NIHR | Applied Research Collaboration East of England

NIHR ARC East of England Research & Impact Fellowship

We are pleased to share the success of our 13th cohort and celebrate all that they have achieved during the Fellowship programme.

2024-2025

NIHR | Applied Research Collaboration
East of England

Introduction

This booklet celebrates the outstanding work of the 13th 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 150 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 13th 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 Fellowship

Since 2010, over 150 fellowships have been awarded to professionals, from varying clinical and non-clinical backgrounds, social care services and third sector organisations.

Eunice Ann Doctolero

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The Journey Behind the Needle: Insights from My Haemodialysis Needling Study - The Role of the NIHR ARC EoE Fellowship

As a Renal Research Nurse at East and North Hertfordshire NHS Trust, I primarily supported the delivery of research studies. However, when I was awarded the NIHR Applied Research Collaboration (ARC) East of England (EoE) Fellowship, my career took a significant turn. This fellowship allowed me to lead my own research project, transforming my approach to research and personal development.

A Personal Connection: Why the Research Needed to Happen

The inspiration for my project, “Behind the Needle,” came from both my professional experience as a dialysis nurse and a gap in the literature. As a dialysis nurse, I’ve seen firsthand how important the needling process is to haemodialysis, but also how emotionally challenging it can be for both patients and healthcare professionals (HCPs). While much research focuses on the patient's experience, very little has explored the perspectives of the staff performing the procedure.

This gap became clear during my clinical work. I remember when I first started in dialysis a shared care patient in one of our satellite units taught me how to needle. It was a humbling experience that shifted my perspective on the procedure. I realised that needling wasn’t just a technical task—it was emotionally demanding for both the patient and the healthcare professional. Few studies address the emotional and technical challenges faced by healthcare professionals, which motivated me to lead this study.

The Role of the NIHR ARC EoE Fellowship: A Supportive Platform for Growth

The NIHR ARC EoE Fellowship was the perfect platform for my research journey. While I had experience supporting research studies, leading my own was a new challenge. The fellowship equipped me with the skills to navigate the entire research process, from writing the protocol and applying for Health Research Authority (HRA) approval to conducting interviews and analysing data.

> “The fellowship allowed me to transition from a research-supporting role to a research-leading one.”

It wasn't just about learning research techniques; it was about understanding how to design, implement, and evaluate a study. The mentoring I received from Professor Natalie Pattison, Professor Ken Farrington, and Dr Currie Moore was invaluable. Their guidance on structuring the study, formulating the research question, and handling ethical approvals gave me the confidence to proceed. Additionally, I received support from our lead research nurse and renal research manager, who ensured the study aligned with the Trust's goals and was feasible within our resources. This support was essential in gaining the necessary approvals.

The fellowship also helped me develop my communication skills. I had the opportunity to present my project to the Research and Development (R&D) department for approval and share it with the Patient and Public Involvement (PPI) group of dialysis patients. Presenting my ideas to these groups helped refine my approach and provided valuable feedback. The ARC fellowship taught me how to clearly articulate my research goals, a skill that has been invaluable throughout the project.

I remember telling my manager during my annual appraisal two years ago, "I want to join the NIHR ARC and do my own study." At the time, I wasn't sure how or when it would happen, but that conversation marked the beginning of my journey. Completing this project has been incredibly rewarding.

Research Process: Designing and Conducting the Study

The design and execution of the research was the most exciting part of the project. I conducted semi-structured interviews with twelve healthcare professionals (HCPs) involved in haemodialysis needling to understand their emotional and technical experiences. Recruiting participants was challenging, as healthcare professionals have busy schedules. However, with purposeful sampling, I gathered a diverse group whose experiences provided valuable insights into the needling process.

> What I enjoyed most were the interviews. It became therapeutic for me to listen to these healthcare professionals, learn about their challenges, and hear their personal stories."

The research process also had challenges. Transcribing interviews, coding data, and searching for themes was time-consuming and overwhelming. There were moments when I felt like giving up. But each time I faced these challenges, I pushed through, drawing strength from the process and the support I had.

Overcoming Challenges: Personal and Professional Growth

The journey wasn't without its challenges. With a clinical background and limited experience in leading research projects, I faced moments of self-doubt. I questioned whether I could carry out the project to the high standards I had set for myself. However, the support from my mentors and colleagues, both within the NIHR ARC EoE fellowship community and my Trust, helped me push through these doubts.

Through this process, I grew not only as a researcher but also as a person. I learned that research is not just about collecting data; it's about connecting with the people involved, Whether they are patients or healthcare professionals. Being a researcher requires listening, empathy, and constant reflection on the broader impact of the work. The action learning sessions in the NIHR ARC workshops became a therapeutic space for me. These sessions allowed me to share my experiences, receive feedback from fellow NIHR ARC fellows, and gain valuable perspectives that strengthened my emotional resilience and confidence.

Moving Forward: Impact and Future Directions

I hope the findings from the "Behind the Needle" project can help improve the needling process in our Trust and ultimately improve outcomes for haemodialysis patients. The study provides insights into improving training, mentorship, and support for staff. Moving forward, I plan to apply for funding for further research into cannulation practices. Additionally, I hope to publish the findings in a journal and present them at conferences to continue the dialogue on improving the needling experience for both staff and patients.

Conclusion: The Power of Research and Collaboration

Looking back on this journey, I am incredibly grateful for the opportunity to lead this research project. The NIHR ARC EoE Fellowship has been a rewarding experience, providing me with the skills needed to design and conduct a research study and the confidence to take on new challenges. This journey has reinforced my knowledge about the importance of collaboration, mentorship, and continuous learning in research.

> As I continue my career in renal research nursing, I remain inspired by the potential to make a lasting impact on both patient and healthcare professional experiences in the dialysis setting.”

Ultimately, this fellowship has truly been a journey—a journey of growth, challenges, and, positive change. I am excited to continue this path and I am looking forward to the next steps of my research career.

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NHS East and North Hertfordshire NHS Trust

A QUALITATIVE EXPLORATION STUDY OF HEALTHCARE PROFESSIONALS' PERSPECTIVE IN HAEMODIALYSIS NEEDLING TO ENHANCE PATIENT'S OVERALL EXPERIENCE

Eunice Ann Doctolero, *Renal Research Nurse*
Supervised by Ken Farrington, Natalie Pattison, and Currie Moore

INTRODUCTION

Haemodialysis requires regular and accurate vascular access, typically achieved via arteriovenous fistulas or grafts. Cannulation, the insertion of needles, is is a crucial component of successful haemodialysis. Although important, cannulation tends to cause the patient significant pain, distress, and fear.

Healthcare professionals (HCPs), predominantly nurses and healthcare assistants, are at the core of this procedure, and their level of competence directly influences patient outcomes. Needling is also recognised as challenging for HCP. Inadequate knowledge, skills, or behaviours can exacerbate needle-related distress, posing significant problems for both patients and staff. Despite its importance, this area is under-researched.

AIMS

This study aimed to understand HCP perspectives on cannulation to:

1) identify areas where additional training or support might be needed; and

2) explore how staff manage their role and ensure optimal patient care.

METHODOLOGY

Twelve HCPs currently performing HD cannulation were recruited from three Renal units within an NHS Trust in England. Purposive sampling ensured a diverse range of experiences and perspectives, encompassing variable work experience, shift patterns, and professional grades.

Semi-structured interviews explored various aspects of HCP cannulation experience: training, communication, patient management, work environment, and future improvements. Thematic analysis, using Braun and Clarke's framework, was employed to identify commonalities and differences, developing a comprehensive understanding of HCP cannulation experiences.

FINDINGS

Braun & Clarke Thematic Analysis

① EXPERIENCE AND SKILL DEVELOPMENT

"Experience definitely improves my confidence" (HCP2)

"The hands-on training helped me to develop my technique. At first, it felt overwhelming, but now, I feel more confident. I know that practice makes perfect."(HCP11)

② EMOTIONAL IMPACT AND STRESS MANAGEMENT

"I just laugh, talk to my colleagues to release stress" (HCP5)

③ PATIENT-CENTERED COMMUNICATION AND CARE

Communication. I mean, if they speak the same language and like you know, it is important that we avoid medical jargons when we're explaining to the patient.." (HCP2)

④ TEAMWORK AND SUPPORT

"We learn from each other and share experiences"(HCP8)

"Whenever I get stuck,I ask for help from a senior nurse" (HCP1)

⑤ TRAINING & DEVELOPMENT

"Mentorship is so important. Sometimes, you just need someone with more experience to guide you through the more difficult cases. They can offer invaluable insights." (HCP 12)

⑥ WORK ENVIRONMENT AND RESOURCES

"Good lighting is crucial. Without it, you can't see the veins properly, and that makes the whole procedure more difficult."(HCP6)

⑦ PATIENT EDUCATION AND PARTNERSHIP

"I always make sure the patient knows what's going to happen. When they understand the process, they feel more comfortable." (HCP5)

"Once the patient trusts you, they're more at ease. I always ensure that I communicate openly with them, so they know they're in good hands." (HCP11)

⑧ TECHNICAL CHALLENGES IN NEEDLING

"I always make sure that I use a tourniquet to stabilize the vein, making sure patient is pain free " (HCP2)

CONCLUSION

- Need for hands-on experience, mentorship, and stress management, as well as importance of teamwork, resources, and patient education improve the process
- Commitment to skill improvement and collaborative patient care
- Findings inform training, enhance practice, and guide future research

ACKNOWLEDGMENT AND CONTACT

Eunice Doctolero 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.

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Poster by Eunice Ann Doctolero

Giles Conneely

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My experience as an ARC Research Fellow researching GPS trackers and people living with dementia at home - What can we learn from Social Care?

My name is Giles Conneely, and I work for Norfolk County Council as a Technology Enabled Care Practitioner. I wanted to write this blog as a record of my experience as an Applied Research Collaboration (ARC) Fellow. I came into the programme with no academic background and have blossomed in this environment.

I became aware of the ARC Fellowship programme after becoming involved with the Social Care Research in Practice initiative (SCRiPT). This initiative was exciting because there had been lots of funding for research in Health and there was now a door opening for research to be conducted in Social Care. I joined the SCRiPT programme as a Research Associate, spending one day a month supporting a research project capturing people's attitudes towards sharing data gathered by technology enabled care sensors with Social Care Authorities.

It was involving because it related to my job and I met many interesting people, including those working in patient and public involvement (PPI). It's extremely important that the voice of the public should be heard. As a frontline practitioner, it was useful to work with people in this way, outside of a day-to-day professional relationship. Discussing the seeds for my own research project with a PPI member helped me plant and grow my ideas.

My specialism is the deployment of GPS sensors for people living with dementia who are at risk of getting lost. As part of this, I would collect monthly usage data but would only have time to look at the headlines. My motivation for doing the ARC Fellowship was to inform frontline services with the hope of improving them for people using GPS sensors.

> "The ARC Fellowship offered an opportunity to take a deep dive into the usage data and understand what lay beneath."

The application process seemed quite daunting, but there was plenty of guidance and support from the ARC and my supervisor, which helped me shape my application. Being invited to join the Fellowship was a validation of my dedication.

The programme started with a series of workshops over the course of eight weeks in Cambridge. With my cohort colleagues, we learned about subjects that would be helpful to us as we began our research journey. This included effective literature searching, the importance of research ethics, research design, methodologies, implementation, and critical appraisal. It was full-on but very helpful to have this learning at the start of the course. During those eight weeks, I really bonded with my cohort as we formed into our Action Learning Sets.

Then the hard work began. I was fortunate to have a very supportive supervisor who guided me towards my objectives and gave me just enough of a clue to work things out for myself. We devised the methodology for my research project. This consisted of a literature review so I could learn about existing research in my specialism. Alongside this was an analysis of the service usage data that I had been gathering, using descriptive and statistical analysis. Whilst ambitious for the time available, I was determined to find out more about my specialism and learning more.

> One of the highlights for me was going to the library at the University of East Anglia (UEA), which I found fascinating. It was a great space to work in and open all day every day.”

I would recommend any researcher make use of their library. Of course, there were lots of access to electronic resources as well, and I found I had a real flair for using these and funnelling the detail down to precise information. Growing this skill really helped me in my day job too!

I made sure to set myself targets and break down objectives into smaller tasks so I could stay on course alongside my work. At times, frontline social care can be quite distracting, but I was able to develop my time management skills. This ensured I was staying on top, or slightly ahead of my project.

Another highlight was meeting up with my Action Learning Set. These meetings were an opportunity to discuss the difficulties we were facing individually and find strategies for overcoming them together. It was great to have a space where we could just express ourselves, and it was very freeing.

In terms of my own personal development, this has been a fantastic year for me. I feel like I've grown quickly in a short space of time. I'm now able to apply the research skills I've learned and take a more critical approach to the work that I do. It’s led to being seconded into an exciting new role.

I've hit my objective of conducting my research, which has uncovered some very interesting findings. The fruits of my labour are very relevant to social care and will inform provision of GPS sensors.

At times I've faced difficult challenges; life still goes on outside the project. It's important to recognise that you need to be mindful about well-being and seek support. I found was always freely given by my cohort in the Action Learning Set meetings, the ARC team, or through work.

> This has been an amazing experience for me, and I'm looking forward to seeing where my journey will take me. Much like research, the future is unknown.”

It's quite true to say that the more I learn, the less I know, but that really drives me on to learn more.

I'm extremely grateful for this opportunity to have been a part of the ARC Fellowship, and I'm looking forward to my continuing growth in this nurturing environment.

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GPS trackers and people living with dementia at home –
What can we learn from Social Care evidence?

Giles Conneely[1], Sol Morrissey[2] and Michael Hornberger[2]
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Norfolk County Council

UEA University of East Anglia

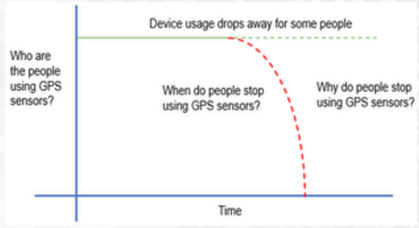
Background

40,000 people with dementia go missing every year in the UK

Incidents impact caregivers and services and can result in serious harm, or death

GPS sensors are used to support people at risk

Observation



Aim and Objectives

What Influences Adoption and Retention of GPS Sensors?

WHAT DOES THE LITERATURE SAY?

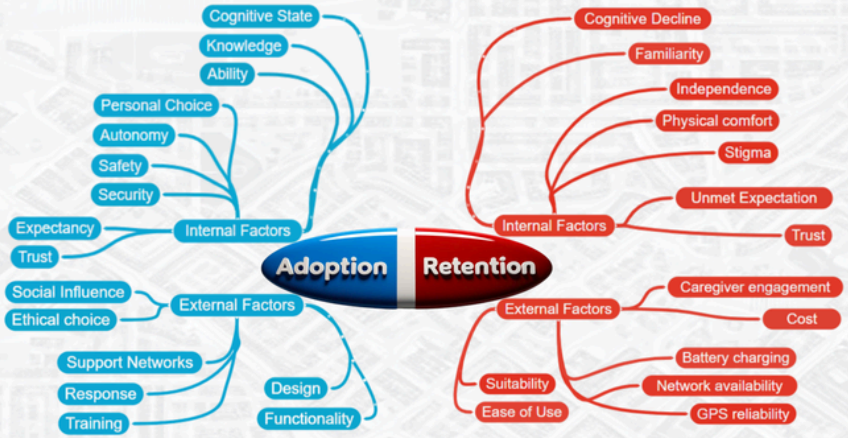
WHAT DOES THE REAL WORLD DATA SAY?

Method

Systematic Review

Analysis of Service Data

Themes Emerging from the Literature

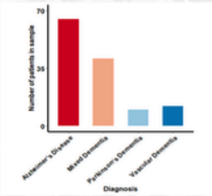


Adoption
- Internal Factors
  - Cognitive State
  - Knowledge
  - Ability
  - Personal Choice
  - Autonomy
  - Safety
  - Security
  - Expectancy
  - Trust
- External Factors
  - Social Influence
  - Ethical choice
  - Support Networks
  - Response
  - Training
  - Design
  - Functionality

Retention
- Internal Factors
  - Cognitive Decline
  - Familiarity
  - Independence
  - Physical comfort
  - Stigma
  - Unmet Expectation
  - Trust
- External Factors
  - Caregiver engagement
  - Cost
  - Battery charging
  - Network availability
  - GPS reliability
  - Suitability
  - Ease of Use

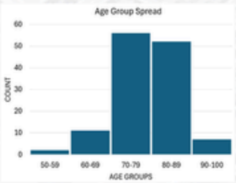
Results from the Service Data Analysis

Number of Participants = 128



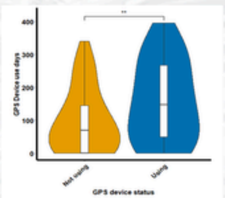
Both Alzheimers Disease and Mixed Dementia are linked with the loss of Spatial Awareness

Male 52 % - Female 48%

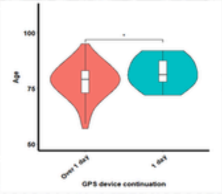


Most participants in the representative sample were between 70 and 89 years old

Overall Average Age = 79

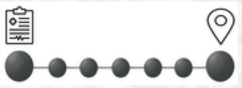


Participants were observed in two groups. Those Not using and those Using GPS sensors



Some participants used the GPS sensors only on the first day that they were issued

GPS Sensor Usage
Not using 50% - Using 50%



Median delay between diagnosis and GPS sensors being issued is approximately 16 months

Reasons for the non-use of GPS sensors are shown as External and Internal factors

Conclusions

- Literature is sparse and no clinical trials exist
- Adoption and Retention are a complex interplay of factors
- Conditions associated with the loss of Spatial Awareness are the main predictor of GPS sensors being issued
- There is a delay between diagnosis and GPS sensors being issued
- The median use of GPS sensors is 127 days
- An eighth of GPS sensors are not used beyond day 1
- User age influences continuation of use beyond day 1
- Change in circumstance and issues managing the device are the main reasons for non use

Acknowledgements

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The views expressed are those of the author and not necessarily those of the NIHR or the Department of Health and Social Care.

With much thanks; Chris Metcalf, Chris Clark, Jeremy Dearling,
Liz Wiggins, Sol Morrissey, Michael Hornberger, ARC Cohort 13

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Bridging the gap between research and practice on an inpatient neurorehabilitation unit

For the first five years of my career, I worked part-time in research at University of East Anglia and part time as an occupational therapist for the NHS. While both roles were fulfilling, I often felt frustrated by the disconnect between the two. In research, clinical practice was frequently misunderstood, whilst in healthcare, research findings were often met with scepticism. Given this, it wasn't surprising to learn that current estimates suggest that it takes 17 years for research to be implemented into clinical practice.

> I joined the ARC EoE Research Fellowship with the aim of narrowing the gap between research and practice by conducting research about, and in, my clinical setting."

I developed and led the MERIT project, which explored family members' expectations of recovery in inpatient rehabilitation for people with moderate to severe brain injuries, and how these expectations are managed when they do not align with clinical opinion. MERIT comprised a scoping review and qualitative interviews with my colleagues at Colman Hospital, Norwich.

Aligning my clinical and research interests provided numerous benefits I hadn't experienced as a 'siloed' researcher-therapist. First, it gave me the opportunity to identify a research question that was highly relevant to the service. The recurrent challenge of families' 'unrealistic expectations'– an issue frequently reported by colleagues and encountered personally – became the catalyst for my research project. By ensuring that the research focused on a priority area, I gained greater buy-in from colleague participants. In my previous work as a researcher, recruiting staff for interviews was often difficult, but this time I had more participants than I had capacity to interview. This was also partly due to my increased presence in the clinical setting (through my therapist role), which allowed me to be more flexible in responding to clinical needs. For example, interviews could be scheduled outside of working hours or rearranged to accommodate colleagues' workloads.

Being a familiar clinical colleague appeared to facilitate trust and open communication during interviews. Colleagues frequently referenced our shared experiences, and many disclosed the emotional and psychological impact of misaligned expectations. I believe this openness may have been less likely had I been an unfamiliar researcher. While it's important to acknowledge that familiarity could have introduced bias, overall, I feel it positively influenced the quality of the research.

In terms of my personal development, the project has had a significant impact on the way I work with families. While conducting the data analysis for the scoping review, I was deeply moved by the experiences shared by families. I hadn't previously considered how some of my seemingly innocuous actions or responses could negatively impact their well-being or understanding.

> The research held a mirror up to my practice and broader healthcare norms, which I now feel more empowered to challenge in order to foster positive change."

As a result of this project, I have made a series of seemingly small changes to my practice and have already noticed their positive impact on my relationships with family members. I now aim to meet each family as soon as possible to introduce myself and explain ward processes. I work with the patient and their family as a unit, treating them as integral members of the multidisciplinary team. I also encourage families' involvement in the rehabilitation process as far as they feel able. While I remain realistic about a patient's current situation, I am more confident in acknowledging and validating a family member's hopes for the future. Additionally, I've gained a deeper respect for my colleagues, who demonstrated such compassion, wisdom, and insight during their interviews.

Conducting research alongside my clinical role was not without its challenges. Interpreting data from both the review and the interviews through the lens of a healthcare professional did introduce potential biases. This came to light when sharing the results with a carers' group as part of a Public and Patient Involvement and Engagement (PPIE) activity. In this group, my assumption that healthcare professionals were already sharing information in a way that families could access (a recommendation within the scoping review) was challenged. This prompted me to reflect on areas of unconscious incompetence in my practice, reframed my interpretation of the review, and reminded me of the importance of PPIE in research.

Balancing the demands of my clinical role with a research project I was deeply passionate about was challenging at times. With a heavy caseload and limited NHS budgets, I wasn't able to devote more than the allocated 40 days to the project. As a result, I found myself working evenings and weekends – making it a true labour of love.

> I suspect that developing as a clinical academic in this climate will not be easy. I anticipate that developing as a clinical academic in this environment will continue to be difficult.”

I’ll likely need to secure my own funding for future research and make a strong business case for reducing my clinical hours. However, with a range of available opportunities through NIHR, I feel optimistic that with some initiative and creative thinking, this is achievable.

I am proud of what I have accomplished through the ARC EoE Research fellowship. I look forward to disseminating my findings further and continuing my mission to close the research-practice gap.

How do healthcare professionals address ‘high’ expectations of family members in brain injury rehabilitation?

NIHR | Applied Research Collaboration East of England

Jessica Blake*, Guy Peryer, Sheryl Parke, Rachel Dance, Aidin Aryankhesal, Morag Farquhar

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Introduction

- 60-67% survivors of severe acquired brain injuries will have significant long-term disability [1-2].
- Rehabilitation often focusses on living well with disability (‘disability management’), rather than restoring function.
- Family members frequently have expectations of recovery that do not match healthcare professional (HCP) opinion.
- There are currently no guidelines on how HCPs can identify and address these expectations to best support family members and clinical workflow.

Aims

- To understand how expectations are currently managed.
- To determine the impact of misaligned expectations on HCPs.
- To identify modifiable areas for improvement.

Methodology

- A scoping review [3].
- Qualitative interviews with staff (n=18) at a rehabilitation unit for people with complex brain injuries.

Key Findings

- There is inconsistent messaging from HCPs about prognosis and what rehabilitation is likely to achieve.
- Healthcare systems can devalue family contributions.
- HCPs often lack the physical and emotional resource to support families.
- Poorly managed expectations can have severe consequences for HCPs and service provision.

Recommendations

- Explore and set expectations early.
- Check in regularly to prevent problems escalating.
- Consider a ‘rebranding’ of rehabilitation to include disability management and family-centred care.

Impact on HCPs

“If you end up in conflict, then that will spill over, you'll get complaints...it'll actually impact on the whole team working with the individual. And it will impact on length of stay.”

“Physiotherapy and speech and language therapy were getting increasing...verbal abuse from this family and at one point some of the family members were banned from coming in.”

“It is really horrible... even though you can reason it all and it's not anyone's fault that he's not made the progress, when it's aimed at you, it's really hard to not feel guilty, to not feel like you haven't achieved something for these people.”

Next Steps

- Disseminate findings both internally and externally.
- Understand perspectives of family members and patients.
- Quantify impact of misaligned expectations (e.g. on length of stay, staff resource, complaints).
- Consider development of an intervention, co-designed by families and PPIE representatives.

1.Ruet, A., Bayen, E., Jourdan, C., Ghout, I., Meaude, L., Lalanne, A., Pradat-Diehl, P., Nelson, G., Charanton, J., Aegerter, P., Vallat-Azouvi, C. and Azouvi, P. (2019). A detailed overview of long-term outcomes in severe traumatic brain injury eight years post-injury. Frontiers in Neurology, 10(120). doi:https://doi.org/10.3389/fneur.2019.00120. 2. Rosenfeld, J.V., Maas, A.I., Bragge, P., Morganti-Kossmann, M.C., Manley, G.T. and Gruen, R.L. (2012). Early management of severe traumatic brain injury. The Lancet, 380(9847), pp.1088–1098. doi:https://doi.org/10.1016/s0140-6736(12)60864-2. 3. Blake, J. et al. (2025) ‘How can healthcare professionals work with families to address misaligned expectations of recovery in brain injury rehabilitation? A scoping review’, Brain Injury, pp. 1–14. doi: 10.1080/02699052.2025.2450603

UEA University of East Anglia

NHS Norfolk Community Health and Care NHS Trust

Jessica Blake and Norfolk Community Health and Care 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[s] and not necessarily those of the NIHR or the Department of Health and Social Care.

Poster by Jessica Blake

Joanne Clark

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Seeking to address the evidence-base gap; one occupational therapists' contribution

As an occupational therapist I believe that it is essential for people's health and wellbeing that they can participate in meaningful activities. There is limited evidence to guide practice on the most effective way to help people affected by brain injury in resuming meaningful activities.

> My desire to change this situation [lack of evidence on how best to support people affected by brain injury in resuming meaningful activities] was why I applied for a Fellowship.”

One consequence of moderate-to-severe brain injury can be a disorder of consciousness; the person affected shows little, or no, awareness of the world around them. Several research studies have shown that Structured Sensory Stimulation Programmes can improve level of consciousness during acute care, particularly if family members are involved in delivering stimulation. However, anecdotal evidence suggested that the use of these programmes was not consistent.

The mixed methods study I carried out aimed to identify what stimulation was being carried out and what factors influenced the use of sensory stimulation. I carried out a retrospective review of documentation within one Major Trauma Centre and distributed an electronic survey of healthcare professionals to people working in all the Major Trauma Centres in the UK.

I had opportunity to discuss my plans for surveying staff with the ARC PPI Hub group who would enthusiastic, encouraging and asked (useful) probing questions. The PPIE group at CUH were crucial in developing the survey forms; their insight and experience led to several fundamental changes to the documents used. This was my first experience of interacting with patient/public involvement groups and I found it a very constructive and valuable process.

I reviewed documentation relating to 74 patients who had been admitted to the Neuro-Critical Care Unit at Addenbrooke’s Hospital and received survey responses from 39 healthcare professionals working in 7 Major Trauma Centres across England and Scotland.

> The results of my study have shown that the use of sensory stimulation is variable and inconsistent; the use of structured programmes is even less common."

I reviewed documentation relating to 74 patients who had been admitted to the Neuro-Critical Care Unit at Addenbrooke's Hospital and received survey responses from 39 healthcare professionals working in 7 Major Trauma Centres across England and Scotland. The results of my study have shown that the use of sensory stimulation is variable and inconsistent; the use of structured programmes is even less common.

Family members are rarely given education/training to participate in providing sensory stimulation – despite evidence showing that they want to be involved. Factors influencing the use of sensory stimulation included; knowledge/skill, time, working environment/resources and confidence.

Throughout the Fellowship I have been supported and guided by my research supervisor, Dr Virginia Newcombe, who has provided practical support as well as signposting to training and networking opportunities to aid in developing my research knowledge, skills and career. I have also valued the support of my peers in the Action Learning Set meetings. These have provided a safe space to share experiences as well as providing an opportunity to learn about research and systems processes in settings that are different from the one I work in.

Now that I have identified current clinical practice and the views of healthcare professionals as to enablers and barriers to use of structured sensory stimulation the next step is to develop resources and processes to support better practice.

> I am looking forward to undertaking an Impact Fellowship to co-design training and support materials for healthcare professionals and family members to use."

My advice for anyone wanting to undertake an ARC EoE Fellowship; be realistic about what you can achieve in the timeframes, link with others and get lots of feedback and advice, take time to set up folders and work systems. Above all – my advice is that if you have a research idea that can improve clinical practice – apply for a Fellowship and give it a go you will learn lots, work with some fantastic people and have some fun along the way. into an exciting new role.

Brain Injury Rehabilitation in Acute Care - Are We Stimulating Enough?

Joanne Clark: Advanced Occupational Therapist - Critical Care, Cambridge University Hospitals (CUH) NHS Foundation Trust https://orcid.org/0009-0000-2984-8337
Dr Virginia Newcombe: Consultant Cambridge University Hospitals NHS Foundation Trust, Associate Professor University of Cambridge https://orcid.org/0000-0001-6044-9035
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Introduction

Over 66,000 people in the UK will have a moderate-to-severe brain injury each year [1, 2].

These brain injuries can result in a Disorder of Consciousness (DoC); a low awareness state [3].

Structured Sensory Stimulation Programmes, involving systematic application of stimuli, have been shown to improve consciousness; particularly with family involvement [4].

Family members have stated they want to be involved in patient care [5].

Objective

Anecdotal evidence suggests that the use of Structured Sensory Stimulation in practice is variable in nature and inconsistently delivered.

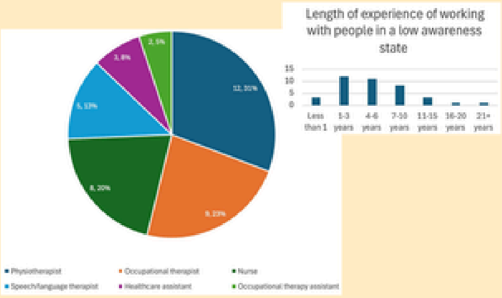
The aims of this project were to;
1. Identify what sensory stimulation is used in practice
2. Identify enablers and barriers to the use of Structured Sensory Stimulation Programmes

Methodology

- A retrospective documentation review was undertaken.
- Inclusion criteria: admission to adult critical care unit between April 2022 and March 2024, Coma Recovery Scale-Revised (CRS-R) assessment undertaken (n = 74).
- Exclusion criteria: patients who had had a CRS-R but who died during their admission (n = 25).

	Trauma patients	Non-trauma patients
Age, mean (range)	47 (17-81)	58 (23-78)
Sex, male	32 (82%)	16 (46%)
Primary diagnosis		
- Traumatic brain injury	39 (100%)	0
- Intracerebral haemorrhage	0	23 (66%)
- Spontaneous subarachnoid haemorrhage	0	9 (26%)
- Other	0	3 (9%)

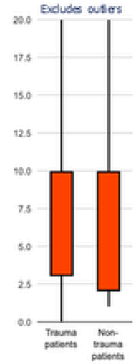
- An electronic survey was distributed via snowball dissemination to healthcare professionals working with patients with moderate-to-severe brain injury within Major Trauma Centres in the UK (n = 39).
- Responses obtained from 7 out of 28 centres.



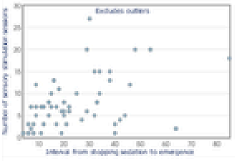
Length of experience of working with people in a low awareness state

Results

Median number of **sensory stimulation sessions** received = 6.5 (range 1-40)

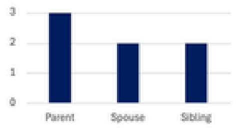


Frequency of sensory stimulation vs. time to emerge from DoC



9 patients received a **structured** sensory stimulation programme

7 (9%) patients' **family** members received training in sensory stimulation, 2 involved **structured** sensory stimulation

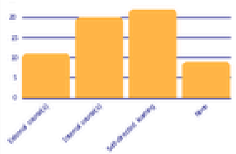


Family training was most frequently provided by occupational therapists (60%)

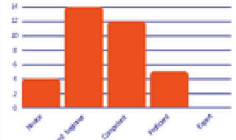
Change in level of consciousness

Best behavioural level observed	Initial CRS-R assessment	At transfer from acute care
Emerged	1 (1%)	52 (70%)
Emerging	0	5 (7%)
Minimally Conscious State Plus	5 (7%)	9 (12%)
Minimally Conscious State Minus	26 (35%)	5 (7%)
Vegetative State	26 (35%)	5 (7%)
Coma/ No Response	4 (5%)	0

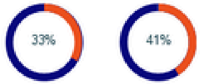
Training in the assessment/ treatment of DoC



Self-rated confidence to treat DoC



Awareness and use of **Structured** sensory stimulation programmes



Respondents report of provision of family training (usually face-to-face using a formal programme

Factors influencing use of SSSP;
- Lack of knowledge/skill - 14 (36%)
- Insufficient time - 11 (28%)
- Non-conducive working environment - 9 (23%)
- Lack of confidence - 8 (21%)
- Lack of appropriately trained staff - 7 (18%)
- Lack of awareness of Structured Sensory Stimulation Programmes - 7 (18%)
- Lack of treatment materials - 4 (10%)
- Insufficient access to interpreters - 2 (5%)

Reasons for not providing family training in the use of sensory stimulation included:
- Lack of confidence - 21 (54%)
- "Not my role" - 12 (31%)
- Lack of access to resources - 8 (21%)
- Lack of time - 6 (15%)
- Family not visiting during working hours - 2 (5%)
- Lack of interpreters - 1 (3%)

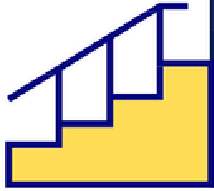
Conclusions

- The use of sensory stimulation in practice is variable and inconsistent
- Little training is provided for family members to enable them to use sensory stimulation
- Healthcare professionals lack knowledge, skill and confidence to deliver Structured Sensory Stimulation
- Lack of access to training and support materials impacts on the provision of sensory stimulation

Next steps

Next step… **NIHR ARC EoE Impact Fellowship**
Co-design training programmes and support materials;
- Training programme to help staff to deliver Structured Sensory Stimulation Programmes
- Training programmes for staff members to use when training family members
- Examples Structured Sensory Stmiulation Programmes to ease implementation

Future steps…
- Study to evaluate the feasibility of using the co-designed materials to enable consistent use of SSSP
- Study to evaluate the impact on family members feelings of self-agency and quality of life through involvement in the use of SSSP



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Acknowledgements

Joanne Clark and Cambridge University Hospitals 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 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.

Thanks go the NIHR ARC EoE PPI Hub and CUH PPI Panel, along with the numerous colleagues, family members and friends who have provided practical advice and support.

Poster by Joanne Clark

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Twists and turns: navigating the Fellowship through a period of change

Over the past year I have had the privilege of participating in the ARC Research Fellowship programme. I came to the Fellowship having unexpectedly found myself in a Research Director role in the voluntary sector. My work was focused on qualitative research with community members and groups to inform local priorities and distribution of funding, while building partnerships with researchers across the 'system' who were interested in strengthening community voice in their work.

Although many of my earlier roles had involved secondary research to involve strategy, policy and innovation, I had limited experience of primary research."

Although many of my earlier roles had involved secondary research to involve strategy, policy and innovation, I had limited experience of primary research. In some ways this was exciting because I was on a steep learning curve and testing how to do things in the moment. However, I was also aware of the importance of doing the work ethically and to a high standard and felt that I lacked the knowledge to do this. I also recognised that because my organisation was operating outside the academic system, I didn't have the safety net of a more experienced supervisor or ethics committee to help guide my work.

I started to look for guidance on ethics and doing research 'well' that felt proportionate to the type of work we were doing and the capacity within the team. Whilst I identified some great resources that touched on the issue of ethics in community-based research (including ARVAC's Community Research Toolkit and the work of Durham University's Centre for Social Justice and Community Action), there still seemed to be a gap in terms of ethical guidelines for community research carried out by non-academic organisations.

Through my project I wanted to understand the current literature on ethics in community research to test whether there was in fact a gap. From the insight gained through my literature review and interviews with voluntary sector colleagues, I also hoped to be able to develop a practical framework that I could use in my community research work. This was intended to help me to identify and manage ethical issues and could be shared with others working in similar roles within the voluntary sector.

Things didn’t quite go to plan. I found carrying out a literature review much more time consuming and complex than I had expected. I had to learn from scratch at every step, from setting up my EndNote software to help with citation management, to carrying out database searches. As a result, I leaned heavily on YouTube tutorials, Helen Aveyard’s book on conducting literature reviews in health and care, and the (fantastic) video guide to carrying out a literature review, produced by Matthew Hawkes, one of the UEA Librarians. It all took longer than I’d expected.

> Whilst learning what to do took time, working out *how* to do it was also a challenge.”

I felt a tension between following the research process in a structured ‘correct’ way (as recommended in the ARC introductory sessions and the literature review guides) and taking a more relaxed approach where I followed my interest and was less concerned with the ‘rules’ (as urged by my supervisors, recognising the limitations of my time on the project). I’m still not sure that I have fully reconciled that tension, but I am pleased to understand the process in full, even if I didn’t manage to complete every step.

As I grappled with the complexities of my project, I was also experiencing a period of change in my career. I was fortunate to be successful in applying for an exciting new role in a different organisation but by the end of November, a challenging few months had taken their toll, and I fully stepped back from the Fellowship for a few weeks to regroup and rebuild some energy for a fresh start in the new year.

Although my Fellowship didn’t fully go to plan and, at the time of writing (early January), I haven’t finished my project, I am so grateful to have been part of the programme. Without exception my fellow Fellows have been the loveliest, most supportive, inspiring group of people. It has been a privilege (and a lot of fun) to get to know them and travel through the Fellowship together. The Action Learning Sets with Liz have been a highlight of the programme, creating a safe space for us to share the highs and lows of our research journeys. The ARC team have been supportive throughout, open to hearing feedback and adapting the programme to help meet our needs. I’m also grateful to my supervisors for generously sharing their time, knowledge and experience with me and helping me successfully navigate the formal ethics committee process.

Whilst my next steps in research aren't completely clear at this stage, I have learned a huge amount over the past year that I will apply in my day-to-day work.

> I have always been passionate about community-based research and the importance of people's voices being heard, but now have a better understanding of how to do this ethically and well."

I have always been passionate about community-based research and the importance of people's voices being heard, but now have a better understanding of how to do this ethically and well. I hope to be able to share this learning as I move forward with my role in health.

ETHICAL RESEARCH APPROACHES (IN COMMUNITIES) STUDY

A study to explore the ethical issues that may arise in community-based research, how these can be managed, and what effects an increased focus on ethics could have on this type of research and the communities involved.

INTRODUCTION

In recent years, there has been increasing interest in community-based participatory research (CBPR) and the involvement of the public in shaping policy and service design, particularly within health.

Whilst there are clear ethical frameworks and processes for CBPR carried out within academic institutions and the NHS, there appear to be few published ethics guidelines for community research carried out by non-academic organisations, such as volunteer-led groups or charities.

The absence of ethical guidance and processes may have several effects, such as discouraging the participation of diverse communities in research. The study therefore focused on identifying what ethical issues are relevant in community research and how they can be practically managed.

AIMS

To scope existing literature on ethics in community research and identify the ethical knowledge gaps (for example, in relation to community-based organisations carrying out research).

To understand potential effects of a clearer framework for ethics in community research.

To create a workable practice framework for identifying and addressing ethical issues to be usefully identified and managed in community research.

METHODOLOGY

The main research question developed was:

'What are characteristics of an ethics framework to fit community-based research? What effects could a clear framework for ethics in community research have?'.

To identify studies and reports relevant to my literature review I searched electronic databases (Web of Science, Medline EBSCO) and the reference lists of key studies. Searches combined terms from two themes – community-based research (community-based participatory research, CBPR, community-engaged research) and ethics (ethic*).

Terms were searched as both keywords in the title and/or abstract and subject headings as appropriate. The research was restricted to English-language studies. No date limits will be applied. A range of exclusions were applied including studies that were not qualitative, studies that are non-EU/G7/AUS/NZ-based, studies that focused exclusively on Indigenous population and studies that focused on one specific method, e.g. Photovoice.

EndNote software was used for citation management. Findings were collected and analysed iteratively using qualitative thematic analysis (Braun & Clarke, 2006).

I hoped to carry out semi-structured interviews with members of community-based organisations with experience of involvement in community research to explore the needs, benefits and risks associated with establishing an ethics framework for community research but these were not completed.

Author

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Katy Rutherford (Norfolk and Waveney Integrated Care Board) is supported by the National Institute for Health and Care Research (NIHR) Applied Research Collaborative 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.

Affiliations

NIHR | Applied Research Collaboration East of England
UEA University of East Anglia
NHS Norfolk and Waveney Integrated Care Board

> 'Ethical review forms and guidelines overwhelmingly operate within a biomedical framework that rarely takes into account common CBPR experience'.
> (Flicker et al, 2007)

FINDINGS

There is ongoing interest in community-based participatory research (CBPR), particularly amongst North American academics (all selected studies were US or Canadian-based).

Studies focused on characteristics of 'good' CBPR from an academic perspective, with consideration of ethics core to this, e.g.

- Equitable, co-operative and collaborative, generates knowledge that is useful to communities, relational, long-term commitment and process, focus on equity, reflexive, leaves lasting capacity within communities.

A small number of studies offered practical guidance on carrying out 'ethical' CBPR, e.g.

- Creation of community advisory boards, training for Institutional Review Boards/ethics committees, ethical frameworks or terms of reference to guide projects with communities.

There was limited discussion of effects of a stronger consideration of ethics in CBPR. Again, studies primarily focused on the academic perspective. Some studies found that focusing on ethics leads to better quality research, ensures community relevance of research, and can build community voice, capacity and trust.

A future project could fill the apparent evidence gap by exploring the issues of ethics in research from a community-led perspective.

> 'The principles involved in conducting ethical CBPR are largely synonymous with the principles of CBPR itself - close collaboration, trust, mutuality, shared power and decision-making, and joint data ownership'
> (Mikesell et al, 2013)

> 'We conceive of ethical conduct in research as that which maximises beneficence and minimises harm... it entails the continued adjustment of research practice'.
> (Cordner et al, 2012)

CONCLUSION

The study has identified an apparent evidence gap in the exploration of ethics in research from a community-led perspective.

A future project could carry out primary research with community organisations and academics to explore this in more depth and create a practical framework for identifying and addressing ethical issues in community research.

Poster by Katy Rutherford

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First Episode Psychosis in women at mid-life: An evaluation of clinical presentation and treatment in CAMEO Early Intervention Service (EIP) across a three-year period 2016-2019 and recommendations for practice guidelines..

Psychosis is a severe mental illness which affects up to 3% of the population and is associated with significant impairment in social functioning and shorter life expectancy. It is ranked as one of the top causes of disability and most expensive illnesses worldwide through costs related to hospital admissions, physical health co-morbidities and unemployment.

Early Intervention in Psychosis (EIP) are multi-disciplinary teams set up to seek, identify and reduce treatment delays at the onset of psychosis and promote recovery by reducing the probability of relapse following a first episode of psychosis. Timely access to EIP is shown to have a significant long-term impact on the lives and livelihood of individuals with psychosis and their families.

Early Intervention in Psychosis (EIP) services have been youth-focused since their inception. In England, recent NICE guidelines and the new National Health Service Standards for EIP recommend the expansion of the age acceptability criterion from 14-35 to 14-65.

> As we move to develop services within Early Intervention for Psychosis to include those up to the age of 65 there are several issues that EIP teams need to take stock of when planning care and treatment for women in the 'over 35 years' age bracket."

During a three-year period of treating women over 35 years of age at CAMEO the Early Intervention service for Psychosis, covering areas around Cambridge and Peterborough, we observed a higher rate than expected of women at mid-life age experiencing their First Episode of Psychosis. There is clear evidence that the onset and course of other psychiatric presentations such as mood disorders at mid-life relate to changes and symptoms associated with menopausal transition. However, although well recognized, women at midlife have a second peak of vulnerability for developing psychotic symptoms, there is little researched relevance or consideration of the role or impact of menopausal transition in First Episode Psychosis. As a result, there is currently no mention of this subject in formal clinical guidelines.

With over 35s having rejoined our caseload at CAMEO, we see an opportunity to better understand clinical presentation and treatment of women with FEP in the mid-life age range (aged 40-60) and the well-recognized, but little researched relevance of menopausal transition to First Episode Psychosis in women.

Methodology

We have completed 44 electronic case note reviews of all relevant cases taken from a 3-year period between 2016-2019 when CAMEO Early Intervention Service were accepting over 35s referrals.

I applied the PANSS assessment tool and data points to the same number of cases for the under 35-year group.

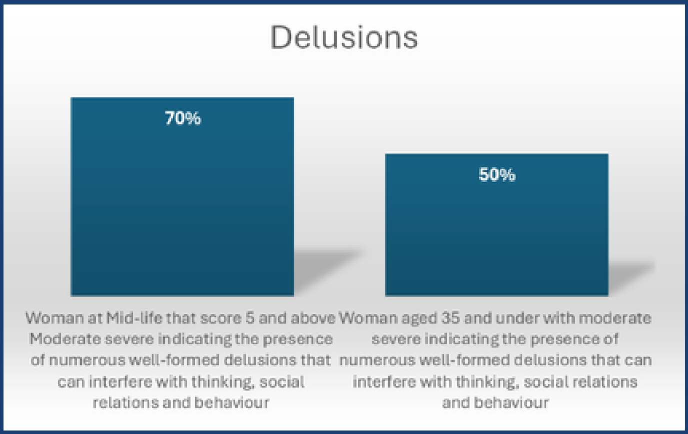
We chose midlife as aged 40 to 60 because although we accept that menopausal status cannot be predicted reliably by age (Culbert et al, 2022), this age range covers the menopausal transition years and would cover up to 5 years before clinical symptoms appear, and when psychological symptoms may be more prominent than biological signs (Kulkarni, 2018). This age range is also consistent with the consensus age range of late-onset schizophrenia-type illness (Howard et al, 2000).

We chose the PANSS assessment tool as a standardized, clinical interview that rates the presence and severity of positive and negative symptoms, as well as general psychopathology for people with psychosis and was published in 1987 by Stanley Kay, Lewis Opler, and Abraham Fiszbein. We reviewed the electronic case notes during the acute phase of illness and scored symptoms noted to be present by all health care professionals, possibly by different health care settings such as A&E, in-patient care, Crisis Team assessments and of course our cameo assessments.

Results

Here are our results from the PANSS assessment applied to the women's case notes 70% of women at midlife scored delusions at or above moderately severe indicating the presence of numerous well-formed delusions that can interfere with thinking, social relations and behaviour compared to 50% of the under 35 age range.

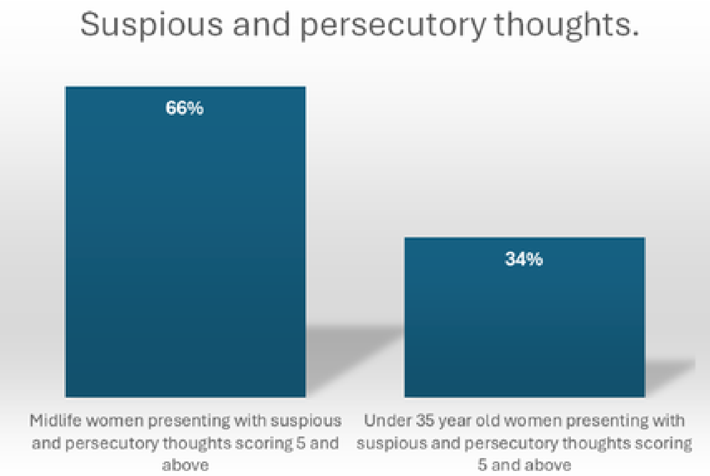
Delusional disorder most often first occurs in mid-life, a time that corresponds with the menopause in women, and menopausal age correlates with increased development of both somatic and psychological health problems in women. It is associated with a rise in the prevalence of depression and a worsening of prior psychotic symptoms. Importantly, women with



delusional disorder show low compliance rates with both psychiatric treatment and with medical/surgical referrals. (Alexandre Gonzalez-Rodrigues et al 2021). With this in mind and our clinical experience we wondered if these women would score with Somatic concerns on the PANSS with delusional themes, interestingly only 14% scored severe symptoms compared with 5% for the under 35 cohort.

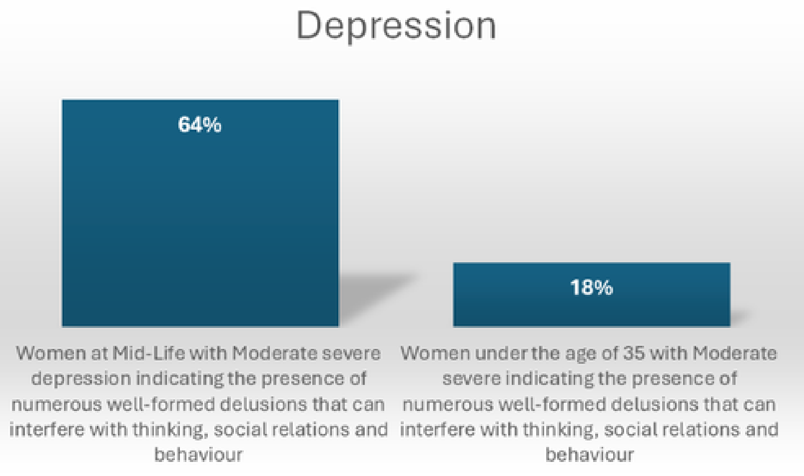
> Our clinical experience left us being curious about the struggles of engaging these women at mid-life, I have to say all this research was about us being curious!!!”

This could be explained by suspicious and persecutory thoughts scoring high on the PANSS assessment characterised marked distrustfulness with major disruption to interpersonal relations with evidence of persecutory delusions. 66% of our women at midlife reported such symptoms compared to 34% of women under the age of 35.



We then wondered about the impact of depressive symptoms characterised by a major impact on social inclusion, isolation, negative thoughts. 64% of our women at midlife expressed obvious sadness, pessimism, loss of social interest, psychomotor retardation, interference with sleep and appetite, compared to 18% of our younger population.

But as looked at the scores for severe and extreme depression described as feelings that seriously interfere in major functions with possible depressive and nihilistic delusions and/or suicidal thoughts or action, 50% of our women at mid life suffer compared to 9% of our comparison group.

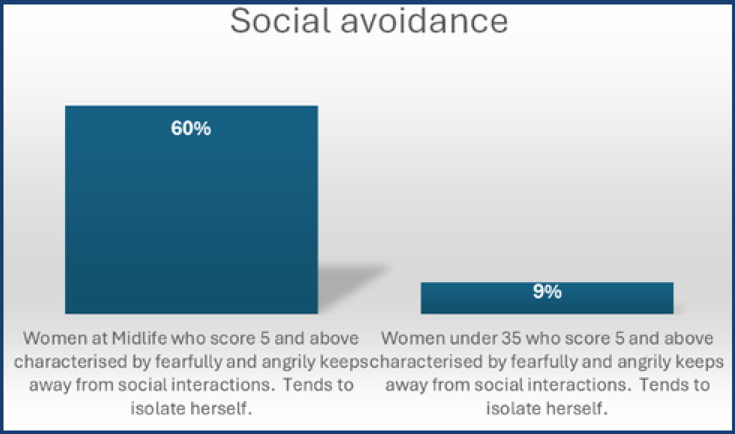


Middle-aged women (age 40-55) have been found to be at higher risk of depression. Part of it stems from the natural hormonal alterations of perimenopause and menopause. However, it tends to be about more than just hormone changes: Midlife can be a time marked with greater losses, like empty-nest syndrome, ailing and/or deceased parents, career changes, and a loss of former friendships, marital and love partnerships. Additionally, women in midlife have reported higher rates of pain and physical ailments.

Again, this theme is confirmed when we looked at women’s avoidance of social activities.

> “60% of woman at mid-life fearfully and angrily kept away from social interactions and would tend to isolate herself, compared to 9% of women aged 35 and below.”

This again could lead to women at midlife struggling to engage with mental health services.



We chose data points from our scoping literature review – which will play a role in our write up, these points were evidenced within the literature as playing an important role for women at midlife.

We found that women whatever age were hitting EIP teams at around 60% through our in-patient settings.

Historically EIP teams were set up to avoid these devastating admissions to psychiatric hospitals, reducing the impact of duration of untreated psychosis and set up to take referrals from any setting even encouraging self-referrals. We need to take stock of this finding and discuss again the important role of health promotion and engagement with the community.

Disappointingly we found women were not being asked about their trauma history when we know high rates of trauma, particularly multiple childhood victimisation is noted in women experiencing psychosis compared to the general population. However since this time we have recruited a clinical psychologist whose role it is to embed trauma informed care within the service and recently we have started to recruit to the NETp trail which hopes to see whether it is feasible and acceptable to deliver, and test through a pilot randomized control trail, to reduce symptoms of post-traumatic stress disorder as they are known to impact on recovery from psychosis.

As for only 2 women at Mid-life being asked about menopause and symptoms associated with that, Dr Cate Treise has devised a Mid-life, Menopause Screening tool which has been set up as a service evaluation so every woman between the ages of 40 and 60 will have the opportunity to discuss symptoms with mental health professionals within EIP teams adopted this.

Conclusions

- Women at Mid-life experience more severe psychotic and psychiatric symptoms in many domains compared to the under 35-year-old population.
- Women suffer greatly with symptoms of depression, social avoidance and suspiciousness which can affect engagement with mental health services.
- Mental health services within CPFT between these dates are not asking about symptoms of menopause when there is clear evidence that this hormone transition time has an impact on women's mental health.
- We need to acknowledge the role of trauma in the client group and offer personalised care to support recovery from psychosis.
- At menopausal transition estrogen is in decline which creates a greater vulnerability for psychotic symptoms.
- Anti-psychotic response appears to be worse during the menopause period, probably due to the impacts of estrogen decline and the reduced sensitivity to dopamine, this means higher doses are needed leading to greater risk of side effects on a population which is already struggling with metabolic challenges and other physical health care needs.
- It is still important to point out other relevant physical and psychosocial factors related to the aging process in women such as physical disability, retirement, financial difficulties, marital status, changes in home situation, career, caretaking responsibilities, bereavement and deaths of peers that represent additional stress and can increase the vulnerability for psychosis.

First Episode Psychosis in women at mid-life: An evaluation of clinical presentation and treatment in CAMEO Early Intervention Service (EIP) across a three-year period 2016-2019 and recommendations for practice guidelines.

Lizzie Kenedler, Dr Cate Treise, Dr Liliana Galindo-Guarin and Professor Peter Jones

> *As we move to develop services within Early Intervention for Psychosis to include those up to the age of 65 there are several issues that EIP teams need to take stock of when planning care and treatment for women in the 'over 35 years' age bracket'.*

At menopause transition eastrogen js in decline which creates a greater vulnerability for psychotic symptoms.

Scoring the Results. % score of symptoms Moderate/Severe and above on the PANSS Scale, 1987 by Stanley Kay.

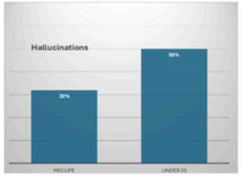
Methodology

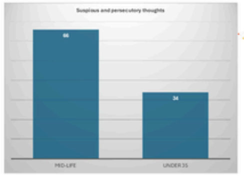
We did a historical electronic case note review of 44 women at mid-life and a comparison cohort of women under 35 years old treated by CAMEO Early Intervention Service over a 3-year period between 2016-2109. The aims are:

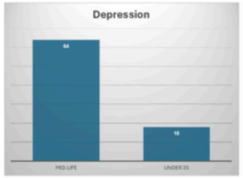
1. **describe the clinical presentation and psychiatric history of women presenting with First Episode Psychosis treated by CAMEO over a three-year period, in these 2 cohorts.**
2. **describe for this group any documented co-occurring conditions, including menopause status, environmental issues, trauma and physical health of women treated for FEP.**
3. **use the findings to inform service guidelines to support treatment and recovery for this group.**

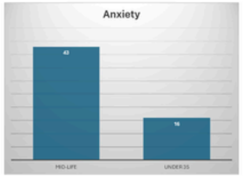
Lizzie Kenedler and Cambridgeshire and Peterborough NHS Foundation Trust is supported by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration East of England (NIHR ARC EoE) at Cambridgeshire and Peterborough NHS Foundation Trust. The views expressed are those of the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

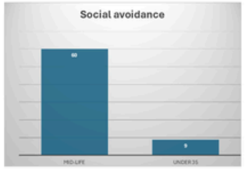
Results











Pro

Proposed Outputs:

At mid-life women suffer longer periods of illness and difficult-to-treat symptoms of psychosis. Although the 'second wave' of illness is well-recognised in the literature and on the front line, The role of menopausal transition in the onset of psychotic illness is acknowledged, but still poorly understood. A better understanding will allow us to enhance clinical interventions and target additional support to improve outcomes.

2 out of 44 cases at Midlife were asked about menopause symptoms.

19 out of 44 cases at Midlife were not asked about history of trauma.

Most reported environmental stressors at Midlife are Caring Responsibilities, Work Stress, Financial concerns and interpersonal relationships.

Anti-psychotic medication response appearsworse at menopause period, due to estrogen decline and reduced sensivity to dopamine.

Women at midlife experience more severe psychotic symptoms (excluding hallucinations) compared to the under 35 population.

Poster by Lizzie Kenedler

Paul Inalegwu Iyaji

Mental Health Nurse, Norfolk and Suffolk NHS Foundation Trust
paul.iyaji@nsft.nhs.uk

The research journey...

The research fellowship programme has been a journey with it's up and downside. But overall, it's been fulfilling and satisfying for me by every standard. It is hard to know where to start in recounting the journey so far. However, there is always a place to start.

After my graduation from UEA and registering with the Nursing and Midwifery Council (NMC) as a mental health nurse, I wondered what next in terms of academic pursuit. I shared my concern and research interest with a lecturer, Dr. S. Oduola who encouraged me to look out for research opportunities with NIHR. And it so happened that one year into my practise as a mental health nurse, I was a research fellow with NIHR ARC EOE. Dr Sheri was very helpful in guiding me through the application process. I would like to appreciate my then Manager, Dawn Fisk and Modern Matron Beth Oughton for signing off to allow me pursuit the fellowship programme.

> The induction programme and various workshops were valuable in improving my research skills."

I would like to appreciate all facilitators; their contributions are much appreciated. It was worth travelling all the way from Norwich for each of the session. But also wonder if online meetings could be explored for some of the sessions. The Action Learning Sets (ALS) was a brilliant idea. It created a much-desired safe space to share concerns and exchange ideas. It provided an avenue for bonding and support from fellow researchers. The facilitator, Liz, was good at her job. It was great to see Liz and our colleague Jo, travel to Norwich for one of the sessions. This is appreciating Liz and all my co-research fellows.

> The research work itself was demanding. Obviously the 7.5 hours/week allocated, as paid for in backfill to employers is not enough to see through the research work."

Health science librarian at UEA, Matthew Smith was supportive in formulating my search strategy. Having to screen almost three thousand articles was hectic. I used every available time including part of my annual leave. I had to sacrifice lots of family time for the work. And I sincerely want to appreciate my lovely wife and wonderful kids for their support and understanding.

> It was tough striking a balance between office work, research work and taking the kids to their various extracurricular activities.”

Thank so much Nkem.

The software, Endnote, and app Rayyan were valuable in the screening of articles. A work colleague, Metabel was selfless in agreeing to independently screen 20 percent of the articles and then compare her findings with mine to ensure I am on the right track. I appreciate her. I have been with three different work teams during this fellowship. In July 2024 I was redeployed to a different team and then moved to a different team in a different town from home in January 2025. This has impacted on the progress of the research work as the work has been slowed down each time I had to adjust to my new team.

My supervisors, Dr Sheri Oduola and Prof Margaret Greenfields have been wonderful throughout the programme. They have brought their wealth of experience into supporting and guiding me. They have made time for meetings in the mist of their tight schedules and have responded to mails as promptly as possible. I cannot thank them enough. Though, there are still works to be done, I commit to complete them and get it ready for publication.

Finally, I bless God for His goodness, faithfulness, mercies, and blessings in seeing me thus far.

University of East Anglia

NHS Norfolk and Suffolk NHS Foundation Trust

EFFECTIVENESS OF INTERVENTIONS, INITIATIVES AND CAMPAIGNS AIMED AT IMPROVING ACCESS TO MENTAL HEALTH SUPPORT FOR PEOPLE WITH MENTAL HEALTH DIFFICULTIES LIVING IN RURAL AND COASTAL AREAS

-A SYSTEMATIC REVIEW

NIHR | Applied Research Collaboration East of England

a.r.u.

Paul I. Iyaji[1], S. Oduola[2], M. Greenfields[3]

1 Norfolk and Suffolk NHS Foundation Trust, 2 University of East Anglia, 3 Anglia Ruskin University

Background Information

Significant mental health inequalities exist in rural and coastal communities, largely due to poor infrastructure, geographical isolation and deprivation. A key challenge is access to timely mental health support in these communities. However, a consensus on effective interventions for improving access to care in rural and coastal communities is lacking.

Research Aims

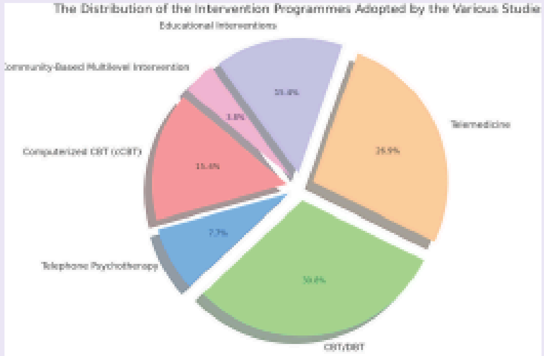
- To identify and describe interventions aimed at improving access to mental health support in rural and coastal communities.
- To assess the effectiveness of interventions aimed at improving access to mental health support in rural and coastal communities.

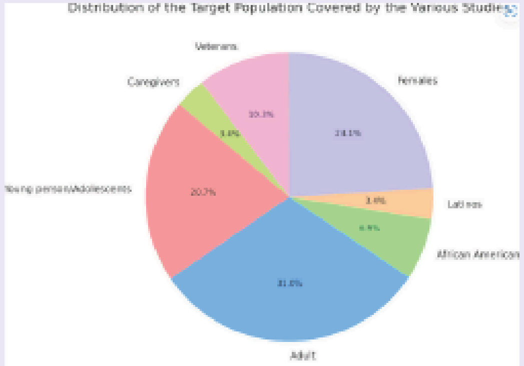
Methodology

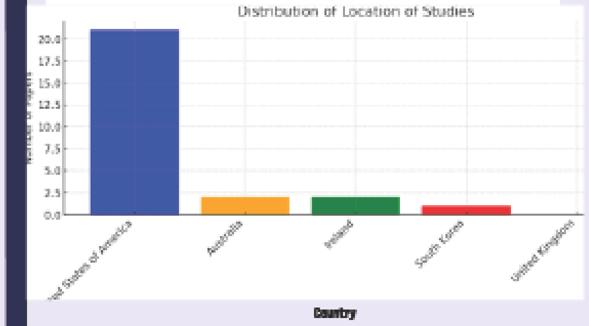
- Literature search on databases; Medline, PsycInfo, Embase, CINAHL and ASSIA was limited to papers published in English and from OECD countries. Study protocol was registered with PROSPERO (CRD42024552855). Patient and Public Involvement and Engagement was done (e.g. Public Involvement Hub of ARC EOE, PIRG@herts etc)
- Study must be on interventions aimed at improving access to mental health support for individuals in rural or coastal area suffering common mental disorders such as anxiety and depression; and/or psychotic disorders to be included in the review. Key outcomes include measures of and description of help-seeking patterns and pathways to care.
- Abstract and full text screening. Twenty percent of eligible papers were rechecked by SO (supervisor). Quality assessment of included papers was conducted using Mixed Methods appraisal Tool (MMAT) (Hong et al., 2018). Data extraction and then analysis using narrative synthesis

Results

26 papers met inclusion criteria. Study characteristics of all included papers were extracted but access to mental support data were extracted from only 14 papers due to time constraint.







Key Findings

- Studies of all included papers were conducted in rural areas, there was no study on coastal areas.
- The review found no study conducted in the UK.

The following findings are based on access to mental health support data extracted from 14 papers.

- Severity of Mental Illness and Duration of Crisis Period:

Six studies showed significant mental illness treatment improvements, though results varied by illness type. For instance computerized CBT improved anxiety in a study but not depression. Interventions in a study reduced depressive symptoms but lacked statistical significance. Various intervention programmes (except educational materials) were employed.

- Change in Help-Seeking Attitude:

All Four studies with this outcome used educational interventions, with three showing improved help-seeking attitudes. In one study educational tools helped improved willingness to seek help but failed to reduce mental health stigma. Two studies scored low in quality.

- Key Pathway to Care Agent:

Two studies used telemedicine, one employed telephone CBT. Culturally tailored CBT improved psychotherapy access for Latinos. Telehealth reduced emergency department wait times and increased scheduled appointment utilization, improving healthcare access.

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Acknowledgement and Disclaimer

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Poster by Paul Inalegwu Iyaji

Impact Fellowship

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

Christy Tse

Senior Stroke Occupational Therapist, Cambridge University Hospitals NHS Foundation Trust

christy.tse@nhs.net

From idea to impact: My journey in creating and delivering an occupational therapy band 5 to band 6 development programme

I have always been passionate about Occupational Therapy (OT)—not just in practice but in strengthening the evidence base that supports our profession. This passion led me to explore research and innovation opportunities, ultimately shaping my journey into the NIHR ARC Implementation Fellowship.

The journey before my Fellowship

In 2023, I had the privilege of joining the first cohort of the Chief Nurse Internship Programme at Cambridge University Hospitals (CUH). This programme was instrumental in equipping me with research and innovation skills while fostering my leadership development. As part of the programme, we conducted a qualitative study on “The factors affecting staff retention among Nurses, Midwives, and Allied Health Professionals” at CUH.

When the internship ended, I was eager to turn our findings into action. The NIHR ARC Implementation Fellowship seemed like the perfect opportunity to do just that—implement meaningful change within my immediate work environment. With the support of Louise Bonner, then Deputy Manager of the OT department, I proposed a Band 5 to Band 6 Development Programme to support junior therapists in their career progression. Thanks to the encouragement of my CUH research leaders—Petra Polgarova, Colin Hamilton, and Alexandra Malyon—and the OT department, I was awarded the Fellowship, marking the beginning of an exciting new challenge.

The Fellowship experience: Learning the art of implementation

> “The ARC Implementation Fellowship provided invaluable teachings, interactive workshops, and Action Learning Set sessions, deepening my understanding of the theory behind effective change implementation.”

I was fortunate to have Sophie Knight as my supervisor and to receive guidance from Jyothika Kumar at Health Innovation East, who offered practical support and regular check-ins. Their mentorship was instrumental in keeping my project on track. Within CUH, Rachael Green, Deputy Manager of the OT department, oversees my project and actively supports my professional development, ensuring its success and sustainability.

Bringing the Programme to Life

To ensure my programme truly addressed the needs of our team, I conducted focus groups with OTs across different bands—Band 5, Band 6, and Band 7+. The goal was to gather insights on:

- The developmental needs of Band 5 OTs
- Key differences between Band 5 and Band 6 roles
- Stakeholder perspectives on the structure and content of the programme

Using thematic analysis, I meticulously examined the data, which played a crucial role in shaping the programme's content. In hindsight, these focus groups were essential—they ensured the programme was tailored to real needs, making it practical, relevant, and impactful.

> “Designing the developmental programme was both exciting and challenging. I focused on setting clear learning objectives, structuring key topics, and sourcing credible resources.”

Using thematic analysis, I meticulously examined the data, which played a crucial role in shaping the programme's content. In hindsight, these focus groups were essential—they ensured the programme was tailored to real needs, making it practical, relevant, and impactful.

Designing the developmental programme was both exciting and challenging. I focused on setting clear learning objectives, structuring key topics, and sourcing credible resources. To create an engaging learning experience, I developed PowerPoint presentations complemented by reflective workbooks—tools that could be used during and after sessions for deeper reflection.

Course Content:

1. Role of an Acute Band 6 OT
2. Are You Ready to Apply for a Band 6 Post?
3. Making the Most of Supervision
4. Audit, Research, and Quality Improvement Projects
5. Being a Clinical Supervisor
6. Deputising in the Absence of a Band 7 Team Lead
7. Handling Complex Cases (and Supporting Others)
8. Supporting Others' Learning
9. Future Career Aspirations
10. Band 6 Interview Preparation

To recruit participants, I promoted the programme through departmental briefings, emails, and one-on-one conversations with colleagues. The response was overwhelmingly positive—not just from Band 5 OTs but also from senior staff, who recognised the value of the initiative and offered their support.

Reflections on Delivery and Impact

> The process of designing and delivering this programme was both fulfilling and eye-opening. It not only strengthened my own practice by aligning my work with up-to-date standards, but also deepened my appreciation for mentoring and supporting others.”

One of the most rewarding aspects was building relationships with my delegates—encouraging open discussions, sharing experiences, and seeing them gain confidence. The sessions were dynamic, filled with interaction and reflection, making the learning process truly engaging.

To measure the programme’s impact, I collected baseline, midway, and post-programme surveys from delegates. The midway survey was particularly insightful, allowing me to refine later sessions based on constructive feedback. I made sure to action every suggestion, ensuring that the programme evolved in response to participants' needs. Looking at the survey results, I was overwhelmed by the programme's success across several key areas.

Beyond the Fellowship: Expanding the Reach

One of the most unexpected but rewarding aspects of this journey has been the connections and collaborations formed through the Fellowship. Being surrounded by like-minded professionals passionate about research and service improvement has been both inspiring and motivating. A special mention to Codrin Buleu Tinganescu, a fellow Implementation Fellow, who encouraged me to expand the programme beyond CUH. With his support, I have begun exploring opportunities to introduce this development pathway in other NHS Trusts, further increasing its reach and impact.

Final Thoughts

As the Fellowship comes to an end, I find myself reflecting on just how transformative this year has been. While I feel a tinge of sadness that this chapter is closing, I am excited for the future—both for myself and for the incredible colleagues I have had the privilege to work alongside. This journey has reinforced my belief that small changes can lead to meaningful impact. Moving forward, I will be delivering this programme annually in the OT department while also working to expand it across other NHS Trusts. My hope is that it continues to support and inspire the next generation of OTs, helping them take confident strides in their careers. To anyone considering applying for the ARC Implementation Fellowship—go for it. The journey is worth it.

GROW OUR OWN: UPSKILLING OUR OCCUPATIONAL THERAPY WORKFORCE

Creating and delivering the Occupational Therapy Band 5 to Band 6 Development Programme

Christy Tse - Senior Occupational Therapist, Cambridge University Hospitals

1. BACKGROUND

A significant proportion of Band 6 Occupational Therapists (OTs) at Addenbrooke's Hospital have progressed internally from Band 5 roles. However, there is a lack of structured support to facilitate this transition, resulting in gaps in leadership, coaching, and other essential skills in a Band 6 OT. A departmental review identified this issue as a priority for service improvement. This project aimed to address the gap by implementing a structured developmental programme.

2. AIMS

The programme sought to:

1. Enhance the confidence, skills, and knowledge of Band 5 OTs in preparation for Band 6 roles.
2. Equip newly promoted Band 6 OTs with leadership, teaching, clinical, and research skills required.
3. Improve understanding of expectations and responsibilities of a Band 6 OT.

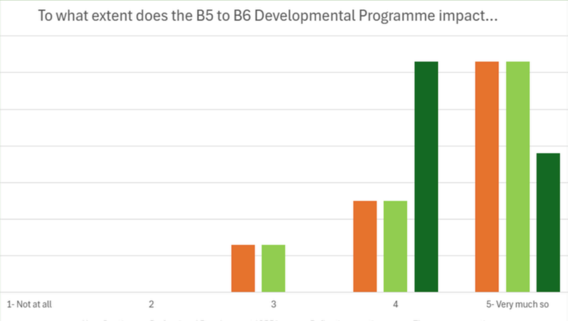
3. METHODS

Three focus groups were conducted with Band 5, Band 6, and Band 7+ OTs to inform the programme's content and approach to ensure service gap is met. Eight delegates were recruited for a ten-session course, delivered fortnightly within the OT department. Sessions included PowerPoint presentations delivered by the author, complemented by reflective workbooks for in-session and independent reflections. Surveys were conducted at baseline, mid-way, and post-programme to evaluate its impact.

4. RESULTS

Survey data indicated positive outcomes, demonstrating improved confidence, skills, and knowledge among participants.

Notably, 100% of delegates would recommend the programme to other Band 5 OTs, with suggestions to adapt it for other allied health professionals and extend it across NHS Trusts.



5. CONCLUSION

The Band 5 to Band 6 Development Programme effectively supports OTs transitioning into senior roles, addressing critical skill gaps through structured teaching and peer support. The success of the programme highlights the value of investment in staff development. Plans are in place to run the programme annually and explore its expansion to other NHS Trusts.

ACKNOWLEDGEMENTS

Christy Tse 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.

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Poster by Christy Tse

Codrin Buleu

Physiotherapist and Joint Team Lead, Queen Elizabeth Hospital King's Lynn
codrin.buleutiganescu@qehkl.nhs.uk

Follow your passion, drop your 'anchor', weather the storms and make a difference

Implementation is Difficult. I wish things would just run smoothly, especially when you're under pressure (most of it self-imposed). But just like traffic jams when you're already late (an Alanis Morissette reference from her song 'Ironic') you learn first-hand that the things that are out of our control can turn out to be the most frustrating to deal with.

I am a physiotherapist working in a hospital, and I was so lucky to be offered the chance of an implementation fellowship with ARC. To make good use of this opportunity I wanted to build on previous work looking at barriers to mobilisation of patients in the Queen Elizabeth Hospital King's Lynn (QEHKL). I did the legwork, and I established the top 5 reasons why our inpatient population is not routinely encouraged out of bed and is rarely given the opportunity to be more involved in their journey of recovery on the ward.

My frustration:

The evidence saying that hospital deconditioning is very detrimental on so many levels is stacked up high. Even more, everybody working in the hospital knows that if you are more active you get better quicker and if you spend a long time in bed, you lose strength, endurance and even quality of life. So, if we're all on the same page, why is it that getting our patients out of bed and mobilising is not business as usual on every ward?

My project

> My implementation project was going to do just that: change the world (oh little did I know)!"

I entered the Fellowship with this passion to design an intervention that would finally turn the tide on the culture of reactivity and point it in the direction of proactivity and prevention of hospital deconditioning. I did not know at the time what the intervention would be, but I had the evidence to indicate what the barriers were. Apparently, it is good to involve the patients and the public in any research and implementation. And it makes sense too. So, I did. I heard even more stories of how important it is as a patient to feel guided and empowered in an environment where everything seems to be moving at 100 miles per hour. It soon became clear that my project had to be an educational and supportive intervention that would be done with the staff and not to them. I was not naïve though: changing culture in the NHS can take a very long time. Changing habits and minds may arguably take even longer. I was hoping that I can at least be the spark that starts that change. With the fire in my heart and with a fantastic cause (that was fought many times before under many names, one of them being 'Pyjama Paralysis'), I set off to make a change in the QEHKL.

My voyage:

This year's 'winter pressures' didn't seem to have eased off from last winter… By the contrary! It felt that the hospital was at the highest alert level more often than it wasn't. With patient acuity increased and the ambulances queueing at the 'front door', it is difficult to convince yourself that researching and implementing change should take priority. But if you think how many patients your work could touch you will realise that seeing your regular number of patients that day doesn't compare. But that's not what comes to mind in the heat of the moment… And then there's absences in your team which, on top of the already existing vacancies, add an extra layer of complexity to the day-to-day. You plough along and, in the process, an idea is sprouting. You need the stakeholders on side. Your dedicated fellowship day that suits your clinical team is a Thursday, but your most high-powered and high-influence stakeholders work Tues, Wed and Fri. They're busy and the meetings need to be booked weeks in advance. That's fine. You found a way and got to them. They're keen to help but you should also speak to three other people as they should also be involved. Two of them don't work Thursdays and the third is on annual leave for a week. Your sponsor in your organisation is amazing and somehow, likely by using black magic, helps you corner them and they're all on board. Let's present this to the COO for the final sign off – your idea is not in line with the Trust's objectives or it's overlapping with another initiative. Can you change it 'slightly'? Sure!! I don't have any family or a personal life. I'll do it now.

Looking at your project tracker you realise that you're now officially behind and you need to show something for your time off the wards. By now, all the literature reviews, the Gant charts, the stakeholder maps, the logic models, the PPI and the knowledge mobilisation sessions all seem like a long time ago…

> “You finally have a breakthrough. Deep sigh of relief…… Things are finally starting to fall into place.”

You get your PowerPoint presentations up to scratch and punchy, you send the emails out and get lots of people around the table, some smiles down the corridor here and there and now there is a spring in your step. But you haven't had much time off work. Exhaustion has a bad habit of creeping in, and you find yourself in need of a break. You wonder if you've put things in motion enough to allow you a week or two over the summer...

Boom! You're back. Pick up where you left off? Well, do you remember that request you put through for your Comms department to publish your piece? That hasn't happened. More so, the materials you provided seem to have been misplaced and you now need to put another meeting in your diary to catch up. No Thursdays available for Comms, I'm afraid. Eventually, that being sorted, you fall behind on your clinical work because you think you can be flexible and do some meetings for your project during your working time. But then work spills into your project time too and the productivity drops. How's your mandatory training going?

A quick 'pick me up' and more time in the gym helps with the focus. You're back on track, you have the merchandise on order, the newsletters are out, evaluation is all weaved in neatly, the stakeholders are behind you and you're ready for the big day: the implementation. It's all set. Ding! Outlook sends this notification that you look at quickly because you have the work emails on your personal phone - the merchandise, the posters and the pull up banners will not be ready in time for the big day. You only have some merch from the other initiative you're taking on board to get the support of a specific stakeholder. Here you are putting some stuff together last minute. Not quite the branding you wanted but 'they should be ok'. And it's happening. It's today. You get to work earlier than normal, and the hospital's main foyer is ready and organised.

You have passion and this shines through, this is why the event is a success and people turn up to talk to you and see what's going on, what you've been up to working tucked away in a library room or at home in front of your computer on your project days. Interest is stirred, promises are made, and a successful day is concluded.

> "It's the energy, the enthusiasm and the passion that moves things forwards and touches hearts and minds. A feeling of belonging and of teamwork. Success is possible despite all apparent barriers."

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NHS
The Queen Elizabeth Hospital King's Lynn
NHS Foundation Trust

Health Innovation East

'Let's Get Moving' to Prevent Hospital Deconditioning in The Queen Elizabeth Hospital King's Lynn

Codrin Buleu – Specialist Physiotherapist and Joint Team Lead for the Medical Therapy Team

Introduction

Why hospital deconditioning? Quite simply because it has a negative impact on patient outcomes[1,2,3], on staff and the hospital[4], on the social and community services[3,4,5], on the patients' perception of hospitals[6] and even on the planet.

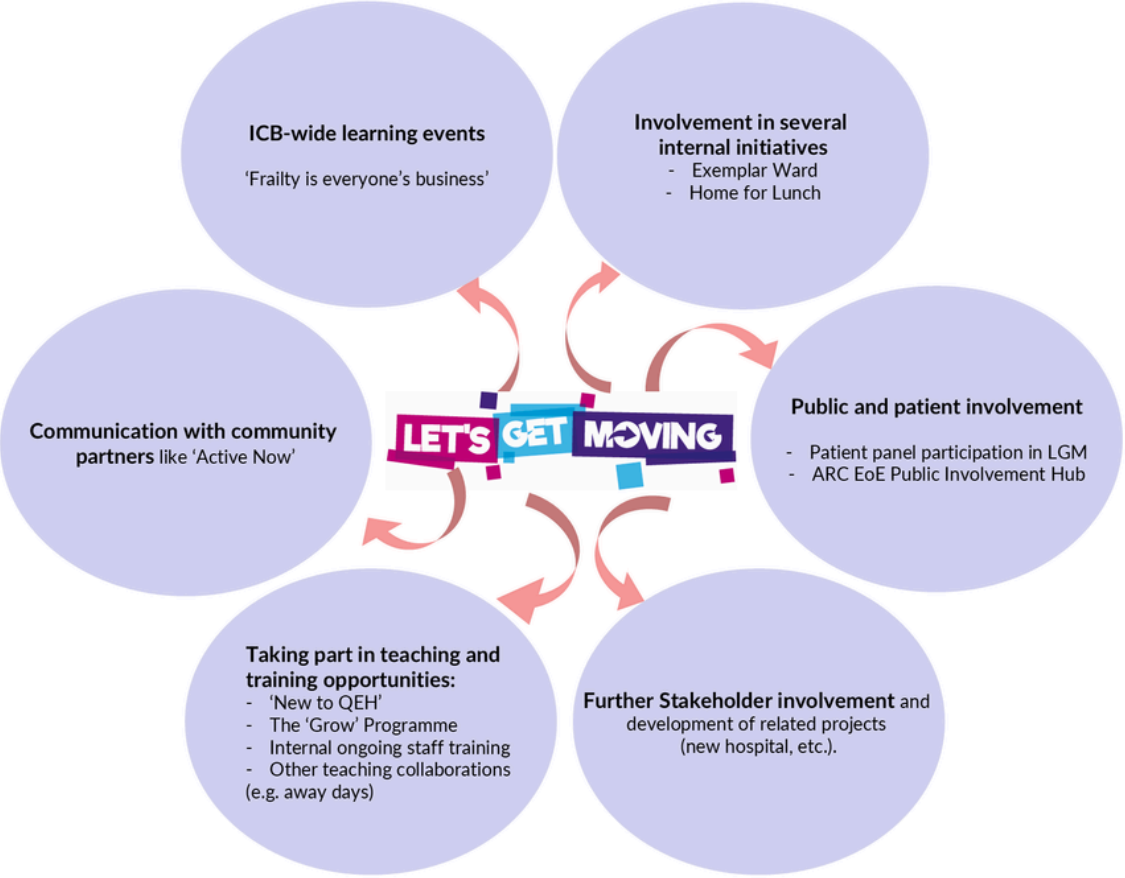
Aim

To build on previous work that revealed the top 5 barriers to mobilisation in the Queen Elizabeth Hospital King's Lynn (QEHKL) and to implement an intervention to address these barriers.

To light the spark that will lead to a turn in the tide of culture in the QEHKL around the importance of mobilising the people we care for during their hospital stay.

Implementation

- I joined nurse leaders and got involved in an existing small-scale local initiative – 'Let's Get Moving' (LGM).
- The LGM Campaign secured hospital Board and Chief Nurse backing.
- I put together and delivered evidence-based education and training to stakeholders and LGM Champions.
- I participated in Patient and Public Involvement (PPI) initiatives – Public Involvement Hub – ARC EoE.
- I invited the hospital patient panel members to join the LGM campaign and attend the meetings.
- I initiated and coordinated the creation of the LGM 'brand'.
- I initiated a full hospital re-launch of the LGM initiative with a hospital foyer event in September 2024 – the challenge was to cycle the length of a tour of Norfolk.
- The re-launch was sponsored by a local gym – 4 bikes were provided for the event.
- Community partner 'Active Now' attended the launch.
- LGM Initiatives for staff – monitored in the staff newsletter – led by the Trust Communications department.
- I started monthly meetings with the LGM Champions.
- Structure now in place for the meetings (pledges, action log, minutes, trackers, training, external speakers, knowledge mobilisation sessions, etc.).
- Ongoing stakeholder involvement.



LET'S GET MOVING

ICB-wide learning events

'Frailty is everyone's business'

Involvement in several internal initiatives
- Exemplar Ward
- Home for Lunch

Communication with community partners like 'Active Now'

Public and patient involvement
- Patient panel participation in LGM
- ARC EoE Public Involvement Hub

Taking part in teaching and training opportunities:
- 'New to QEH'
- The 'Grow' Programme
- Internal ongoing staff training
- Other teaching collaborations (e.g. away days)

Further Stakeholder involvement and development of related projects (new hospital, etc.).

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Codrin Buleu is a physiotherapist at the Queen Elizabeth Hospital in King's Lynn and 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.

Results and Conclusions

The 'Let's Get Moving' initiative raised the awareness on hospital acquired deconditioning and created opportunities to participate in other Trust-wide and ICB initiatives to disseminate information and to educate healthcare professionals. Changing the culture on promoting physical activity in the Queen Elizabeth Hospital is under way.

Next Steps

- Continue the involvement in the LGM and build on the progress made so far (bespoke sessions for individual teams or wards, events, sustainable evaluation, etc.).
- Explore further avenues for funding.
- Follow up on discussions about LGM implementation in the 'New Hospital'.

Acknowledgements

I would like to acknowledge that this project would have not been possible without the invaluable support from:

- Ben Jackson (Senior HIE Advisor) – thank you for the patience and support.

- Karon Strong (Head of Nursing, Medicine Directorate, QEHKL) - thank you for the trust and the great work partnership.

- Suzy Sarsby (Directorate Operations Manager, Division of Clinical Support and Cancer Services, QEHKL) – thank you for your energy and dedication.

- The Medical Therapy Team at the QEHKL – thank you for putting up with me for the duration of this amazing ARC Fellowship.

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Poster by Codrin Buleu

Philip Linnegar

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Introducing SignVideo into a primary care setting

> “I was frustrated. Reports from national charities underscored countywide public engagement and anecdotal recollections – Deaf patients, when faced with years of inaccessible information and communication support in primary and secondary care, felt ‘barrier fatigue’.”

Turning barriers into bridges

For 30 years I have been CEO of Hertfordshire Hearing Advisory Service, a Charity supporting people who are profoundly Deaf, or have hearing loss. For over 20 years, I was vice chair of Friends Of Bennetts End Surgery, FOBES, becoming chairman. Locally, the Charity hosted GP Link Workers with two Primary Care Networks, and countywide, I introduced colleagues to Video Remote Interpreting, that led to adoption by Hertfordshire, Bedfordshire and Cambridge Constabularies. Nationally, I became a Trustee with the National Association for Patient Participation, NAPP – the Voice of the patient in primary care.

Additional funding from Hertfordshire County Council supported our new, small, enthusiastic, Deaf Services team. Technology now delivered stable, on-line Video Remote Interpreting, providing accredited British Sign Language interpreters via an app. Unlike secondary care developed since the creation of the NHS, primary care has largely remained resolutely independent, with surgeries often being small business partnerships, strongly independent of the Department of Health and the NHS. Would it be possible, to reduce health inequalities for Deaf People by introducing Video Remote Interpreting into two surgeries and widen the adoption across their Primary Care Networks?

Moment of Truth

The idea was simple: Deliver ‘Proof of Concept’ by provide each surgery with up to 5 tablet devices downloaded with the VRi app, (SignVideo) to acquire a BSL Interpreter, and surgery website app (eConsult) to ‘Request an appointment’. These would be located at specific points in a patient's engagement with a surgery, the ‘Moment of Truth’:

- Reception desk - FAQs
- Pharmacy counter – FAQs
- Administration – request an appointment

- Pharmacy – request for repeat prescription
- Test results
- Consultation or Treatment

The NHS app, by accident or design, was going to help Deaf patients, to request an appointment or a repeat prescription, and test results. For consultations or treatment, it emerged that 'Interpreting and Translation Services' for Non-Spoken language provision also existed in the East of England Region, for Face To Face and British Sign Language, BSL. Datasets showed that most of the time, services were available within 2 days when booked in advance. Guidance stated "These services are for appointments where NHS treatment is provided and should not be used for private appointments".

Policies and procedures

NHS providers are required to work within the applicable mandatory guidelines and Law including the General Data Protection Regulations, Accessible Information Standard, Disability Discrimination Act, and British Sign Language Act.

"Listen carefully, I will say this only once…"

Using 'Meaningful Engagement', NHS managers and staff were carefully listened to when asked their Personal Views on people and processes:

Q: How were Deaf Patients supported?

The responses included that, when face to face with a Deaf patient, they would:

- Use pen and paper
- Ask the family
- Phone a friend (a hearing patient "who signs")

We then asked some Deaf people the same question.

Q: How were Deaf Patients supported?

The average written English reading age of a profoundly Deaf adult who uses BSL is 9½. The 'lived experience' over a lifetime of being supported using writing, family members or strangers, caused Personal Feelings of:

- Embarrassment
- Isolation
- Anxiety
- Frustration

> This is how the ‘barrier fatigue’ was built up, and the location of this appeared to be before the consultation or treatment – at the Reception Desk.”

The Knowledge To Action model, was very useful when considering other comments made highlighting barriers to implementation of Video Remote interpreting. Several people stated, “There is no time for F2F training” and “Use video shorts”

The learning here was that ‘Training’ is good for skills – hardware and software informs personal skills, whereas ‘Education’ such as Deaf Awareness, changes Personal Values and views.

This problem was a ‘People Fail’, that education takes time that busy staff haven’t got.

People Fails and Process Fails
Problems can be either People Fails or Process Fails. We discovered a Process Fail.

In the surgery, the communication requirements of Deaf patients could be recorded using one of six SNOWMED codes, that flagged a bespoke message when their record was open. For example, “Requires BSL Interpreter. Allow double consultation.” Or, “Please contact by SMS Text only. Patient unable to hear on phone.” Although staff sometimes remember a Deaf patient, to ‘create’ an appointment at the surgery, the patient record does not have to be opened and the flag does not appear. Patients are frustrated. Staff are blamed. This is a Process Fail and needs to be addressed at a national level.

Results
The aims of this Fellowship were to learn and disseminate information to aid others who follow. The outcomes have formed into local, countywide, regional and national activity. Every surgery has to work with a Patient Participation Group. We started trialling a ‘Deaf Patient Participation Group, and convened the ‘Hertfordshire Deaf Health Forum’ working on a thematic agenda. We have been encouraged by practice management and staff, and clinical directors.

Countywide, we are working to raise attention to ICB Primary Care Leads, and point out that ‘Custom and practice’ is counter to Policy and Procedure, under the existing Legal duties and responsibilities. At either a regional or national level, some consideration of the existing provision is required, to make service joined up a point of delivery, and capable at the ‘moment of truth’. This will involve further engagement with NHS Commissioners and

Interpreting Service providers.

Still at a national level, I am working to convene a ‘Video Remote Interpreting User Group’, within the structure of the National Association for Patient Participation, and with colleagues, produce a “What works...Video Remote Interpreting guide”

Lessons learned

I’ve learned some lessons along the way, including engaging with front-line and ICB staff is essential for effective national research. Additionally, national interpreting services should cover reception desks and pharmacy counters for FAQs, that have an important value for Deaf patients, but which can be done at no extra cost to surgeries, and is nearly cost neutral to the ICB. When implementing changes for our Charities Beneficiary Group, our most effective tools are goodwill, influence beyond formal authority, and persistently asking “WHY?”. These elements drive meaningful and sustainable change.

Conclusions

> Don’t react! Everyone wants to help – they just don’t know it yet; and Everyone wants to help – you don’t know it yet...”

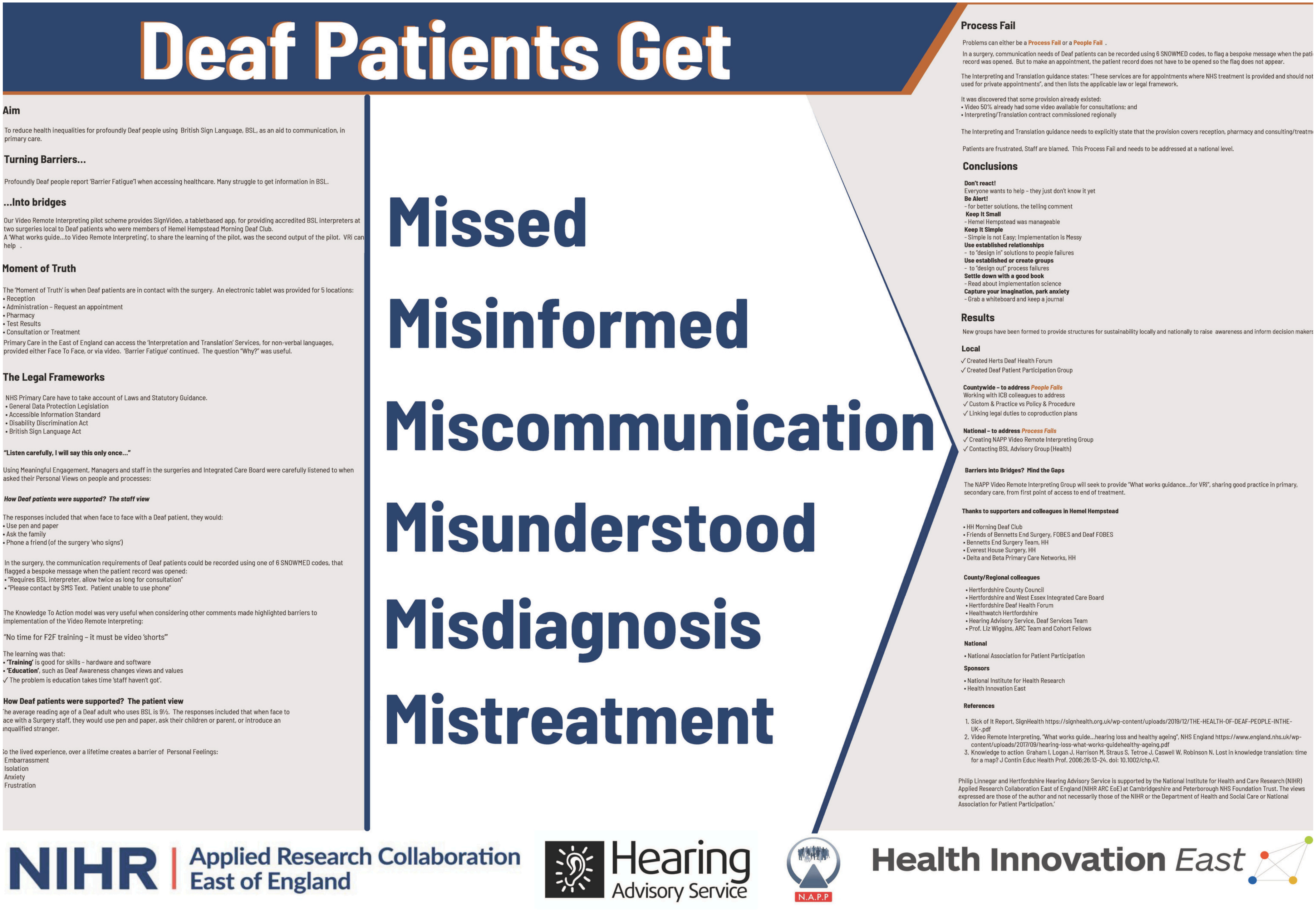
Be Alert! Be poised for better solutions, the telling comment, the personal values that motivate actions

Keep It Small, Keep It Simple
- Hemel Hempstead was manageable. Simple is not Easy; Implementation is Messy

Use established relationships
- Established relationship can help “design in” solutions to ‘People failures’, and similarly, creating new groups can help to “design out” process failures.

Settle down with a good book
- Read about implementation science before Fellowship

Capture your imagination, keep your ideas, park anxiety
- Grab a whiteboard and keep a weekly journal



Deaf Patients Get

Missed

Misinformed

Miscommunication

Misunderstood

Misdiagnosis

Mistreatment

Aim

To reduce health inequalities for profoundly Deaf people using British Sign Language, BSL, as an aid to communication, in primary care.

Turning Barriers...

Profoundly Deaf people report 'Barrier Fatigue'1 when accessing healthcare. Many struggle to get information in BSL.

...Into bridges

Our Video Remote Interpreting pilot scheme provides SignVideo, a tabletbased app, for providing accredited BSL interpreters at two surgeries local to Deaf patients who were members of Hemel Hempstead Morning Deaf Club.
A 'What works guide...to Video Remote Interpreting', to share the learning of the pilot, was the second output of the pilot. VRi can help .

Moment of Truth

The 'Moment of Truth' is when Deaf patients are in contact with the surgery. An electronic tablet was provided for 5 locations:
- Reception
- Administration – Request an appointment
- Pharmacy
- Test Results
- Consultation or Treatment

Primary Care in the East of England can access the 'Interpretation and Translation' Services, for non-verbal languages, provided either Face To Face, or via video. 'Barrier Fatigue' continued. The question "Why?" was useful.

The Legal Frameworks

NHS Primary Care have to take account of Laws and Statutory Guidance.
- General Data Protection Legislation
- Accessible Information Standard
- Disability Discrimination Act
- British Sign Language Act

"Listen carefully, I will say this only once..."

Using Meaningful Engagement, Managers and staff in the surgeries and Integrated Care Board were carefully listened to when asked their Personal Views on people and processes:

How Deaf patients were supported? The staff view

The responses included that when face to face with a Deaf patient, they would:
- Use pen and paper
- Ask the family
- Phone a friend (of the surgery 'who signs')

In the surgery, the communication requirements of Deaf patients could be recorded using one of 6 SNOWMED codes, that flagged a bespoke message when the patient record was opened:
- "Requires BSL interpreter, allow twice as long for consultation"
- "Please contact by SMS Text. Patient unable to use phone"

The Knowledge To Action model was very useful when considering other comments made highlighted barriers to implementation of the Video Remote Interpreting:

"No time for F2F training – it must be video 'shorts'"

The learning was that:
- **'Training'** is good for skills – hardware and software
- **'Education'**, such as Deaf Awareness changes views and values

✓ The problem is education takes time 'staff haven't got'.

How Deaf patients were supported? The patient view

he average reading age of a Deaf adult who uses BSL is 9½. The responses included that when face to ace with a Surgery staff, they would use pen and paper, ask their children or parent, or introduce an nqualified stranger.

o the lived experience, over a lifetime creates a barrier of Personal Feelings:
Embarrassment
Isolation
Anxiety
Frustration

Process Fail

Problems can either be a **Process Fail** or a **People Fail** .

In a surgery, communication needs of Deaf patients can be recorded using 6 SNOWMED codes, to flag a bespoke message when the pati record was opened. But to make an appointment, the patient record does not have to be opened so the flag does not appear.

The Interpreting and Translation guidance states: "These services are for appointments where NHS treatment is provided and should not used for private appointments", and then lists the applicable law or legal framework.

It was discovered that some provision already existed:
- Video 50% already had some video available for consultations; and
- Interpreting/Translation contract commissioned regionally

The Interpreting and Translation guidance needs to explicitly state that the provision covers reception, pharmacy and consulting/treatm

Patients are frustrated, Staff are blamed. This Process Fail and needs to be addressed at a national level.

Conclusions

Don't react!
Everyone wants to help – they just don't know it yet
Be Alert!
- for better solutions, the telling comment
Keep It Small
- Hemel Hempstead was manageable
Keep It Simple
- Simple is not Easy; Implementation is Messy
Use established relationships
- to "design in" solutions to people failures
Use established or create groups
- to "design out" process failures
Settle down with a good book
- Read about implementation science
Capture your imagination, park anxiety
- Grab a whiteboard and keep a journal

Results

New groups have been formed to provide structures for sustainability locally and nationally to raise awareness and inform decision makers

Local

✓ Created Herts Deaf Health Forum
✓ Created Deaf Patient Participation Group

Countywide – to address *People Fails*
Working with ICB colleagues to address
✓ Custom & Practice vs Policy & Procedure
✓ Linking legal duties to coproduction plans

National – to address *Process Fails*
✓ Creating NAPP Video Remote Interpreting Group
✓ Contacting BSL Advisory Group (Health)

Barriers into Bridges? Mind the Gaps

The NAPP Video Remote Interpreting Group will seek to provide "What works guidance...for VRi", sharing good practice in primary, secondary care, from first point of access to end of treatment.

Thanks to supporters and colleagues in Hemel Hempstead

- HH Morning Deaf Club
- Friends of Bennetts End Surgery, FOBES and Deaf FOBES
- Bennetts End Surgery Team, HH
- Everest House Surgery, HH
- Delta and Beta Primary Care Networks, HH

County/Regional colleagues

- Hertfordshire County Council
- Hertfordshire and West Essex Integrated Care Board
- Hertfordshire Deaf Health Forum
- Healthwatch Hertfordshire
- Hearing Advisory Service, Deaf Services Team
- Prof. Liz Wiggins, ARC Team and Cohort Fellows

National

- National Association for Patient Participation

Sponsors

- National Institute for Health Research
- Health Innovation East

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Philip Linnegar and Hertfordshire Hearing Advisory Service 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 or National Association for Patient Participation.'

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N.A.P.P

Health Innovation East

Poster by Philip Linnegar


Volunteer

Looking ahead

By Professor Eneida Mioshi,
Academic Career Development Lead of NIHR ARC East of England

As we mark the closure of our 13th cohort of Fellows, there is a lot to celebrate and reflect on. Projects have been completed, posters presented, new learning and networks established. Another year of a strong, successful partnership with Health Innovation East, who lead on our Impact Fellows development.

While closing the 13th cohort, we also celebrate some changes to the ARC Fellowship programme. Responding to fellows' feedback, it is fair to say that the whole ARC Fellows programme has been revamped for our upcoming cohort, from the application process to the training format and deliverables. To guide this process, a substantial amount of consultation, planning and organisation occurred in the last few months - we are extremely grateful to Alice Wreford for taking the leadership in innovating and relaunching the exciting new programme. And all within two months of taking on her new job!

Huge thanks also to the CPFT ARC core team in supporting the many changes and the transition to the new ARC Fellows programme. Finally, many thanks for everyone who contributed with ideas for the new format.

2025-2026 cohort
We will be welcoming our 14th Fellows cohort in April 2025: Research and Impact - Implementation and Knowledge Mobilisation.

This year we will be hosting the highest number of ARC fellows in a single year, to date. This is the result of successful additional funding that our ARC EoE has secured, enabling the creation of more additional fellowship places for 2025-2026.

In future, the number of places for fellows will likely be reduced again, depending on the variations of funding. Still, we aim to support at least 12 new fellows every year.

Looking ahead, we are likely to continue to promote fellows in Social Care, and continue co-funding places.

I would like to take this opportunity to highlight the contribution from various partners in recent years, who contributed with essential funding to support the sustainability of our programme: Anglia Ruskin University; Norfolk Initiative for Coastal & Rural Health Equalities - NICHE Anchor Institute; UEA Health and Social Care Partners and East of England RRDN. We are very grateful and look forward to continuing (and new) partnerships.

Keep in touch:

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