

Health Innovation Network

Local change, national impact

Patient Involvement Impact Report

2025/26



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Introduction

Meaningful patient and public involvement and engagement (PPIE) is fundamental to delivering a health and care system that is equitable, effective, and responsive to the needs of the populations it serves.



Across the Health Innovation Network, our commitment to embedding the voices of patients, carers, and communities in all aspects of our work reflects a wider national shift towards co-production as a cornerstone of innovation, improvement, and system transformation.

This report highlights the collective impact of Patient and Public Involvement and Engagement (PPIE) activity over the last year, showcasing how insights from lived experience are shaping the design, delivery, and spread of innovation. From early-stage research and development through to implementation at scale, patient insight strengthens relevance, improves outcomes, and ensures that innovation is not only clinically effective, but also accessible and acceptable to those who need it most.

Our approach aligns closely with the ambitions set out in the 10 Year Health Plan, which articulates a ten-year vision for a more preventative, personalised, and digitally enabled health service. PPIE is a critical enabler of this vision, supporting the shift towards prevention, enabling more personalised care, and ensuring digital transformation is inclusive, accessible, and grounded in real-world need. By embedding PPIE within innovation pathways, we ensure that new technologies, care models, and pathways are designed

with, not just for, the populations they serve, while also helping to reduce health inequalities and empower people to take an active role in their health and care.

PPIE is also fundamental to delivering NHS England's **Working in Partnership with People and Communities** guidance, which sets out expectations for how organisations involve people in decision-making. Through building trusting relationships, valuing community assets, and addressing barriers to participation, PPIE enables organisations to move from engagement as an activity to partnership as a way of working.

In parallel, the UK Government's Life Sciences Vision emphasises the role of patient-centric innovation in improving health outcomes and driving economic growth. Embedding PPIE across the innovation lifecycle is key to realising this ambition, ensuring that innovation is shaped by patient perspectives, accelerating adoption, and increasing the likelihood that solutions are relevant, effective, and scalable in practice.

As this report demonstrates, the Health Innovation Network continues to play a pivotal role in bridging the gap between innovation and lived experience. Through collaboration with patients, communities, clinicians, and partners, we are building a culture where insight is not an add-on, but an integral driver of impact. This strategic commitment positions us to support a health and care system that is more inclusive, more innovative, and ultimately more effective for all.

We would like to sincerely thank patients, carers, and members of the public whose time, insight, and lived experience continue to shape and strengthen our work, ensuring that healthcare innovation remains grounded in what matters most to the people and communities we serve.

Adele Bunch, Network PPIE Forum Chair

Head of Portfolio – Patient and Public Involvement & Engagement and Health Inequalities, Health Innovation Yorkshire & Humber

Practical recommendations for high-quality Patient and Public Involvement and Engagement

In this selection of case studies, showcasing projects from across the health innovation networks, several consistent themes emerged regarding what enables meaningful, inclusive and impactful PPIE.

While each project used different approaches depending on its context, population and objectives, common principles underpinning high-quality involvement were evident throughout. The following recommendations draw together learning from across the case studies and provide a practical framework to support future health innovation, service improvement and research programmes.



1. Involve Early and Continuously

Engage patients and the public from the earliest stages of idea development – not just during evaluation or dissemination. Continuous involvement helps shape priorities, improves relevance, and builds trust over time.



4. Invest in Relationships, Not Just Activities

Effective PPIE is built on long-term relationships rather than one-off engagement exercises. Allocate time and resources to develop trust, maintain communication, and support ongoing collaboration.



2. Prioritise Diversity and Inclusion

Move beyond “usual voices” by proactively reaching underrepresented communities. Tailor engagement approaches to different groups, address barriers to participation (e.g. language, accessibility, digital exclusion), and work with trusted community partners.



5. Provide Support and Build Capacity

Offer training, guidance, and appropriate support for both public contributors and professionals. This includes clarifying roles, building confidence, and ensuring contributors can participate meaningfully.



3. Be Clear About Purpose and Impact

Clearly communicate why involvement is happening, what influence participants will have, and how their input will be used. Close the feedback loop by showing how contributions have shaped decisions or outcomes.



6. Value Contributions Fairly

Recognise the time, expertise, and lived experience of contributors through appropriate payment, reimbursement, and acknowledgment. Follow established National Institute for Health and Care Research guidance on public involvement payments. >



7. Use Flexible and Creative Approaches

Adopt a range of engagement methods (e.g. workshops, co-design sessions, digital platforms, community outreach, one to one interviews) to suit different needs and contexts. Flexibility increases accessibility and participation.



8. Embed PPIE in Governance and Culture

Ensure PPIE is not an add-on but a core part of organisational culture and decision-making. Include public contributors in governance structures and leadership discussions where possible.



9. Evaluate and Learn

Regularly assess the quality and impact of PPIE activities. Use feedback from participants and stakeholders to improve approaches and share learning across programmes.



10. Collaborate and Share Practice

Work across networks and organisations to share insights, tools, and resources. Avoid duplication and build on existing good practice to strengthen the overall PPIE ecosystem.

Collectively, these case studies demonstrate that effective PPIE is not a standalone activity, but an ongoing process that strengthens innovation, improves trust, and helps ensure services reflect the needs and experiences of the communities they serve.

Embedding meaningful involvement throughout programme design, delivery and evaluation supports more equitable, acceptable and sustainable healthcare innovation. Continued collaboration, shared learning and investment in inclusive involvement approaches will be essential to strengthening PPIE practice across health and care systems.



Digital and AI



Evaluating AI to Reduce Unplanned Hospital Admissions

As artificial intelligence (AI) is increasingly used in healthcare, it is essential to understand how acceptable and trustworthy this feels to patients and the public. As part of evaluating BraveAI, an artificial intelligence tool that can predict a patient's risk of sudden medical crisis, one-to-one interviews were carried out to explore public views on AI-supported proactive care. Discussions focused on trust, transparency, communication and fairness. This work ensures that the programme is shaped by patient expectations and that communication about AI use is clear, accessible and person-centred.



Engaging Participants

Eight members of the public took part in interviews, most aged over 50 and many living with long-term conditions. Participants were recruited through existing networks and community contacts to enable timely and accessible engagement. One-to-one interviews were conducted using plain-language materials and a short explainer video to support informed discussion. The interview guide was co-designed with patient representatives to ensure accessibility and clarity. Insights from these interviews complement a wider embedded evaluation capturing patient-reported experience of care following proactive intervention.



Key Insights from Participants

Participants were broadly open to AI where it demonstrably improves care, but support was conditional on strong safeguards and evidence of effectiveness. They emphasised that AI should support clinicians rather than replace human decision-making, and that transparency about data use, governance and regulation is essential. Patients also highlighted concerns about data accuracy, fairness, service capacity and the right to be informed when AI is used in their care. >





Impact of Participant Insights on the Project

Patient involvement has strengthened BraveAI's communication approach from an early stage. Insights informed the development and refinement of patient-facing materials, including clearer explanations about how AI works, how data is handled and what proactive outreach means in practice. Feedback also shaped messaging around trust, safeguards and choice, helping ensure implementation is acceptable and responsive to public expectations.



Evidence of Impact

Patient perspectives are informing ongoing refinements to communication and implementation approaches. The embedded evaluation is capturing uptake of proactive multidisciplinary review, personalised care planning and patient-reported experience of care, with findings due in summer 2026.



Equality, Diversity & Inclusion Considerations

Interviews were designed to reduce barriers, using plain-language materials and accessible online delivery. Participants reflected a range of familiarity with AI and experience of long-term conditions. The wider evaluation accommodates vulnerable populations, including people living with frailty or dementia, through brief validated tools, proxy completion options and multiple formats to support accessibility.

Learnings and Recommendations

- Participants were highly engaged and willing to explore complex issues around AI and data use.
- Future engagement should broaden recruitment to include more diverse communities and people with lower digital confidence.
- Working with community organisations could strengthen reach and ensure wider representation in future AI-enabled programmes.

To find out more, contact:

Nic Ferreira nic.ferreira@healthinnovationsouthwest.com

Artificial Intelligence – Guided Clinical Coaching in Urgent and Emergency Care

As AI is increasingly used in healthcare, it is essential that patients understand and trust how it works. This project embedded patient and public involvement throughout the rollout of an AI-guided Clinical Coaching programme across North East London. Patients and carers helped shape how information about the service and data use was communicated and contributed to the design of the programme’s evaluation. Their involvement ensures the service is acceptable, accessible and responsive to patient experience.



Engaging Participants

Patients and carers with lived experience of urgent and emergency care and long-term physical health conditions were involved. Participants were recruited through established lived experience networks and the North East London People’s Panel, with additional recruitment through the clinical coaching service itself. Across activities, over 80 people contributed to workshops, focus groups and

evaluation reviews. Involvement was embedded across the programme lifecycle, including pre-launch workshops, implementation focus groups and evaluation testing. Data acceptability workshops explored public perceptions of AI and data use, while material review sessions refined patient information leaflets. Messaging focus groups reviewed invitation materials, and evaluation workshops and user testing ensured the evaluation process was accessible and fair. >





Key Insights from Participants

Patients were generally supportive of AI being used to improve outcomes but emphasised the importance of transparency about data use and security. They highlighted that trust in the NHS, the innovator and the communication methods used was essential. Accessibility and fairness, including how AI algorithms operate and how people are invited to participate, were seen as critical to ensuring equity.



Evidence of Impact

Patient involvement has directly shaped programme materials, data communication and evaluation processes. Changes informed by involvement have improved clarity, strengthened trust messaging and enhanced accessibility across the service rollout.



Impact of Participant Insights on the Project

Patient feedback led to a full redevelopment of patient-facing information materials, including a new data leaflet to address concerns about privacy and security. Insights from focus groups refined invitation messaging and influenced communication methods to improve trust and engagement. Evaluation protocols were also adjusted to remove barriers and improve accessibility, ensuring patient experience is captured effectively and inclusively.



Equality, Diversity & Inclusion Considerations

A mix of in-person and online activities enabled flexible participation. Accessible venues, assistive technology, varied session lengths and payment for participation helped reduce barriers. Materials were shared in multiple formats, and contributors were reimbursed for travel and caring responsibilities to support equitable involvement.

Learnings and Recommendations

- Offering a range of involvement formats helped engage diverse participants.
- Creating space for open discussion and challenge strengthened the programme’s approach to AI and data communication.
- Embedding involvement across implementation and evaluation has enabled continuous learning and adaptation.

“The public want innovation and are ready for change.”

Participant

“I don’t know where the time went! I had so much fun, and it was so nice to hear everyone’s views.”

Participant

“I’m really pleased that we partnered with UCLPartners for the crucial PPIE component of our chatbot and screening tool project. They have done far more than simply recruit suitable contributors to the multi-phase PPIE process - their expertise has helped us refine our objectives and has helped us to improve the process so that it fully involved parents of neurodiverse children in shaping our product.”

Dr Frank Burbach, Assembly Co-founded and Chief Clinical Officer

To find out more, contact:

Ellie Boden ellie.boden@uclpartners.com / Natt Day natt.day@uclpartners.com

Review of Digital Platforms Used to Access Health Information by Children and Young People in South West London

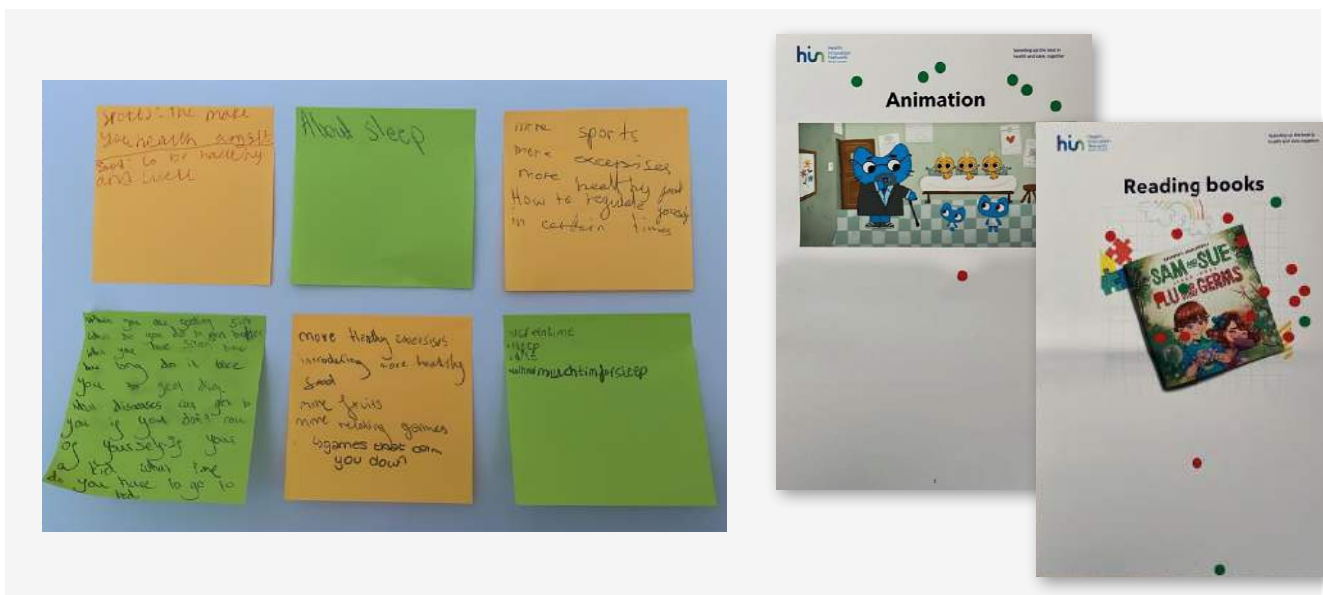
As more children and young people (CYP) turn to the internet for health information, it is important to understand how they search for, interpret and trust what they find. This project explored how CYP and families access digital health information and what helps or hinders their confidence online. Surveys, interviews and school workshops were used to gather insight from over 120 participants. The findings are helping shape recommendations to improve the quality, accessibility and trustworthiness of digital health information for CYP.



Engaging Patients

Over 120 participants took part, including children, young people and parents or guardians. Engagement included survey responses, interviews and interactive workshops in both primary and secondary schools. Participants reflected a range of experiences in accessing health information online. An online survey explored digital

platform use, trust in online sources and ideas for improvement. Semi-structured interviews provided deeper insight into individual experiences, while interactive school workshops used age-appropriate activities such as drawing and voting to encourage participation. Survey questions were co-designed with lived experience partners to ensure accessibility and clarity. >



Left: Post-it notes from the primary school where children described what health information they would want to look up online. Right: Dot voting was used to understand how children preferred to learn. Amongst primary school children, animations were much more popular than books (as shown in these images), whereas secondary school children preferred comics and videos.



Key Insights from Patients

Children and families regularly use digital platforms such as search engines, social media and NHS websites to look for health information. They emphasised the importance of clear, visual and age-appropriate content, and expressed greater trust in NHS-branded sources. Participants also highlighted challenges including conflicting information, digital access barriers and uncertainty about which sources can be trusted. An inclusive NHS-branded hub, signposted through schools and youth clubs was identified as an opportunity by participants.



Evidence of Impact

The project generated clear, actionable recommendations now informing digital strategy and resource development in South West London. Feedback from CYP and parents directly shaped priorities around trust, design and accessibility.



Impact of Patient Insights on the Project

Patient insight informed six priority areas for action to improve digital health information for CYP. Recommendations focus on strengthening trust through NHS branding, improving accessibility and design, addressing digital inequalities and embedding co-design in future development. These findings are supporting local system partners to design more inclusive, user-centred digital resources.



Equality, Diversity & Inclusion Considerations

The project aimed to include a broad range of CYP and parents, collecting demographic data to understand representation. Engagement was delivered in schools to reduce participation barriers and used age-appropriate methods to support inclusion. Findings highlighted ongoing digital inequalities, including limited device access, data constraints and lack of multilingual or culturally relevant content.

Learnings and Recommendations

- Engaging directly in schools helped reach young people who may not usually volunteer for research.
- CYP demonstrated strong digital awareness and healthy scepticism about unregulated online health information.
- Future involvement should allow sufficient time for engagement and continue to use flexible, age-appropriate approaches to gather meaningful insight.

“Social media isn’t regulated – how do you know what’s true or not.”

Participant

To find out more, contact:

Sophie Lowry sophie.lowry2@nhs.net / Shilpi Shobowale shilpi.shobowale@nhs.net

GM Health Innovation Accelerator Programme Co-Production and Engagement Project

Many serious conditions, including heart failure, liver disease, and lung cancer, are often diagnosed late, particularly in underserved communities. This project worked with local people to understand barriers to accessing screening and early diagnosis services and improve engagement with care and treatment provided by the NHS. Patients, carers and community members shared their experiences through community events, interviews, and creative engagement activities. Their insights helped shape approaches to improve access, increase awareness and support earlier diagnosis.



Engaging Patients

Patients, carers and community members from underserved and high-risk communities were involved, including people from ethnic minority backgrounds, LGBTQ+ communities, and those experiencing homelessness or social disadvantage. Over 430 people contributed insight through engagement activities across Greater Manchester via community events, peer-led interviews, discussion groups and creative engagement activities. These methods helped gather lived experience insight, raise awareness of early diagnosis, and support participation in research studies. Engagement through community partnerships ensured the programme reached diverse and underserved populations.



Key Insights from Patients

Patients highlighted the importance of culturally appropriate and accessible communication to improve understanding and engagement. They emphasised that delivering services in trusted community settings helps build confidence and encourages participation. Patients also stressed that barriers such as language, digital exclusion and lack of tailored support continue to limit access and must be addressed. Finally, a commitment to prioritise further co-production with communities was highlighted to tackle current barriers and reinforce relationships.



Impact of Patient Insights on the Project

Patient insight helped identify the barriers and enablers to early detection and screening, strengthened relationships with community and faith based organisations and increased participation from underserved groups in health research. The learning has also increased our understanding of how the NHS can improve access to NHS services and insights are also contributing to the development of an organisational blueprint to guide future engagement with communities. >





Evidence of Impact

Patient insight contributed to improved engagement approaches and increased participation in early detection programmes. Of the 459 people from Black, African and Caribbean backgrounds that engaged in the Lipids Point of Care Testing project, 54% were from the most deprived communities in the UK.



Equality, Diversity & Inclusion Considerations

The project prioritised underserved communities and worked closely with voluntary sector organisations, community and faith leaders to ensure inclusive engagement. Accessible communication methods, interpreters, and delivering activity in community-based settings helped reduce barriers and support participation. The focus on diverse communities where there are existing health inequalities, also enabled us to gather rich insights to help inform NHS services that meet the needs of different communities and patient groups.

“It was lovely how quieter people were encouraged to speak so that everyone had a voice.”

Participant

“People genuinely want to help you. Everything being done is for your benefit.”

Participant

“Patient and public involvement and engagement (PPIE) has been a key part of the “Detecting EARLY Heart Failure in Greater Manchester (EARLY-HF)” research study. The Health Innovation Manchester PPIE team, led by Nicky Timmis, has been fantastic in organising a series of community events for us, and facilitating our engagement with groups such as the Wai Yin Society and Caribbean and African Health Network. This work has helped to significantly increase our recruitment from underserved communities and improve the diversity within our study population. ~1 in 5 of our participants were from ethnic minorities, and ~1 in 3 were from the most deprived areas of Greater Manchester.”

Dr Nicholas Black, Clinical Research Fellow, the University of Manchester

Learnings and Recommendations

- Working with known community partners helped build trust and improve engagement with underserved groups.
- Creative and culturally sensitive approaches supported inclusive participation and meaningful discussion.
- Continued partnership working and co-production with communities is essential to building trust, improving access and reducing health inequalities.

To find out more, contact:

Nicky Timmis nicky.timmis@healthinnovationmanchester.com

Engaging the Public in the Selection of NHS Productivity Innovations

Improving NHS productivity is essential to reduce waiting times, improve access and support staff. This project involved patients and the public in helping identify and select innovations that could improve NHS services. People with lived experience shared their views on healthcare challenges and the use of digital and AI technologies. Their insight helped ensure innovation priorities focused on what matters most to patients and improved care experiences.



Engaging Patients

Patients, carers and members of the public with a range of health experiences contributed through surveys and advisory discussions. In total, 162 people took part, including members of the **Patient and Public Involvement Senate**. An online survey gathered public views on

NHS productivity challenges and digital innovation. Advisory discussions provided deeper insight into patient experiences and priorities. A patient representative also took part in the innovation funding selection panel to help choose which innovations should be supported. >





Key Insights from Patients

Patients highlighted the importance of improving communication and reducing waiting times to improve their experience of care. They emphasised that digital innovation should improve access while maintaining personalised care and human interaction. Patients also stressed the importance of ensuring digital tools are inclusive, transparent and accessible to everyone. Whilst a large number of patients in the group expressed optimism about using AI and digital solutions in their care pathways, there remains significant potential to build wider public confidence through better awareness of how these technologies can support care across the NHS. In response, the PPIE team at Health Innovation East Midlands is developing a series of webinars to share insights and learning.



Evidence of Impact

Three innovation projects were funded based on priorities shaped by patient and public input. Patient involvement ensured selected innovations reflected real patient needs and experiences.



Impact of Patient Insights on the Project

Patient insight helped shape innovation priorities and ensured selected solutions aligned with patient needs. Public representatives contributed directly to decision-making by participating in funding selection panels. Patient perspectives helped prioritise innovations that improve access and co-ordination across care settings, support patients in managing their care, and enhance healthcare efficiency.



Equality, Diversity & Inclusion Considerations

The project used accessible, plain English materials and engaged diverse patient networks. Patient insight highlighted the importance of ensuring digital innovation improves accessibility and does not exclude underserved groups.

Learnings and Recommendations

- Early and meaningful patient involvement helps ensure innovation reflects patient priorities.
- Using accessible materials and established networks supports wider engagement.
- Future engagement should include additional approaches to reach people who may be digitally excluded.

“I enjoyed taking part in the selection of innovations and bringing what matters to patients.”

Participant

“We are keen to include a patient rep on all future funding panels.”

Participant

To find out more, contact:

Dawn Plummer dawn.plummer@nottingham.ac.uk

Helen Thompson helen.thompson@nottingham.ac.uk

Policy Into Practice



Building Public Trust in Health Data: Co-designing a Social Licence for Kent and Medway Integrated Care System

As the NHS increasingly uses health data to improve services, ensuring public trust and confidence is essential. This project worked with patients, carers and community members to co-design clear principles for how health data should be used across Kent and Medway. Public contributors took part in workshops, surveys and involvement groups to share their views and shape decisions. This helped ensure data is used in ways that reflect community priorities and protect patient interests.



Engaging Patients

Patients, carers and members of the public from diverse backgrounds were involved, including people with physical and mental health conditions, carers and individuals from under-represented communities. Fifty public contributors participated directly in co-design activities, including members of a newly

established **Digital and Data Involvement Group**. Patients and the public contributed through co-design workshops, surveys and involvement groups. Public members were recruited and trained as Digital Citizens to help shape data priorities and decisions. Engagement activities enabled people to share their views, learn about data use and contribute to the development of guiding principles. >



“The beginning of a long-term effort to build trust in the use of health and care data.”

Participant



Key Insights from Patients

Patients highlighted the importance of being involved in decisions about how their health data is used and ensuring their voices are heard. They emphasised the need for clear, honest and transparent communication about how data is used, who can access it and how it benefits patients. Patients also stressed the importance of protecting privacy, ensuring data security and giving people choice and control over how their data is used.



Evidence of Impact

The co-designed Social Licence has been adopted as a core part of the region's digital and data strategy, ensuring patient perspectives shape future data use. Public involvement helped strengthen trust, transparency and confidence in how health data is used.



Impact of Patient Insights on the Project

Patient insight directly shaped the development of a co-designed **Social Licence**, setting clear principles for how health data should be used. This helped build public trust, improve transparency and ensure data decisions reflect patient priorities. The Social Licence is now embedded within the Kent and Medway Integrated Care System's digital strategy, supporting responsible and trusted use of health data. This is now embedded within the Kent and Medway Integrated Care System's digital strategy, supporting responsible and trusted use of health data.



Equality, Diversity & Inclusion Considerations

The project prioritised inclusive engagement by involving people from diverse backgrounds, including under-represented and marginalised communities. Training and support enabled participants to contribute confidently, regardless of prior knowledge or digital experience. This ensured a wide range of perspectives shaped decisions about health data use.

Learnings and Recommendations

- Co-design and training helped empower patients to contribute meaningfully and build trust in data use.
- Ongoing involvement and inclusive engagement approaches are essential for maintaining public confidence.
- Supporting digital inclusion and clear communication helps ensure everyone can participate in decisions about their data.
- Public Members developed expertise quickly, offering robust challenge and shaping decisions more strongly than expected.
- There was also a high appetite for ongoing involvement rather than one off engagement.

“The work that Health Innovation Kent Surrey Sussex have lead on for patient, and public involvement and engagement has been invaluable for the Kent, Medway and Sussex Secure Data Environment in allowing us to have robust and meaningful involvement mechanisms across all our diverse communities as well as embedding public representation within our core governance.”

Catherine Dampney, Director of Innovation & Transformation at NHS South Central and West Commissioning Support Unit; Programme Director for NHS Kent, Medway and Sussex Secure Data Environment

To find out more, contact:

Isabel Clark isabel.clark@nhs.net

South West Secure Data Environment (SWSDE)

As the NHS increases its use of health data for research and innovation, building public trust and confidence is essential. The South West Secure Data Environment (SWSDE) has embedded patient and public involvement at the heart of its governance and decision-making processes. Public contributors are involved in shaping how health data is accessed, protected and communicated. This ensures the programme reflects public values around transparency, accountability and security.



Engaging Participants

Fourteen public contributors are embedded within the programme, including people with lived experience of a range of health conditions. Contributors were recruited through regional networks and partner organisations to ensure diverse perspectives are represented across the South West. Public contributors are embedded within governance and advisory structures, including the Data Access Committee and an independent Digital Critical Friends group. Their role goes beyond consultation, providing structured challenge and scrutiny of commercial partnerships, data access decisions and communication approaches. In addition to formal governance roles, the programme delivers community outreach events, presentations and workshops to raise awareness and gather wider public feedback. Transparent reporting, accessible materials and clear feedback mechanisms help ensure ongoing dialogue and visible accountability.



Impact of Participant Insights on the Project

Public involvement has directly influenced how the SWSDE presents itself and governs data use. Contributors helped refine the articulation of the programme's purpose, ensuring public benefit, trust and transparency are central rather than technical afterthoughts.

Their feedback led to clearer public-facing materials, simplified explanations of complex concepts such as data access and de-identification, and stronger emphasis on privacy and security safeguards. Embedding public contributors within decision-making structures has strengthened accountability and ensured patient perspectives shape ongoing development. >



Evidence of Impact

Public contributors are now integrated into core governance structures, including advisory and scrutiny roles. A **public blog** and accessible reporting demonstrate transparency and active involvement.



South West
SECURE DATA
ENVIRONMENT



Health
Innovation
South West



Equality, Diversity & Inclusion Considerations

The programme has prioritised inclusive recruitment and reduced barriers to participation by proactively recruiting and supporting diverse patient and public representatives, ensuring that participation is not limited to those who already engage with policy discussions.

We recognise and remove barriers that prevent underserved groups from participating, including financial, logistical, and accessibility challenges. Digital Critical Friends are embedded across workstreams to provide independent challenge and represent diverse perspectives. Outreach activities aim to reach underrepresented and geographically isolated communities.

“It gave me an opportunity to get back into research and to make a difference in the wider community.”

Participant

“This is the most transparent and open programme I’ve been involved in as a public contributor.”

Participant

The PPIE work within the SWDE programme is actively ongoing. Learning and recommendations will be evaluated after the project ends.

To find out more, contact:

Harriet Barnett harriet.barnett@healthinnovationsouthwest.com

Wessex Patient Safety Collaborative Programmes

Health Innovation Wessex’s Patient Safety Collaborative embeds patient and community involvement across its Managing Deterioration, Medicines Safety, and Maternity & Neonatal programmes. Patients, carers and Patient Safety Partners contributed insight into how safety initiatives are communicated and implemented. Engagement activities explored awareness of Martha’s Rule, challenges in neonatal feeding, and the need for accessible medicines information. This work ensures patient experience directly shapes improvements in safety, communication and accessibility across Wessex trusts.



Engaging Patients

Patients, relatives, Patient Safety Partners and community groups were involved across multiple programmes. Engagement included people with lived experience of hospital care, mothers of premature babies, and people with learning disabilities. Recruitment took place through hospital wards, established patient networks and community connections across Wessex. Convenience sampling surveys captured awareness and understanding of

Martha’s Rule and Call for Concern within hospital wards. Patient Safety Partners contributed to Breakthrough Series workshops, regional safety forums and pilot projects, influencing communication materials and implementation plans. In the Maternity & Neonatal programme, lived experience stories informed the development of the Early Breastmilk Toolkit, while patient groups are being consulted to co-develop an easy read action plan for medicines safety. >



“I feel assured that hospitals are recognising challenges and taking action to improve patient safety.”

Participant





Key Insights from Patients

Patients highlighted the importance of consistent and clear communication about how to raise concerns in hospital settings. Mothers of premature babies described the need for better guidance and correctly fitted equipment to reduce pain and support breastfeeding. People with learning disabilities identified the importance of accessible, easy read information about medicines to ensure understanding and safety.



Impact of Patient Insights on the Project

Patient Safety Partners influenced the redesign and relaunch of Martha’s Rule communication tools in Wessex trusts. A patient story directly informed the development of the Early Breastmilk Toolkit, providing practical resources and guidance to improve comfort and equity in neonatal feeding support. Feedback from learning disability groups will inform the development of an accessible easy read medicines safety action plan to reduce harm and improve understanding.



Evidence of Impact

Since October 2024, approximately 400 Martha’s Rule calls have been made across Wessex, with all seven acute trusts implementing a method for patients or relatives to raise concerns. The Early Breastmilk Toolkit has been accessed over 9,200 times, with over 1,500 views of the accompanying patient information video.



Equality, Diversity & Inclusion Considerations

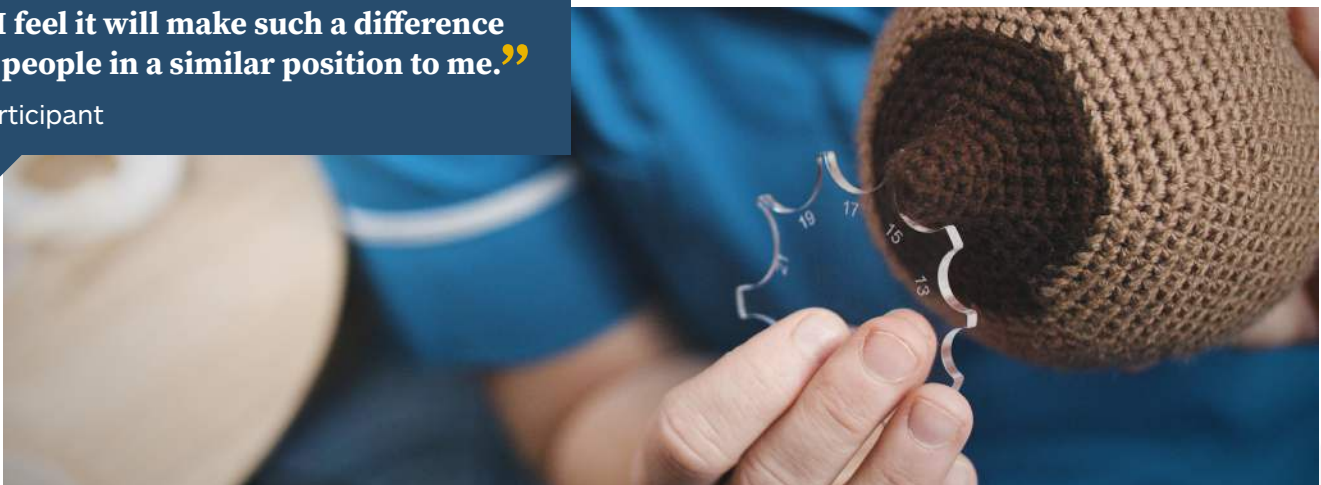
The programmes prioritised equitable access to raising concerns, breastfeeding support and medicines information. The Early Breastmilk Toolkit includes closed captions and multilingual website translation options to reduce barriers. Engagement with people with learning disabilities aims to ensure information is accessible and inclusive.

Learnings and Recommendations

- Building strong relationships with Patient Safety Partners has enabled sustained and meaningful involvement.
- Patients were motivated to contribute when they understood their feedback would directly inform improvement work.
- Future engagement could include more structured focus groups to deepen insight and strengthen ongoing collaboration.

“I feel it will make such a difference to people in a similar position to me.”

Participant



To find out more, contact:

Jo Murray jo.murray@hiwessex.net

Attitudes to Healthcare Data for Planning and Research: Gypsy, Roma and Travellers

This project explored how Gypsy, Roma and Traveller (GRT) communities feel about their health information being used for planning and research. It challenged assumptions that marginalised communities are unwilling to share data, recognising that mistrust is often rooted in historical and ongoing discrimination. Working in partnership with the charity Friends, Families, Travellers (FFT), the project engaged community members to understand their concerns, priorities and expectations. The findings are helping ensure health data policies are more inclusive, transparent and responsive to community needs.



Engaging Patients

42 people from Gypsy, Roma and Traveller communities took part, supported through partnership with Friends, Families, Travellers. A community steering group was established to guide the project from design through to analysis and outputs. A steering group of GRT community members met regularly to shape the project and ensure cultural understanding. Engagement included online group discussions, one-to-one conversations, webinars and an in-person event to gather a range of perspectives. FFT co-facilitated activities and supported interpretation of findings, helping ensure discussions were safe, inclusive and meaningful.



Impact of Patient Insights on the Project

Patient insight has shaped communications and policy development within the Thames Valley and Surrey Secure Data Environment. Findings informed the creation of plain English reports, audio versions and a short animation to improve accessibility and transparency. The work has also been shared across health innovation networks nationally, strengthening understanding of how to engage Gypsy, Roma and Traveller communities in discussions about healthcare data.



Key Insights from Patients

Participants highlighted that Gypsy, Roma and Traveller communities are diverse and should not be treated as a single group when planning services or data policy. They emphasised that conversations about data use must acknowledge historical discrimination and the impact this has on trust. People also stressed the importance of accurate ethnic recording, safe self-identification, and clear explanations about how data is used, who can access it and what choices individuals have.



Evidence of Impact

A publicly available [report](#), [blog](#), animation and webinar series have been developed to share findings and increase awareness. The project is informing ongoing data literacy work, including a Data Guides course, and has strengthened long-term relationships with GRT communities. >



Equality, Diversity & Inclusion Considerations

The project was co-designed with Gypsy, Roma and Traveller communities at every stage. Partnership with FFT helped reduce barriers to participation and build trust. Materials were developed in plain language, supported by illustrations and recorded audio, to account for varying literacy levels and ensure accessibility. The work explicitly addressed historical discrimination, cultural identity and safe self-identification.

“As a man from the Gypsy community, it’s hard for me to talk about health.”

Participant

“A video would be good...I don’t really understand what the doctors are saying.”

Participant

Learnings and Recommendations

- Working through trusted community partners was essential to building meaningful relationships.
- Establishing a steering group ensured the project remained guided by lived experience throughout.
- Community co-production takes time and should be planned accordingly, but it creates stronger, more sustainable engagement and impact.

To find out more, contact:

Sian Rees sian.rees@healthinnovationoxford.org

Women’s Health Across Hampshire & Isle of Wight (HIOW) and Dorset

The National Women’s Health Strategy created an opportunity to improve services and information for women and girls across Hampshire & Isle of Wight (HIOW) and Dorset. This programme placed women’s voices at the centre of service review and redesign. In order to review, improve and enhance services and information available to support Women’s Health, digital surveys, focus groups and community engagement events were used to understand women’s experiences and their priorities including periods, menopause, pelvic health and access to support. Particular attention was given to reaching marginalised and underserved communities to ensure improvements reflected diverse needs.



Engaging Patients

Women and girls with lived experience of accessing health services were involved, alongside carers, community organisations and voluntary groups. Engagement included Gypsy, Roma and Traveller communities, homeless communities, diverse faith groups, children and young people with learning disabilities and Afghan women in resettlement programmes. Over 2,800 survey responses were received across Dorset and HIOW, alongside extensive community engagement.

A combination of digital surveys, in-person focus groups and community engagement events were used to gather insight. Public representatives contributed to steering groups and project teams, including the development of the Dorset Women’s Health Online Resource. Engagement took place through trusted community organisations, women’s networks and local symposia to ensure women felt safe and supported to share their experiences. >





Key Insights from Patients

Women highlighted ongoing difficulties accessing appointments, information and specialist support. Many described feeling dismissed or not listened to, particularly in relation to menopause and pelvic health. Participants emphasised the importance of empathy, clear information and services that respond to women’s lived experiences.



Evidence of Impact

The Dorset digital survey received 978 responses in 2024 and 686 responses in 2025, with 1,150 responses collected in HIOW. Engagement connected with over 20 organisations and led to the adoption of multiple service innovations, including funded access to pelvic health digital tools for over 1,100 women. Ongoing evaluation continues to capture women’s experiences and improvements in access.



Impact of Patient Insights on the Project

Patient feedback directly shaped programme priorities across Dorset and HIOW, including menopause, pelvic health, young women’s health and support for minoritised groups. Insights influenced the development of the Dorset Women’s Health Online Resource, ensuring key topics such as gynaecology, menstruation and menopause were prioritised. Eight innovations were adopted in Dorset to support population feedback, including a non-contraceptive coil fit pathway in the community, a new online website for education and information, four menopause apps and a pelvic health digital pathway with funded licences to improve access and quality of life.



Equality, Diversity & Inclusion Considerations

The programme proactively worked with diverse community groups and trusted leaders to reduce barriers to participation. Multiple engagement formats were offered, alongside culturally responsive approaches and practical support. Continuous reflection on who was included and who was missing helped strengthen inclusive practice and address inequalities.

Learnings and Recommendations

- Women were highly motivated to participate when provided with safe, supportive spaces to share their experiences.
- Working through trusted community relationships increased engagement and revealed hidden barriers.
- Future involvement should continue to prioritise meaningful partnership, accessible formats and shared decision-making to ensure women’s voices shape service improvement.

Service Design



Wellmind: Be Mindful Workplace – Accessible Digital Mental Health Support for Disabled Jobseekers

Managing mental health and preparing for work can be particularly challenging for people living with disabilities and long-term mental health conditions. **Be Mindful Workplace** is a digital wellbeing programme designed to help people manage stress and anxiety, build confidence, and support their journey into employment. From the start, the programme was co-designed with people who have lived experience of managing disabilities and mental health challenges, ensuring it was accessible, supportive, and relevant. A Public Advisory Group worked alongside the project team to shape programme design and content, accessibility features, user experience, and evaluation priorities.



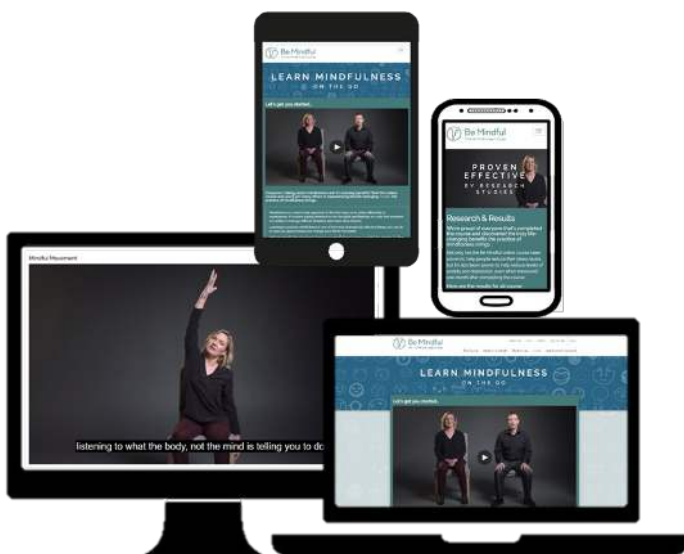
Engaging Patients

11 Public Advisory Group members with lived experience of disability and mental health challenges contributed to programme design. In addition, 296 participants have tested the co-designed programme to evaluate accessibility, usability and early impact. Patients took part in co-design sessions, advisory group meetings and programme testing over an 11-month period. Surveys, interviews and group discussions ensured people with lived experience could influence programme design and improvements throughout development.



Key Insights from Patients

Patients highlighted the importance of flexible support that allows choice and control, clear, plain English content that is easy to understand, accessible features such as BSL, Easy Read and screen reader compatibility for independent use, the ability to skip, pause or return to activities to reduce pressure and anxiety. Users valued transparency and choice, especially around emotionally intense content. >



“It feels like a safe and comfortable space to share our thoughts...it does feel like we’ve been heard.”

Participant

“Just reading through the changes that have been made as a result of this group, I feel incredibly proud to have played a small part.”

Participant



Impact of Patient Insights on the Project

Patient insight directly influenced major improvements to the programme. For example, content was rewritten in plain English, accessibility features such as BSL interpretation and Easy Read formats were added, and exercises were redesigned to offer alternative options and greater flexibility. Clear messaging was introduced to emphasise that participation is optional and user-led. Patient involvement also helped shape how the programme is being evaluated, ensuring it focuses on accessibility, confidence and real-world experience.



Evidence of Impact

The co-designed programme is now supporting people to manage their wellbeing and build confidence as they prepare for employment. Participants reported that the programme feels more accessible, inclusive and supportive because of the changes made.



Equality, Diversity & Inclusion Considerations

The programme was designed specifically with and for people with disabilities and mental health challenges. Inclusive recruitment, independent facilitation and accessible engagement methods ensured people felt safe, valued and able to contribute openly.

Learnings and Recommendations

- Co-design with people who have lived experience leads to more accessible, inclusive and effective digital support.
- Independent facilitation helped create a safe environment for honest feedback.
- Recognising and valuing patient contributions throughout the project helps maintain engagement and strengthens programme outcomes.

“At Evenbreak, we are passionate about removing the barriers disabled people face in accessing meaningful employment. Mental health challenges can be both a consequence of exclusion from the workforce and a barrier to entering it. This partnership with Wellmind Health and Health Innovation Yorkshire & Humber means we can co-create support that is shaped by disabled people themselves. Together, we are ensuring the solution is genuinely inclusive, enabling, and designed to make a tangible difference.”

Adam Hyland, Chief Inclusion Officer Evenbreak



Read more >

[Developing a new platform to represent disabled people in the workforce](#)

To find out more, contact:

Yara Duaik yara.duaik@healthinnovationyh.com

Public and Patient Advisory Group to the National Pathology Imaging Cooperative

Waiting for test results can be one of the most stressful parts of a medical journey. The National Pathology Imaging Cooperative (NPIC) is helping hospitals move from microscope testing to digital pathology, speeding up diagnosis, improving accuracy and making it easier to share expert opinions.

NPIC aims to better understand and appreciate the issues and concerns of all our communities. Their goal is to enable a more inclusive and informed approach that safeguards people’s rights, minimises bias, and ensures services provided by the NHS are widely and equally effective and accessible. From the start of NPICs journey, patients and the public have worked alongside senior leaders to challenge assumptions and ensure change focus on what matters most to people.



Engaging Patients

Eighteen regular members attend NPICs Patient and Public Advisory Group, which is led by Health Innovation Yorkshire & Humber. Members include people with lived experience, carers, those from voluntary organisations and representatives of under-represented communities across the North of England.

Members take part in online and face-to-face meetings, workshops, co-design sessions and have the opportunity to have direct conversations with the NPIC leadership team. Involvement is ongoing rather than one off; this way a strong foundation of trust is being built and has enabled patients to influence the way AI tools are being implemented. >





What This Looks Like in Practice

Patient and public involvement is embedded across NPIC activities. Examples include:

- **AI tool development:** PPAG members reviewed and refined patient-facing materials for AI-enabled cancer diagnostics, helping simplify technical language, improve transparency, and clearly explain how AI supports (rather than replaces) clinical decision-making
- **Data governance and trust:** Patients contributed to discussions on the use of pathology data, shaping clearer explanations of data access, privacy, and consent
- **Programme expansion:** When three London NHS trusts joined NPIC (extending reach to approximately 1.8 million additional people), PPAG input informed more accessible communication materials for new sites
- **Research design:** Researchers developing AI tools engaged directly with PPAG members to ensure studies reflect patient priorities, particularly around acceptability, ethics, and communication

In several cases, patient and public input has also informed academic research outputs, particularly in relation to ethical governance, transparency, and public trust in AI. Further information and related publications can be found via the National Pathology Imaging Cooperative and its academic partners.

“The friendliness of the team and how open everyone was made me feel really valued.”

Participant

“I thought the meeting was well delivered and the content was spot on.”

Participant



Key Insights from Patients

Across activities, patients consistently emphasised:

- The need for honest, transparent communication about AI and data use
- A focus on outcomes that matter to patients, not just system efficiency
- Earlier involvement in decision-making processes
- Building trust through shared decision-making and accountability

In practice, this has included patients challenging the use of technical language in communications, requesting clearer explanations of how AI is used in care, and highlighting the importance of explaining how and why patient data is accessed. Patients also emphasised the need to communicate both the benefits and limitations of AI tools.

These insights are drawn from both participant feedback and programme delivery experience and align with wider research on public expectations of trustworthy AI in healthcare (McKay et al., 2022).



Impact of Patient Insights on NPICs activity

PPAG tasks can be anything from making recommendations on written material, to inputting on the selection of potential programme partners. One example is how patient insight has shaped the design of an AI tool to help speed up cancer diagnosis, through improved and accessible communication materials, and advice on tailoring national guidance on patient involvement in AI tool development.

Another example relates to three London trusts who recently joined the NPIC collective, benefiting around another 1.8 million people. PPAG insights helped to streamline processes and communications, which were made clearer and more accessible. >



Evidence of Impact

Patient and Public insight has ensured projects are more patient-centred, ethically governed, and aligned with public needs by actively shaping their design, implementation, and use of data. Since 2020, the PPAG has had a clear and measurable impact on projects, mainly by shaping how they are designed, governed, and delivered. This includes contributing to published research on the governance and ethics of AI in healthcare, demonstrating how public involvement informs trustworthy data use and AI implementation ([McKay et al., 2022](#); [McKay et al., 2023](#)).



Equality, Diversity & Inclusion Considerations

The PPAG includes 18 members and has been intentionally recruited to reflect a diversity of ethnic, faith, and socio-economic backgrounds across the North of England. Recruitment has been supported through community networks and voluntary sector organisations to broaden representation and ensure a range of lived experiences are included.

Ongoing work aims to further strengthen representation from under-served communities and improve the routine capture of demographic data to support inclusive engagement.

Learnings and Recommendations

Key learnings are drawn from both participant feedback and programme delivery experience:

- Strong leadership commitment is essential to embedding meaningful involvement
- Long-term relationship building enables deeper and more impactful insight
- Smaller, one-to-one conversations often surface more detailed perspectives, particularly on sensitive topics such as data use and trust
- Embedding involvement early leads to more acceptable, ethical, and implementable innovation

For example, one-to-one conversations with participants have provided deeper insight into concerns around data use and transparency that were not always raised in larger group settings, informing how these topics are addressed in wider communications and engagement activities.

“The Public and Patient Advisory Group have been so important to our NPIC programme. They give us guidance on what patients and the public would expect and want from digital transformation in the NHS, help shape our approach to patient data, and engage with researchers as they plan and design their work in artificial intelligence and cancer. Input from the PPAG is one of the most important parts of how we run the programme and we’re very grateful to the team for their efforts.”

Professor Darren Treanor, Director, National Pathology Imaging Co-operative



Read more > [Patient and Public Involvement in Digital and Computational Pathology](#)

To find out more, contact:

Adam Smith adam.smith@healthinnovationyh.com



Impact of Patient Insights on the Project

Patient insights strengthened understanding and emphasised key opportunities for focus and prioritisation and built into the core principles of the redesigned obesity care pathway. Their experiences helped identify barriers and priorities, ensuring the new model reflects real patient needs. This has helped shape a more accessible, supportive and person-centred approach to weight management services.



Equality, Diversity & Inclusion Considerations

The project prioritised inclusion by working with diverse communities and offering flexible participation options. Engagement highlighted the importance of designing services that reflect people’s cultural backgrounds, life circumstances and access needs. This helped ensure future services are more inclusive and equitable.



Evidence of Impact

The project established clear principles for improving weight management services based on lived experience. Participants reported feeling valued and supported through the co-design process.

“I have gained valuable insights from people and their perspectives which is really inspiring.”

Participant

Learnings and Recommendations

- Working with community partners helped create safe and supportive spaces for people to share their experiences.
- Co-design with patients strengthens service design and ensures care reflects real needs.
- Ongoing involvement and collaboration between patients, clinicians and communities are essential for improving services.

“This is the first time we have brought all key stakeholders together to support the reimagining of an obesity pathway in Greater Manchester. Our aim is to co-create a pathway that genuinely works for patients. We understand the needs of our region, and we know that motivation, shared ownership, and a common vision are essential to making meaningful change.”

Professor Bilal Alkhaffaf, Upper GI & Bariatric Surgeon, Clinical Director for Upper GI and Bariatric Surgery at The Northern Care Alliance NHS Foundation Trust

To find out more, contact:

Louise Lawrence louise.lawrence@healthinnovationmanchester.com

Lauren Constable lauren.constable@healthinnovationmanchester.com

North East and North Cumbria Pain Management Citizen's Jury

Persistent pain affects many people and can significantly impact quality of life, with high reliance on medication such as opioids. This project brought together members of the public to share their experiences and help shape future pain management services. Through a Citizens' Jury, people with lived experience explored current challenges and developed recommendations to improve care. Their input helped ensure future pain services better reflect patient needs and priorities.



Engaging Jurors, Citizens and People

Fourteen members of the public from across North East and North Cumbria participated, including people with lived experience of persistent pain. Jurors were recruited to reflect the diversity of the local population and ensure

a wide range of perspectives were represented. Participants took part in structured Citizens' Jury sessions involving expert presentations, group discussions and collaborative deliberation. Over 35 hours of engagement, jurors explored evidence and shared their experiences. This process supported informed discussion and co-production of recommendations. >





Key Insights from Jurors

Jurors highlighted the importance of improving awareness and understanding of persistent pain among healthcare professionals and the public. They emphasised the need for more accessible community-based support and services that recognise persistent pain as a long-term condition. Patients also stressed the importance of co-ordinated care, education and national leadership to improve pain management.



Evidence of Impact

The Citizens' Jury recommendations are being considered as part of regional planning and strategy development. The model provides a scalable approach to involving patients in shaping future services and improving care.



Impact of Juror Insights on the Project

Patient insight led to the development of clear recommendations to improve pain management services and reduce reliance on medication. These recommendations are informing regional strategy and supporting improvements in care. The project demonstrated how meaningful patient involvement can shape healthcare policy and service design.



Equality, Diversity & Inclusion Considerations

The Citizens' Jury was designed to reflect the diversity of the local population and include a wide range of perspectives. Inclusive recruitment ensured people with different backgrounds and experiences could participate. This helped remove barriers to participation and ensure recommendations reflected the needs of diverse communities.

Learnings and Recommendations

- The Citizens' Jury model provided valuable insight and enabled meaningful patient involvement in complex healthcare issues.
- Structured facilitation and inclusive recruitment supported effective engagement.
- This approach can be used in future projects to improve patient involvement and service design.

“The Citizens' Jury has provided a powerful way to ensure the voices of the North East and North Cumbria community shape healthcare decisions. By bringing together diverse perspectives, including those with lived experience, it allows the healthcare and wider system to work towards a more effective and compassionate approach to pain management that meets the needs of our region.”

Julia Newton, Medical Director, Health Innovation North East and North Cumbria

To find out more, contact:

Victoria Strassheim victoria.strassheim@healthinnovationnc.org.uk

Lived Experience Partners: Embedding Involvement Across Health Innovation Network South London

Health Innovation Network South London introduced the Lived Experience Partner (LEP) role to strengthen and embed patient involvement across the organisation. The role was developed to ensure the patient voice influences work from early scoping and bid development through to delivery and evaluation. LEPs work across programmes, supporting staff and innovators to involve people meaningfully and inclusively. This approach helps ensure lived experience shapes decisions at both project and strategic levels.



Engaging Participants

Four Lived Experience Partners have been recruited since 2023, bringing experience of complex health needs and community advocacy. Three of the four partners represent the Global Majority, helping strengthen diversity within the organisation. The role supports engagement with a wide range of patients and communities across more than 50 projects. LEPs co-facilitate workshops and focus groups, contribute to steering groups and support co-design activities. They provide advice to innovators, help shape evaluation tools and support experts by experience to share their stories in psychologically safe ways. Their involvement spans digital innovation, mental health pathways, evaluation projects and service redesign.



Impact of Participant Insights on the Project

LEPs have influenced service design, engagement methods and organisational processes. Their insight has led to more inclusive recruitment, creative facilitation approaches and improved preparation for experts through their experience taking part in public events. These changes have strengthened psychological safety and embedded lived experience more consistently across programmes.



Key Insights from Participants

LEPs highlighted that healthcare environments can feel intimidating and that psychological safety must be intentionally created. They emphasised that accessibility should be planned from the outset, including physical, communication and emotional considerations. They also stressed that flexible, creative and supported involvement enables people with ongoing or complex conditions to contribute meaningfully.



Evidence of Impact

Since 2023, LEPs have supported over 50 projects and contributed to more than 20 projects in 2025 alone. Staff report that involvement has improved evaluation tools, strengthened focus group design and enhanced understanding of patient perspectives. >



Equality, Diversity & Inclusion Considerations

The LEP model was designed to increase diversity and reduce barriers to involvement. Flexible contracts, accessible recruitment processes and inclusive support structures enabled people with ongoing health conditions to participate. Having LEPs who reflect diverse communities has strengthened the organisation's ability to design inclusive and culturally sensitive engagement.

“Collaborating with someone who has lived experience challenged my assumptions and strengthened the overall session design.”

Participant

“Their involvement from the outset... ensured that lived experience was embedded from the very beginning.”

Participant

Learnings and Recommendations

- Embedding lived experience roles within the organisation has strengthened trust, relationships and consistency of involvement.
- Clear role definitions, flexible working arrangements and ongoing review processes have supported sustainability.
- This model demonstrates that employing lived experience partners can meaningfully enhance innovation and service design.

To find out more, contact:

Sophie Lowry sophie.lowry2@nhs.net

Improving Access and Experience



Raising Awareness of Heart Failure Symptoms Among Marginalised Communities Through Trusted Communicators Using a Co-Production Approach

Heart failure symptoms can often go unrecognised, particularly in underserved communities where access to health information may be limited. This project worked with community elders and volunteers to co-produce culturally appropriate awareness materials and deliver health education in trusted community settings. Engagement focused on helping people recognise the signs and symptoms of heart failure and understand when to seek medical advice. The project was delivered using a community-based outreach model centered on trust, cultural competence and accessibility.



Engaging Patients

Community members from minority ethnic and underserved groups at increased risk of heart failure were involved. To date, 365 people attended engagement events, with 191 providing feedback through evaluation surveys. Community engagement events were held in trusted locations including Mosques,

Gurdwaras and community groups. Sessions were delivered by community leaders and volunteers. Educational materials and surveys were translated into multiple languages (including Urdu, Gujarati, Punjabi, Hindi and Tamil), and support was provided to help participants engage and share feedback. >





Key Insights from Patients

Patients highlighted the importance of information being available in their own language, having materials that reflect their community and cultural context, delivering health information through trusted community leaders and information being provided in accessible community locations like libraries or community centres.



Evidence of Impact

Materials and events were representative of the co-production and insight from participants. Participants also reported increased understanding of heart failure symptoms following the sessions, as well as increased trust in health services. As a result of the sessions, 34 people were signposted to their GP after recognising possible symptoms.



Impact of Patient Insights on the Project

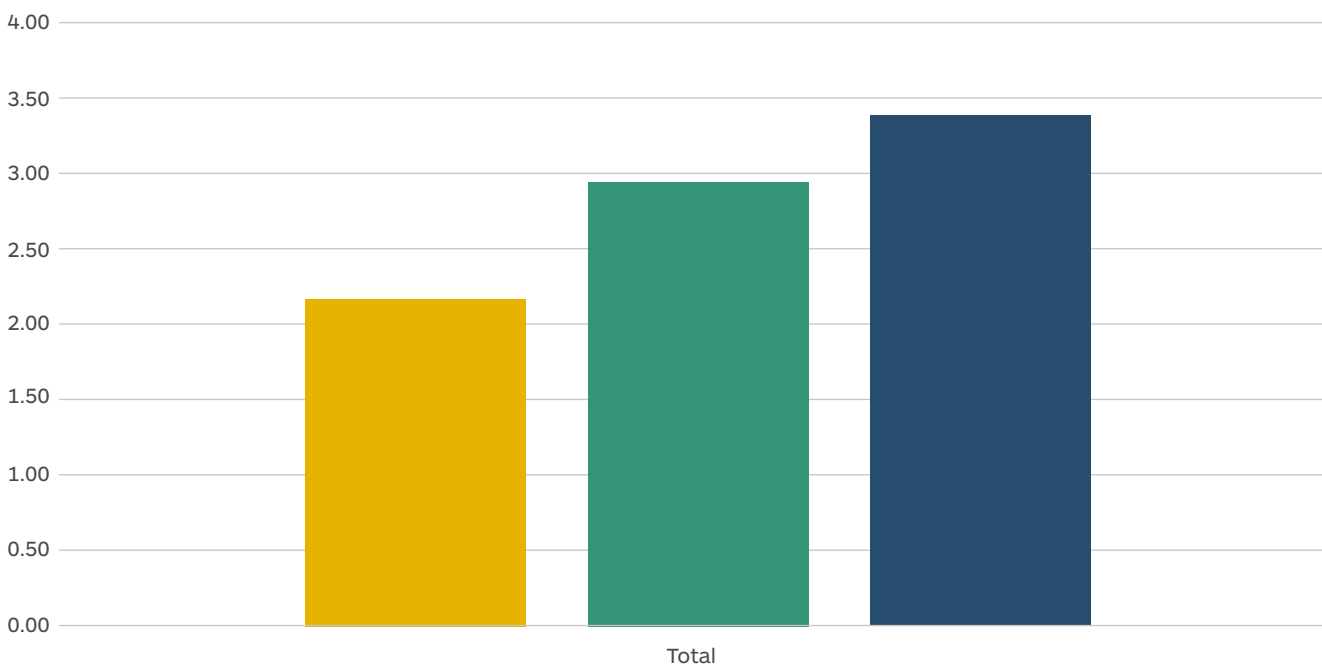
Patient insight helped ensure awareness materials were culturally appropriate, accessible and relevant. Health education sessions were delivered in trusted community settings by respected leaders, improving engagement and trust. Translated materials and accessible surveys enabled more people to participate and share feedback.



Equality, Diversity & Inclusion Considerations

The project prioritised underserved communities by working with trusted local organisations and delivering sessions in familiar settings. Materials and surveys were translated into multiple languages, and support was provided to enable inclusive participation. >

Questions	Average Ratings	Out of
Before today, which option best represented your knowledge of heart failure and its symptoms?	2.04	4
Which option best represents your knowledge of heart failure and its symptoms now?	3.03	4
Overall, how useful did you find the session?	3.46	4



- Average of Before today, which option best represented your knowledge of heart failure and its symptoms?
- Average of Which option best represents your knowledge of heart failure and its symptoms now?
- Average of Overall, how useful did you find the session?

Learnings and Recommendations

- Working with trusted community organisations helped ensure the sessions were well-received and effective.
- Delivering health education in familiar environments helped build trust and improve engagement.
- Community-based partnerships are essential for reaching underserved populations and improving health awareness.
- Community engagement continues to support cardiovascular health awareness and strengthen relationships between health services and underserved communities.

“The [project] reminded us that trust is the foundation of good health. At One Vision, many of the communities we serve are people we worship with, cook with and walk alongside in everyday life. By delivering this work through faith and community spaces, conversations about heart health felt safe, human and accessible rather than clinical. People spoke openly about stress, family pressures, faith and wellbeing, often sharing that this was the first time they felt listened to without judgement. Simple blood pressure checks became moments of awareness, leading to GP follow-ups and real lifestyle changes. Through long-standing relationships with faith leaders, volunteers and families, we reached people often missed by traditional services. This work strengthened trust between communities and the health system and showed what is possible when health is delivered with compassion, cultural understanding and lived experience.”

Enoch Kanagaraj, Director of One Vision



“I will get my family checked for heart failure because of this session.”

Participant

“Good to know what symptoms to look out for.”

Participant

To find out more, contact:

Rachael Ford rachael.ford@healthinnovationeast.co.uk

Engaging with Deaf People to Achieve Health Equity

People in the Deaf community often face barriers when accessing healthcare, which can lead to poorer health outcomes. This project worked with Deaf people and community organisations to improve understanding of these barriers and help health professionals provide more accessible and inclusive care. Deaf people with lived experience co-produced and co-delivered a webinar and practical guidance for health professionals, ensuring the content reflected real experiences and priorities. The activity aimed to raise awareness, improve communication, and support more equitable access to healthcare services and included the production of a top tips document.



Engaging Patients

Deaf people with lived experience were involved in research, co-production and delivery of the project. Forty-four Deaf people contributed insight through research, and 94 professionals attended the co-produced webinar. Focus groups, co-production and a

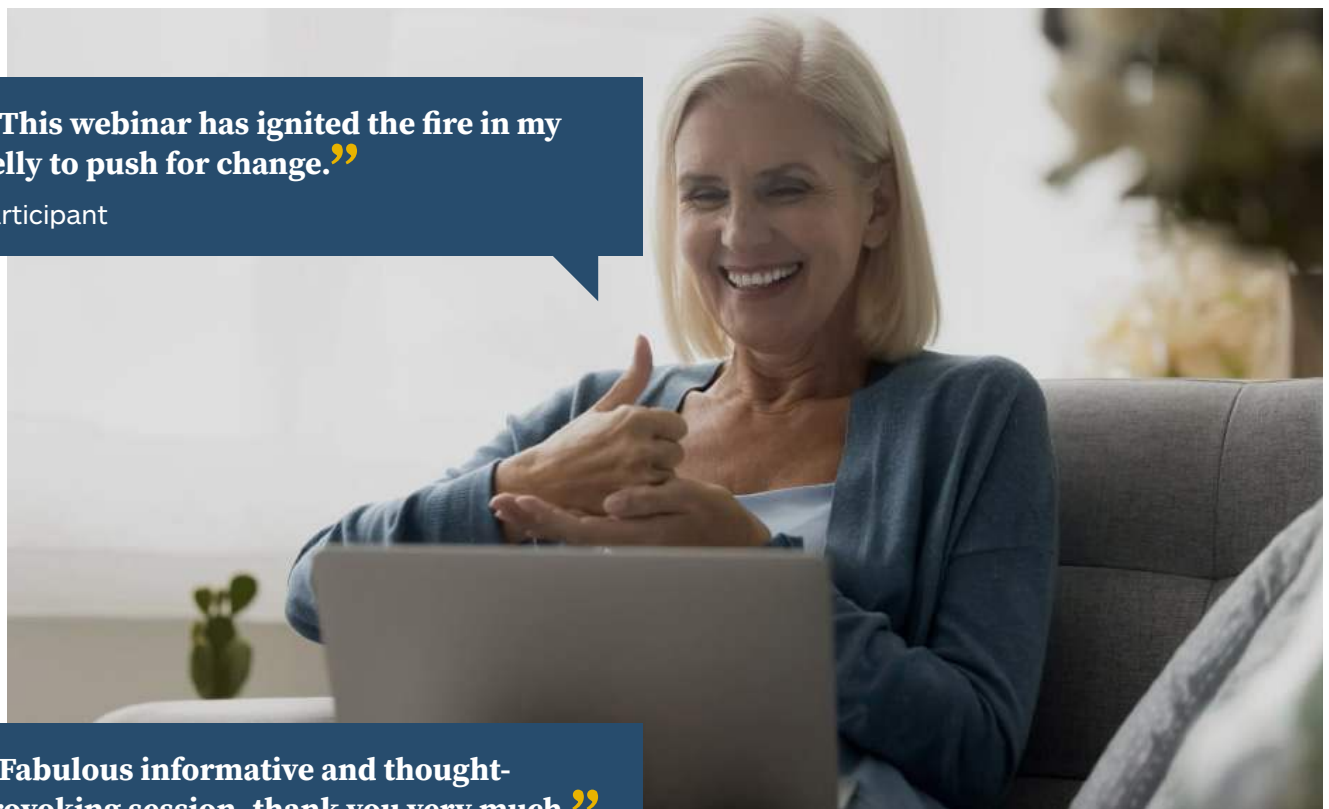
virtual webinar were used to gather lived experience insight and share learning. Deaf people worked alongside researchers to develop guidance and deliver the session, ensuring patient perspectives shaped the content and recommendations. >

“This webinar has ignited the fire in my belly to push for change.”

Participant

“Fabulous informative and thought-provoking session, thank you very much.”

Participant





Key Insights from Participants

Participants highlighted the importance of planning communication support such as British Sign Language (BSL) interpreters in advance, asking individuals about their preferred communication methods. Face-to-face engagement is best but it is important to create accessible environments for both online and face-to-face engagement, using inclusive communication approaches that reflect Deaf culture and language as well as improving the awareness of barriers faced by Deaf people when accessing services.



Impact of Patient Insights on the Project

Patient insight directly shaped the webinar content and the development of practical guidance for health professionals. The project helped increase awareness of barriers faced by Deaf people and provided clear actions to improve communication and accessibility. Health professionals were encouraged to apply this learning in their own services to



improve access and inclusion.

Evidence of Impact

The webinar was well-attended and positively received, with participants reporting increased awareness and motivation to improve accessibility.



Equality, Diversity & Inclusion Considerations

The project prioritised inclusion by co-producing the webinar with a member of the Deaf community and ensuring accessible delivery. BSL interpreters, adapted technology settings and inclusive facilitation supported full participation and modelled best practice.

Learnings and Recommendations

- Co-producing work with Deaf people ensures guidance is rooted in lived experience and improves relevance and impact.
- Accessible planning and inclusive delivery are essential for meaningful participation.
- This approach helped raise awareness and motivated professionals to improve accessibility in their own services.

To find out more, contact:

Deborah Wilson deborah.wilson@nottingham.ac.uk

Helping People with Learning Disability, At Risk of Behaviour that Challenges, to Reduce Harm from Psychotropic Medication

This project explored the experiences of people with learning disability who may be prescribed psychotropic medication for behaviour that challenges. It formed part of the Medicines Safety Improvement Programme and aimed to ensure the national safety programme was shaped by lived experience. People with learning disability, carers and advocates took part in focus groups to share how medication decisions affect their daily lives. Their insight helped inform the development of a patient-centred safety programme that has now been adopted nationally.



Engaging Patients

Eight people took part, including individuals with learning disability supported by carers and advocates. Participants were recruited through a self-advocacy group to ensure involvement took place in a trusted and familiar environment. Two focus groups were organised to explore experiences of medication,

support and desired improvements. An Easy Read leaflet was shared in advance to introduce the project and questions in accessible language. The successful group was hosted within an established self-advocacy meeting, enabling participants to contribute in a supportive and familiar setting. >





Key Insights from Patients

Participants highlighted challenges with continuity of care and communication between professionals, which can affect understanding of medicines and side effects. They emphasised that medical language is often not accessible and that appointments may not allow enough time to fully understand individual needs. Patients and carers stressed the importance of ongoing medication reviews, clearer information in Easy Read formats, and support from trusted professionals to ensure medicines are used safely and appropriately.



Impact of Patient Insights on the Project

Insights from people with learning disability directly informed the development of the National Patient Safety Improvement Programme focused on reducing harm from psychotropic medicines. Feedback contributed to a theory of change model and shaped programme priorities, communication approaches and design materials. The consultation formed part of the evidence base supporting a £2 million NHS England commission to implement the first year of the national programme through the Patient Safety Collaboratives.



Evidence of Impact

The consultation findings informed the design and national rollout of the safety programme, including the development of patient-facing materials and engagement approaches. Lessons learned have also been shared across wider patient safety workstreams to strengthen future involvement.



Equality, Diversity & Inclusion Considerations

Engagement was designed to support full participation, including use of Easy Read materials and trusted advocacy settings. Collaboration with a self-advocacy group created a safe environment for discussion. The involvement of carers and specialist support was recognised as essential to enabling meaningful participation for people with learning disability.

Learnings and Recommendations

- Working through trusted community partners significantly strengthened engagement and participation.
- Accessible materials, sensitive facilitation and flexible formats are essential when involving people with learning disability.
- Meaningful involvement requires early planning, resilience and a commitment to embedding lived experience throughout programme design and delivery.

To find out more, contact:

Jordan Leith jordan.leith@healthinnovationwm.org

Black Maternity Matters Working Across Systems in True Co-Production

Black Maternity Matters (BMM) is a co-produced programme developed in response to urgent patient safety concerns raised by women and families racialised as Black. Launched in the West of England in 2021, the programme centres lived experience to address racial inequities in maternity care. Working in partnership with Black Mothers Matter, BCohCo, Representation Matters and Health Innovation West of England, BMM delivers immersive anti-racist education, peer support and quality improvement (QI) initiatives across maternity and neonatal services. The programme recognises racism as a patient safety risk and works across systems to improve trust, safety and outcomes for Black mothers and families.



Engaging Patients

Women and birthing people racialised as Black, alongside partners, carers and wider community members, have shaped the programme from its inception. Community organisations including Black Mothers Matter, BCohCo and Representation Matters are embedded as equal partners in design and delivery. BMM is grounded in true co-production, led by people

with lived experience. Engagement includes co-designing curriculum content, reflective tools and case studies, community-led insight work and immersive six-month anti-racist education programmes. Psychologically safe peer-support spaces and co-produced QI projects enable clinicians and leaders to reflect, learn and implement change alongside community partners. >



“Innovation that truly responds to the needs of Black mothers.”

Participant



Key Insights from Patients

Women racialised as Black reported experiences of mistrust, inequity and not feeling heard within maternity services. Participants highlighted that traditional equality and diversity training does not lead to meaningful behaviour change, and that racial literacy among clinicians directly affects safety and outcomes. Lived experience must shape solutions from the outset, with co-production built on psychological safety, cultural humility and recognition of paid expertise.



Impact of Patient Insights on the Project

Lived experience insight shaped the immersive and trauma-informed design of the programme and confirmed racism as a patient safety issue requiring system-level action. Patient perspectives informed quality improvement priorities, including equitable pain management and improved communication around preterm birth. The programme now works across maternity, neonatal and perinatal teams, influencing senior leaders and embedding anti-racist approaches into workforce development and safety initiatives.



Evidence of Impact

To date, 23 perinatal cohorts and three senior leader cohorts have completed the programme regionally and nationally, with over 600 staff and leaders trained. Multiple co-produced QI projects have been implemented across trust and community settings, strengthening equity and safety in maternity care.



Equality, Diversity & Inclusion Considerations

The programme explicitly addresses racial inequity as a patient safety issue. Co-production is led by community organisations and delivered through racially congruent facilitation, trauma-informed practice and paid lived experience leadership. This approach ensures that voices of Black mothers are centred and that systemic inequities are openly addressed.

Learnings and Recommendations

- Deep partnership between community organisations and system leaders enabled meaningful, sustained change.
- The six-month immersive model supports genuine reflection and behaviour change beyond traditional training approaches.
- Sustainable funding and wider rollout are recommended to embed anti-racist QI methodology across perinatal and maternity services nationally.

“The Black Maternity Matters Collaborative and Programme shows what is possible when co-production is done with integrity. By centring lived experience and respecting each partner’s approach and role in addressing racial disparities, we have created a collaborative model built on trust, shared purpose and accountability. This approach has strengthened the work and enabled innovation that truly responds to the needs of Black mothers.”

Sonah Paton, Director and Founder of Black Mothers Matter

To find out more, contact:

Noshin Emamiannaeini - Menzies noshin.menzies1@nhs.net

Preterm Birth Experiences of Women Racialised as Black in BNSSG

This project explored the preterm birth experiences of women racialised as Black across Bristol, North Somerset and South Gloucestershire (BNSSG). Co-produced by BNSSG Local Maternity and Neonatal System, Health Innovation West of England and Black Maternity Matters, the work formed part of the NHS Race & Health Observatory Learning and Action Network. Six race- and trauma-informed interviews examined how racism, bias and systemic inequities influenced care pathways, triage decisions and communication. The findings are informing targeted improvements in safety, equity and anti-racist practice across maternity services.



Engaging Patients

Six women with lived experience of preterm or traumatic birth participated, alongside engagement with families and community organisations. Participants were women racialised as Black or of Mixed Black heritage and were recruited through BNSSG networks, community groups and maternity teams.

Semi-structured interviews were conducted virtually by Black Maternity Matters anti-racist education leads, using a trauma-informed and racially congruent approach. The BNSSG preterm birth pathway guided discussions to explore clinical and emotional experiences. Interview findings were thematically analysed and aligned with quantitative data to strengthen learning and validation. >





Key Insights from Patients

Women described experiences of symptoms being minimised or dismissed, leading to delayed care and increased anxiety. Participants highlighted self-protective behaviours, including “code-switching” and fear of being judged, which affected help-seeking. Lack of clear information about preterm birth risk, limited racial literacy among clinicians and inequities in NICU communication were identified as significant concerns.



Impact of Patient Insights on the Project

Patient insight reframed racism as a patient safety risk and shaped system-level priorities within the BNSSG action plan. Findings informed improvements in triage processes, equitable pain management, trauma-informed care and NICU communication pathways. Themes also validated quantitative data showing missed optimisation opportunities and strengthened the focus on racial literacy within workforce development and quality improvement work.



Evidence of Impact

Qualitative findings aligned with quantitative data, reinforcing evidence of inequities in care pathways. Insights have been embedded within Black Maternity Matters training and informed the co-development of multilingual preterm birth symptom leaflets. Staff survey findings identified awareness gaps, prompting targeted education and training.



Equality, Diversity & Inclusion Considerations

Interviews were conducted using racially congruent facilitation and trauma-informed principles aligned with Black Maternity Matters’ Anti-Racism Theory and Practice. The project explicitly addressed structural inequities affecting women racialised as Black. Findings highlighted systemic issues in triage, pain management, communication and decision-making processes.

Learnings and Recommendations

- True co-production built trust and enabled authentic insight gathering on sensitive experiences.
- Continued investment in racial literacy, trauma-informed practice and safe mechanisms for raising concerns about racism is recommended.
- Embedding anti-racist quality improvement approaches across maternity services will be essential for sustained change.

To find out more, contact:

Noshin Emamiannaeini - Menzies noshin.menzies1@nhs.net

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✉ info@thehealthinnovationnetwork.co.uk

🌐 thehealthinnovationnetwork.co.uk

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