducted by Dr Aneeba Anwar

Number of new patients discussed: 8

Number of new dementia diagnoses: 6.

Two new prescriptions were initiated

Two patients are awaiting further assessments.

Shefford Health Centre: Shefford, Hitchin

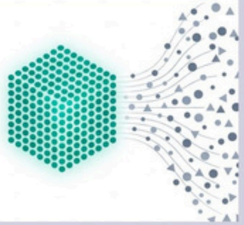
(Dr Roy Boodhun & colleagues)

Dementia Training delivered

Pre and Post Training Questionnaire completed

Bridging the Gap in Dementia Care

Impact Evaluation of the Clinical Dementia Training Programme



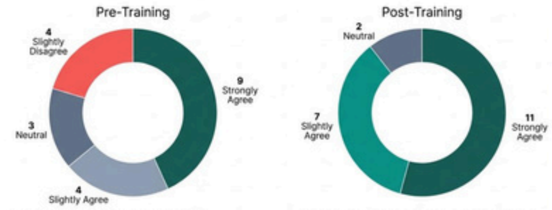
Core knowledge gaps have been closed across the cohort.

Metric: Improvement in Knowledge of Dementia

Pre-training, roughly 27% of staff disagreed that their knowledge was sufficient. Post-training, this was reduced to 0%.

Operational clarity on referral protocols is now the standard.

Metric: When and how to refer patients

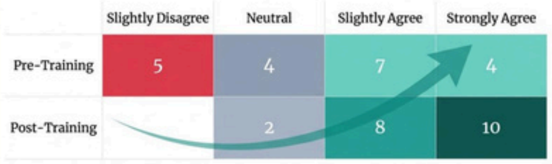


High Variance: Pre-training data suggested inconsistent patient routing.

Standardized: 90% Agreement indicates a unified operational protocol.

The team is better equipped for proactive early diagnosis.

Metric: Better equipped to make an early diagnosis of advanced dementia



	Slightly Disagree	Neutral	Slightly Agree	Strongly Agree
Pre-Training	5	4	7	4
Post-Training		2	8	10

Early diagnosis is vital for effective dementia management. The training successfully migrated the "center of gravity" for this metric from Disagreement/Neutrality (9 staff members) to strong Agreement (18 staff members).

Conclusions:

Clinical Knowledge and Diagnostic Ability

Knowledge of Dementia: The training led to a substantial increase in core knowledge. 90% of participants (18 out of 20) expressed agreement that their knowledge had improved.

Early Diagnosis of Advanced Dementia: Confidence in identifying advanced dementia early increased significantly. In Post-training, 18 out of 20 participants felt better equipped for early diagnosis.

Professional Communication and Referrals

Confidence in Discussing Dementia with Families: Communication skills showed a clear upward trend. After training, 16 out of 20 participants reported being confident in these discussions.

Clarity on Referral Pathways: Post-training data indicate that 18 out of 20 participants agreed they understood the memory services referral process.

Acknowledgements:
Dr Geoff White, GP Frailty Lead, West Street Surgery
Dr Roy Boodhun, Shefford Health Centre
Dr Aneeba Anwar, Memory Services Lead
Sarah Russell, Tibbs Dementia Foundation
Dr Angharad Ruttley, Medical Director, ELFT
Mr Balraj Singh Rai

References:

1) Wells CE, Smith SJ. Diagnostic Care Pathways in Dementia. J Prim Care Community Health. 2017 Apr;8(2):103-111. doi:
2) Diagnosing Advanced Dementia Mandate (https://diadem.apperta.org)
3) Royal College of Psychiatrists. (2024). National Audit of Dementia Memory Assessment Services Spotlight Audit: National Report. London, UK.
4) https://www.england.nhs.uk/publication/models-of-dementia-assessment-and-diagnosis-indicative-cost-review/
5) https://www.alzheimers.org.uk/sites/default/files/2023-05/alzheimers-society-improving-access-timely-accurate-diagnosis-england-wales-full-report_0.pdf

Further Correspondence: Dr Sen Kallumpuram
Mobile: 07968120070.; Sen.kallumpuram1@nhs.net

Dr Sen Kallumpuram and East London NHS Foundation Trust is supported by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration East of England (NIHR ARC EoE) at Cambridge and Peterborough NHS Foundation Trust. The views expressed are those of the author[s] and not necessarily those of the NIHR or the Department of Health and Social Care.

Samantha Nunn

NHS
East of England
Community Health and Care
NHS Trust

Research Facilitator
Cambridgeshire Community Services NHS Trust
E: samantha.nunn@nhs.net

Taking The First Step: Exploring Scalability of the CCS Research Champions Programme Across Health & Care Settings

Multiple national drivers (e.g. 'Saving and improving lives.' policy paper), position research as everyone's business across health, social and wider care settings. Implementation can be a challenge in the context of multiple systemic changes, and across organisations with limited resources and research naivety. Thus it is recognized that workforce development programs aimed at early stage 'researchers' are now required. The Research Champions Programme (RCP), developed by Cambridgeshire Community Services NHS Trust, offers a 'first-step' programme supporting staff awareness, confidence and capability to engage in research. As a community trust, we understand challenges associated with geographical spread of services and supporting research naïve staff. Uniquely, the RCP is open to all staff with a curiosity for research, it builds research culture and recognizes the value of research activities beyond study delivery. We are aware of no other similarly structured programs in the East of England and since its inception in 2019, we have received inquiries from other organisations interested in the RCP. The focus of this Fellowship was therefore to explore appetite for the RCP from health and wider care settings and to co-develop an options appraisal to inform the future sustainable development of the RCP.

Scaling the RCP has the potential to demonstrate multiple positive impacts for the system in the East of England and beyond. I am aware of research teams across the region and beyond who are highly motivated to support staff development in research and are at varying stages of creating similar programs/approaches. Joint working has the potential to reduce the capacity burden required to design and deliver such programs for each organization, an opportunity to share best practice, reduce unnecessary duplication, support organizational readiness for research delivery and strengthen research culture within organisations and across the wider system.
The final options appraisal included developing a train-the-trainer program/implementation package, holding educational webinars, offering fee-paying places to external organisations, adapting to other settings and exploring future partnerships.

Five categories informed interview discussions (appetite, perceived barriers, perceived benefits; context; recommendations) with themes emerging. Appetite and benefits were associated with themes of value (e.g. of 'first step' programs, wrap around support, benefits for the wider system and reducing duplication). Barriers included capacity considerations (i.e. resources required to develop and deliver such programs). Context included themes of variation (between organization type, with acute trusts typically having more resources and less appetite) and the negative impact of multiple system wide changes. Recommendations included building the reputation of the RCP (e.g. through publication, CPD accreditation).

Its Impact

The Fellowship enabled a systematic, robust approach to co-development of an options appraisal. This has been shared with managers and has informed a funding bid. Options appraisal and feedback from interviews will inform key decisions about the ongoing development of the RCP in the coming months.

Recommendations:

- A number of fee-paying spaces should be reserved on the RCP each year to external community organisations. There is scope to offer this widely with sufficient resources.
- To continue exploration of adapting the RCP to other settings with regional and national stakeholders who have appetite to do this.
- To ensure the ongoing development and delivery of the RCP is sufficiently resourced and sustainable.

The options appraisal will support scalability decisions of the RCP. Offering the RCP to external organisations both regionally and nationally would support workforces across health and wider care settings to feel more confident to engage with research, have awareness of how research happens in their organisations and would contribute to staff satisfaction and retention. There is appetite to support staff to be research confident and many organisations do this in a variety of ways. There is potential to create a national community of practice to support best practice of such programs.

Challenges and Lessons Learnt

Framework identification for my project from the teaching sessions was a challenge, but discussions with supervisors helped my thinking around this. I found that the number of project activities varied across the year, with a slight bottleneck towards the end. I think this pattern is common in projects and found acceptance, being flexible where possible and planning for busier times helpful.

Insights for Future Applicants

I would highly recommend that applicants get in touch with potential supervisors early to discuss their proposed project.

NIHR | Applied Research Collaboration East of England

Health Innovation East

NHS
East of England Community Health and Care NHS Trust

TAKING THE FIRST STEP:

EXPLORING SCALABILITY OF THE EEC NHST RESEARCH CHAMPIONS PROGRAMME

Samantha Nunn[1], Research Facilitator, Dr Danielle Tucker[2], Reader in Management; Dr Jyothika Kumar[3], Senior Advisor.

Affiliations: 1. East of England Community Health and Care NHS Trust, 2. University of Essex, 3. Health Innovation East

01 Introduction

The RCP: A Trust-wide introductory programme designed for any staff member with an interest in research or a desire to strengthen evidence-based practice.

The need (national drivers):

- Embedding research in everyday practice across health, care and wider settings.
- Research to be accessible to all.
- Equipping a research ready workforce.
- Research pillar of professional frameworks.
- Unknown: type of organisations that have similar/appetite; capacity to implement.

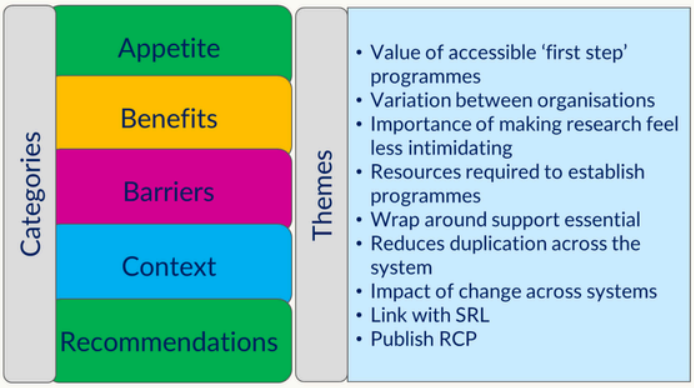
02 Aims

- Understand external appetite for the RCP.
- Learn from other organisation with similar programmes.
- Explore commercial options.

03 Methodology

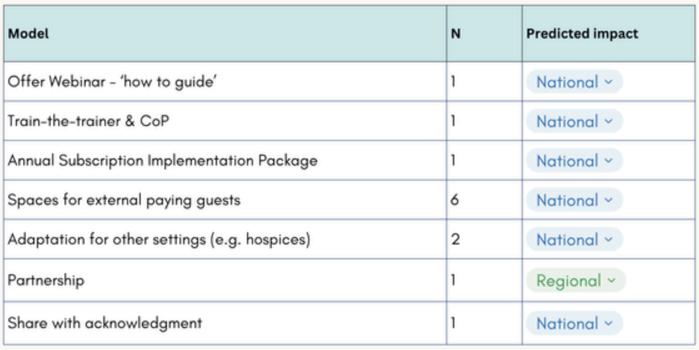
- Purposive sampling - regional and national networks.
- Semi-structured interviews across NHS and care sectors, recorded on MS Teams (N = 6 with established programmes, 6 with no programme, 4 in development).
- A-priori themes: Appetite; Benefits; Barriers; Context; Recommendations.
- Co-development of options appraisal.

04 Outcomes



- Value of accessible 'first step' programmes
- Variation between organisations
- Importance of making research feel less intimidating
- Resources required to establish programmes
- Wrap around support essential
- Reduces duplication across the system
- Impact of change across systems
- Link with SRL
- Publish RCP

TABLE 1, SHOWING A-PRIORI CATEGORIES AND EMERGENT THEMES FROM INTERVIEWS



Model	N	Predicted impact
Offer Webinar - 'how to guide'	1	National
Train-the-trainer & CoP	1	National
Annual Subscription Implementation Package	1	National
Spaces for external paying guests	6	National
Adaptation for other settings (e.g. hospices)	2	National
Partnership	1	Regional
Share with acknowledgment	1	National

TABLE 2, SHOWING CO-CREATED OPTIONS

05 Conclusion

- Community and wider care settings most likely to take the first step!
- Sharing reduces duplication and builds national approach.
- Collaboration creates system-wide value.

> “....just understanding **it's not scary** that's **such a big thing**”
> “.....it's a **massive jump** to say to someone who possibly isn't research active.....you have to be because the four pillars says so..... everyone then expects,....**oh God, I'm going to have to do a PhD**”.
> “ I think there is greater understanding now that if you want to get people on board, you have to **start lower** ” (interviewee)

Stay up to date:

arc-eoe.nihr.ac.uk/newsletter

arc-eoe.nihr.ac.uk

ARCOffice@cpft.nhs.uk

@ARC_EoE

NIHRARCEoE

NIHR | Applied Research Collaboration East of England