Health Innovation Network
Local change, national impact

Forging a more equitable healthy future through Patient and Public Involvement and Engagement

Roundtable report

Spring 2025

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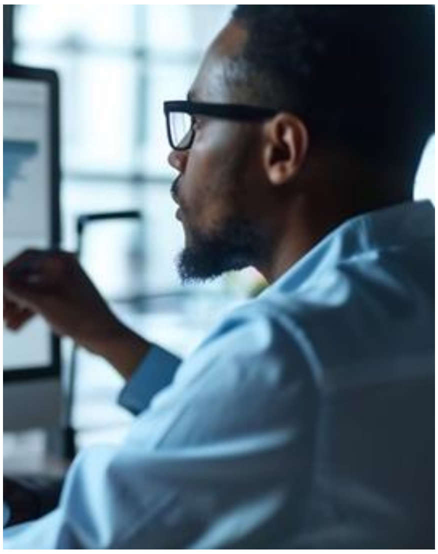

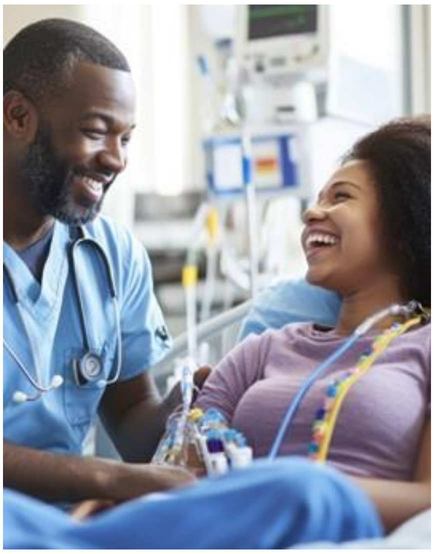

Foreword

The need for fast-paced innovation in healthcare is widely acknowledged. Lord Ara Darzi's Independent Investigation of the National Health Service in England recognised the importance of 'embracing new innovations at the frontiers of scientific possibility', and that 'it is innovation that can make the NHS more sustainable.'[1]

Indeed, fast-paced innovation can be transformative when meaningfully informed by robust patient and public involvement and engagement (PPIE). It can deliver significant benefits, including improved usability, deeper insights into patients' needs and preferences, increased credibility and uptake and more equitable adoption among underserved populations.[2]

Ensuring that healthcare innovation is shaped by the people it serves remains a pressing priority — one made all the more evident by the growing emphasis on health equity and the evolution of digital services in the government and NHS England 10-Year Health Plan. On 26 February 2025, the Health Innovation Network (The Network) convened a roundtable at HETT North in Manchester to explore how robust Patient and Public Involvement and Engagement (PPIE) can deliver more inclusive, sustainable healthcare innovation.

This report captures the roundtable's discussions, bringing together patients, patient entrepreneurs, carers, PPIE experts and innovators to discuss how meaningful involvement of diverse voices can reshape the future of health services. Key to this conversation was the recognition that patient engagement is not simply an add-on, but a vital driver of effective solutions. By systematically integrating patient feedback, whether through real time usability assessments or culturally sensitive service design, healthcare organisations can build innovations that resonate with communities, enhance adoption, and ultimately narrow the gaps in access and outcomes.

A clear consensus emerged that healthcare transformation must be underpinned by genuine collaboration, with patients serving as active contributors rather than passive beneficiaries. This approach not only builds trust but also enables targeted interventions that address longstanding disparities. The evidence is compelling: when individuals feel their voices and experiences are valued, they are more likely to engage with and benefit from new models of care. By harnessing PPIE in a structured, purposeful way, the health sector can move beyond piecemeal improvements towards a more comprehensive, equitable landscape.

It is our hope that the insights presented here will translate into tangible actions and inform policy decisions that prioritise inclusivity at every level. Only by fully embracing patient-centred innovation can we ensure that advances in technology and service provision truly meet the needs of all, creating a healthcare system that is both resilient and just.

Kathy Scott

Deputy Chief Executive Officer, Health Innovation Yorkshire and Humber

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[1] https://assets.publishing.service.gov.uk/media/66f42ae630536cb92748271f/Lord-Darzi-Independent-Investigation-of-the-National-Health-Service-in-England-Updated-25-September.pdf

[2] Baines R, Bradwell H, Edwards K, et al. Meaningful patient and public involvement in digital health innovation, implementation and evaluation: A systematic review. Health Expect. 2022;25(4):1232-1245. doi:10.1111/hex.13506

Contributions

We would like to extend a heartfelt thank you to everyone who participated in shaping the ideas captured in this report. Coming together to generate solutions in a limited time is never easy—especially in a public forum—yet each contributor brought valuable lived experiences and insights on enhancing PPIE at every stage of innovation. Their candour and commitment have helped us shape tangible recommendations that will resonate with a wide audience.

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Background

Patient voices are often cited as central to healthcare innovation, yet in practice, those voices can be overlooked or engaged too late in the process. Recognising this disconnect, the Health Innovation Network organised a dedicated roundtable in February 2025 at HETT North in Manchester. This gathering sought to challenge the status quo by inviting patients, patient entrepreneurs, carers and PPIE experts to assess emerging digital health solutions through hands-on, real-world testing.

Ahead of the formal discussions, patient representatives visited innovators exhibiting at HETT North and were encouraged to share experiences and reflections on PPIE, common challenges and best practices. Their immediate feedback provided a clear, on-the-ground perspective on the barriers and facilitators that can determine a product's success—ranging from cultural sensitivity and language accessibility to usability and trust. The event's central objectives were:

1. To better understand how service design might be adapted to reflect the realities of diverse communities
2. To explore practical ways of embedding Patient and Public Involvement and Engagement (PPIE) across all stages of the innovation pathway.

The theme of ***meeting people where they are*** was consistently emphasised. Addressing health inequalities requires acknowledging how social, economic, and cultural contexts shape individuals' access to—and perceptions of—care. Discussions highlighted the need to move beyond conventional pathways: not simply refining existing technologies but adopting flexible and responsive methods that resonate with patients' lived experiences. Participants also stressed the importance of trust: without transparency about how and why innovations are developed, and where funding decisions originate, patients are unlikely to engage wholeheartedly.

The insights gained through this roundtable highlighted a shared aspiration: healthcare innovation must be co-created rather than imposed. By prioritising PPIE from the outset, organisations can better understand real-world enablers and challenges, improve adoption, and mitigate the risk of perpetuating existing disparities. The subsequent sections of this report capture the insights from these conversations. The result is a comprehensive set of recommendations that outline how sustained, well-structured patient engagement can enable more equitable, impactful and inclusive healthcare innovations.

Summary of recommendations

From the roundtable discussions and immediate patient feedback, five areas emerged where healthcare professionals, innovators, and policymakers can collaborate to deepen Patient Participation, Involvement and Engagement (PPIE).

These recommendations also reflect specific calls to action around building trust, ensuring equitable access, promoting a culture shift, and valuing real-world outcomes.

Move from a 'medical' to an innovative mindset

ACTION:

Shift the focus from a "doing to" approach to an "innovating with" approach, harnessing patient expertise and measuring real-world outcomes.

Build trust through genuine community links

ACTION:

Work through existing community leaders and trusted intermediaries to reach underserved groups and tackle mistrust head-on.

Put patients at the heart of electronic health

ACTION:

Ensure patient voices are embedded in developing electronic health records and data-sharing protocols, with genuine and sustainable co-governance.

Prioritise value-based investment in innovation

ACTION:

Focus funding and procurement decisions on improved patient outcomes and long-term benefits, rather than short-term, lowest cost.

Put patients in power at every level

ACTION:

Formalise patient leadership roles to ensure shared decision-making and genuine accountability across the NHS.

The next step - Getting patients excited about innovation

As a next step in getting patients excited about innovation, we must shift from top-down approaches to genuine collaboration. Many feel disconnected when "innovation" seems too technical or cost-driven, rather than relevant to everyday life. By ensuring open dialogue, personalised guidance, and tangible benefits, we can build trust, spark curiosity, and place patients at the centre of shaping the future of healthcare innovation.

Case study 1:
Straight Talking

Census data shows that nearly 770,000 people in England have limited English proficiency, a challenge that significantly impacts access to healthcare and contributes to poorer outcomes. Ethnic minority groups, particularly South Asians, experience disproportionately high rates of asthma morbidity and hospitalisation. In Kirklees, where uncontrolled asthma is prevalent among the South Asian community, the project team engaged directly with residents to identify effective ways to communicate vital health messages.

Aim

To tackle high emergency care usage among non–English speaking communities with asthma, where misconceptions about triggers and delays in seeking primary care often lead to avoidable hospital admissions.

Approach

- Trusted "Covid Champions" were trained in asthma awareness, capitalising on existing community ties and linguistic skills. This approach reduced fears around "bothering the doctor" and dispelled common myths regarding dietary or cultural factors.
- Short videos, QR code posters, and endorsements from faith leaders were developed through focus groups, helping to communicate early warning signs and the importance of timely care in multiple languages.

Outcome

- More people sought help before conditions escalated, lowering emergency attendance rates.
- Sharing bilingual materials on social media significantly boosted awareness, demonstrating the power of culturally tailored resources.

Health Innovation
Yorkshire & Humber

NHS
Mid Yorkshire Teaching
NHS Trust

LEARNING:

When cultural nuances and local trust networks are front and centre, health interventions can overcome stigmas and promote earlier, more effective engagement with services.

Case study 2:
Greater Manchester Secure Data Environment - Citizens Advisory Panel

Secure Data Environments (SDEs) are highly secure computing environments that provide access to health data for the purposes of health research. The Citizen Advisory Panel (CAP) helps to ensure the public voice is at the heart of the development of the SDE in Greater Manchester.

Aim

To retain public confidence in large-scale health data research, particularly among groups historically mistrustful of data-sharing, by involving them from the outset in governance and oversight.

Approach

- A diverse panel of local residents, including people living with long-term conditions, vets every request to access the SDE. Panel members assess ethical implications, highlight cultural sensitivities, and ask how research will benefit local communities.
- By including public representatives in early decisions e.g., whether to incorporate imaging or genomic data—the programme ensures data usage is openly debated, aligning with patient priorities around privacy, inclusivity, and equitable outcomes.

Outcome

- An independent review praised the panel's "first-class" approach, noting higher acceptance of data-driven initiatives in the communities represented.
- By giving local stakeholders a direct role in governance, the programme reframed datasharing as a collaborative endeavour rather than an imposed.

Health Innovation Manchester

LEARNING:

When patients and citizens guide data governance, trust flourishes, and innovations are more likely to reflect the genuine needs of underserved groups.

Recommendation 1

Move from a ‘medical’ to an ‘innovative’ mindset

Many current healthcare services and innovations still treat patients as passive recipients rather than active co-creators of solutions. By embracing an innovative approach—grounded in lived experience and outcome measurement—we ensure that interventions address actual needs, increase patient self-management, and achieve meaningful adoption.

- **Collaborative Goal-Setting**

  Redesign service pathways and product development with patients at the table from the outset, defining clear outcome goals (e.g., improved self-management).

- **Outcome-Driven Evaluations**

  Replace check-box feedback forms with tools that measure genuine progress, such as whether patients feel more capable of managing their own health.

- **Innovation Sprints with Patients**

  Involve patient groups in rapid prototyping and testing cycles, ensuring products reflect real challenges and priorities.

RECOMMENDATION:

Shift the focus from a “doing to” approach to an “innovating with” approach, harnessing patient expertise and measuring real-world outcomes.

A Framework for driving Innovation adoption through patient insight

Frameworks such as the Health Innovation Yorkshire and Humber's **'Framework for driving innovation through patient insight'** exist to show how patient experience and insights can be gathered, applied and developed to create (in this instance) clear and agreed adoption goals informed by patient feedback and insight.

Recommendation 2

Build trust through genuine community links

Gatekeeping, mistrust of health services, and cultural or familial pressures often prevent vulnerable communities from accessing new innovations. Engaging known and respected figures—who understand local realities—helps break down barriers and ensures people feel heard, safe, and empowered to participate.

- **Local Champions Network**

  Partner with community and faith leaders, who can host 'health huddles' and informal drop-in sessions, providing feedback loops that feed directly into service design.

- **Trust-Building Activities**

  Show real-life results and testimonials from community members who have benefitted from new services, emphasising credibility and positive outcomes.

- **Culturally Tailored Outreach**

  Offer educational materials in relevant languages and formats, clarifying health and research options.

RECOMMENDATION:

Work through existing community leaders and trusted intermediaries to reach underserved groups and tackle mistrust head-on.

Recommendation 3

Put patients at the heart of digital health data

While work on electronic health records and interoperability is already underway, the process must embed meaningful patient input. When patients help shape how data is stored, shared, and used, it creates trust, transparency, understanding and more relevant solutions that genuinely meet people’s needs.

- **Patient-Centred Governance**

  Establish or expand data governance boards or councils with strong patient representation, giving them real authority in shaping data policies and oversight.

- **Co-Design Data Features**

  Involve patients in prototyping portal interfaces, ensuring information is understandable, user-friendly, and sensitive to differing levels of digital literacy.

- **Shared Decision-Making on Standards**

  Grant patients a direct role in setting privacy, consent, and usage protocols so that technical and ethical considerations align with public values.

RECOMMENDATION:

Ensure patient voices are embedded in developing electronic health records and data-sharing protocols, with genuine and sustainable co-governance.

Recommendation 4

Prioritise value-based investment in innovation

Concentrating solely on immediate costs often leads to poorly adopted or unsustainable innovations. By evaluating products on factors like re-admission rates, quality of life and patient experience, we encourage more equitable, person-centred solutions that stand the test of time.

- **Value-Focused Procurement**

  Make criteria such as patient satisfaction, equity improvements, and digital accessibility a central consideration in procurement processes.

- **Public Outcome Reporting**

  Share transparent data on cost-effectiveness and real-world impact, promoting accountability and encouraging best practice.

- **Pilot-to-Scale Pathway**

  Conduct smaller trials that, if they show meaningful patient benefit, unlock further investment for wider adoption.

RECOMMENDATION:

Focus funding and procurement decisions on improved patient outcomes and long-term benefits, rather than short-term, lowest-cost solutions.

Recommendation 5

Put patients in power at every level

Existing patient liaison services often cater more to organisational needs than to patient priorities. Giving patients meaningful leadership ensures lived experience drives major decisions and keeps the focus on care rather than just systems or costs.

- **Senior Patient Roles**

  Appoint executive patient leadership positions across NHS England, NHS Trusts and Integrated Care Boards, with influence over budgets, service design, and strategic decisions.

- **Patient-Led Advisory Boards**

  Involve diverse, representative groups— particularly from underserved communities—in reviewing and approving innovations.

- **Co-Chair Governance**

  Embed patients as co-chairs alongside senior executives to shape agendas, milestones, and outcome measures on an equal footing.

RECOMMENDATION:

Formalise patient leadership roles to ensure shared decision-making and genuine accountability across the NHS.

Next Steps -
Getting patients excited about innovation

Why?

The recommendations in this report show how patient insights are crucial for developing sustainable and targeted healthcare innovation, but genuine enthusiasm at the grassroots level is crucial. Roundtable participants noted that many patients feel disconnected from the concept of “innovation,” viewing it as too technical or removed from their everyday lives.

What Drives This Need?

Contributors highlighted that many patients see new healthcare innovations as disconnected from their daily realities—particularly when a “medical model” mindset frames innovations as something done *to* patients rather than *with* them. Multiple attendees described instances where the focus seemed more on cost savings or staff efficiencies than genuine partnership, leaving patients feeling overlooked, “pushed around the system and ultimately out of the door.” This lack of open dialogue and personalised guidance compounds the issue, leaving individuals unsure how these advancements actually benefit them. Additional barriers—such as limited funding, complicated care pathways, and unclear outcomes—further reduce engagement and trust.

An equally pressing concern was the absence of an accessible, dialogue-based approach—what one contributor referred to as “talking therapy.” Too often, patients receive dense information or are pushed toward digital tools without opportunities for meaningful conversation or personalised guidance. As a result, they may struggle to navigate options, missing the context that could make them feel confident in adopting new services.

Participants noted that insufficient funding, confusing pathways, and a lack of clear, relatable outcomes further discourage patients from embracing innovation. Several contributors underscored the importance of working with grassroots champions and local communities to overcome mistrust, clarify benefits, and highlight the potential for genuine co-creation. PPIE in innovation must deliver a tangible way to spark curiosity, bridge communication gaps, and illustrate how healthcare innovations can actively support and empower individuals, rather than remain an abstract or top-down process.

Where We Go From Here

Looking ahead, the key priority is making innovation relevant and accessible to patients, showing how it can fit naturally into daily life, boost confidence, and empower individuals to play an active role in shaping new ideas. By focusing on clear communication and meaningful examples of how healthcare improvements directly address patient needs, we can foster a sense of collective ownership.

This groundwork paves the way for deeper collaboration in future initiatives, ensuring that patients feel excited about, rather than removed from, emerging healthcare innovation.

Reflections from a contributor:

"PPIE in innovation must deliver a tangible way to spark curiosity, bridge communication gaps, and illustrate how healthcare innovations can actively support and empower individuals, rather than remain an abstract or top-down process."

| Additional Resources

Below we have gathered a list of useful resources for anyone interested in learning more about Patient and Public Involvement and Engagement.

Health Innovation Yorkshire and Humber | ***A Framework for Driving Innovation Adoption Through Patient Insight*** (link)

The Patients Association | ***Improving health equity for patients living with cancer and/or blood disorders*** (link)

NHS Confederation | ***Developing a patient-focused discourse around hospital flow*** (link)

If you would like to learn more about how we incorporate Patient and Public Involvement Engagement across our work, get in touch with us at info@thehealthinnovationnetwork.co.uk