BRACE General Practice Quality Improvement Evaluation

Roundtable: Strengthening Patient Involvement in Quality Improvement Programmes

Summary Report

December 2025

Purpose

This roundtable formed part of the ongoing evaluation of general practice improvement programmes conducted by the Birmingham, RAND and Cambridge Evaluation (BRACE) Centre and led by National Voices. Member charities of National Voices were invited to reflect on emerging findings and share their experience of improvement work in general practice and more widely across the health and social care system. The session aimed to understand how effective change happens from the perspective of organisations that regularly engage in system-level work and represent underserved communities. It also sought recommendations to support more meaningful patient and Voluntary, Community, Social Enterprise (VCSE) sector involvement in the design and delivery of future Quality Improvement (QI) initiatives.

Overview

The session was chaired by Jacob Lant, Chief Executive of National Voices, and facilitated by Matt Heath (Policy and Communications Manager) with support from Catherine Emmanuele (Communications and Events Officer).

Dr Sophie Spitters, Research Fellow at the University of Birmingham's Health Services Management Centre (HSMC), presented BRACE's findings, with Dr Manbinder Sidhu, HSMC Associate Professor, observing.

In accordance with research ethics, the identities of participating member organisations have been anonymised in this report.

Participants received an information sheet and gave informed consent in advance. The discussion was recorded via Zoom.

This roundtable was split into two sections, however, there was often overlap in themes throughout. In the first section, participants were invited to reflect on BRACE's research findings about patient involvement in quality improvement programmes, particularly the gap between genuine co-design and feedback mechanisms (as summarised in the pre-meeting briefing note, see Appendix A). Participants shared concrete examples of how accessibility needs are frequently overlooked, how Patient Participation Groups (PPGs) lack true representation (e.g., partially sighted people not being represented within a patient reference group resulting in inaccessible tools at the GP), and how improvements are designed without meaningful consultation with diverse underserved communities, such as people who belong to minority groups that are not recognised in outcome measurements.

The second section explored recommendations for strengthening partnerships between system actors, namely primary care networks and Integrated Care Boards

(ICBs), and VCSE organisations. Participants emphasised the need for proactive engagement, addressing data gaps, ensuring adequate payment and capacity support, and building trust through community connections rather than transactional relationships. A recurring theme was the tension between meeting national targets, such as PPG engagement requirements, and the time-intensive work of building authentic community relationships.

Throughout the discussion, participants highlighted systemic barriers including the complexity of navigating health system structures (from local service provision to ICB levels), the exclusion of key groups (carers, LGBTIQ+ communities, disabled people) from improvement initiatives, and the challenge of scaling local successes and achieving systemic change. There was strong consensus that meaningful involvement requires early engagement, proper resource allocation, and recognition that frontline administrative staff play a crucial role in implementing reasonable adjustments.

Key findings

1. Feedback versus co-design

The BRACE evaluation found that patient involvement is frequently limited to feedback and consultation mechanisms. Participants strongly agreed. They shared a range of examples illustrating the limitations of current practice, while also sharing positive experiences of more meaningful involvement.

One participant shared an example of "digital pods" (self-service health check kiosks) introduced at a GP practice without consultation with blind and partially sighted people. When they raised the potential accessibility problems, the response was that the practice's PPG had approved it – potentially highlighting both inadequate representation in PPGs and the "tick box" nature of engagement.

Another participant described being asked to review a health service's website just two weeks before launch, exemplifying the pattern of seeking sign-off rather than genuine co-production. The consensus was that true co-design must actively invite and support contributions, creating a culture of trust rather than relying on performative consultation.

By contrast, Cancer Alliances were highlighted as an example of meaningful co-design. One participant described an Alliance providing both funding and in-kind support (e.g., desk research, direct routes to care providers) that built staff expertise rather than relying on "parachuting in" patients or organisations for one-off projects.

Participants felt that successful system partnership models require explicit recognition of both the value and limited capacity of VCSE organisations. They stressed that expecting people to contribute "out of the goodness of their hearts" isn't sustainable, particularly for smaller organisations. One speaker noted that while voluntary sector organisations "do have the links with the community and the trust," they "also need to be more supported in order to do this from a public health approach" because "many of these organisations are very small and stretched in capacity."

National organisations were also seen as playing a valuable role in coordinating and spreading good practice across regions. One example shared was of a visual impairment engagement team supporting GP practices nationwide to adopt more inclusive approaches.

2. Measurement drives (in)equity

BRACE's research found that national targets are often prioritised over sustained engagement with communities or addressing lived experience. Participants strongly supported this finding, warning that rigid metrics can mask exclusion and reinforce inequality.

One participant explained that "because of the way that targets have been designed, in terms of the metrics … you do see that that results in a deprioritisation of certain underserved communities." Another noted that LGBTIQ+ people face systemic exclusion because "there's no systemic way of asking or recording [patients' sexuality and/or gender] in most records," making them invisible in access metrics. Where complex experiences can't be captured in "a nice shiny figure," these communities risk being sidelined.

Others highlighted how disabled people and carers are similarly made invisible when their needs go unrecorded. In the case of carers, participants noted that a lack of systematic data collection makes it harder to plan services around their specific needs. For disabled people, some conditions - such as energy-limiting illnesses without formal Chronic Fatigue Syndrome diagnosis - may not be accurately captured.

Several attendees noted that GP practices may understandably focus on national or income-linked targets due to capacity pressures, often at the expense of patient experience. However, tools like the GP Patient Survey (GPPS), which captures a range of diversity data, and Patient Reported Experience Measures (PREMs) were seen as helpful starting points for more inclusive measurement - especially when triangulated with VCSE insight and local knowledge.

Participants emphasised the need for staff to proactively ask about access needs and record them for future use; otherwise, patients may feel burdensome, unseen, and ultimately disengage from care. One participant described how their 89-year-old mother kept receiving text messages with web links, despite her sight loss and multiple requests for alternative communication. It not only made her feel excluded, but like "an inconvenience to the system." The example highlights the importance of QI processes that embed, and act on, accessibility data.

3. Representation and voice

Participants raised concerns about whose voices are included in patient involvement structures, and how to move beyond tokenistic engagement towards more meaningful representation.

Several participants noted the importance of reaching out to diverse patient and community groups, rather than relying solely on a small number of individual patient perspectives. One attendee emphasised this requires a thoughtful approach, pointing out that unpaid carers are rarely recognised as a distinct patient group with unique needs, instead being "lumped in with everybody else." They argued that "carers are only going to be meaningfully involved when they are considered as their own kind of individual group with their own needs."

Another participant noted that patients and community members involved in QI need capacity and frameworks to "exchange with this system on what improvements need to take place." Enabling them to contribute meaningfully at a strategic level requires sustained capacity-building support, to move beyond personal anecdotes and ensure equitable influence in decision-making.

There was discussion about how to access meaningful involvement, with suggestions including linking with local, regional, or national VCSE umbrella bodies to ensure comprehensive rather than piecemeal engagement. These umbrella organisations were seen as valuable in convening a wide range of voices and avoiding situations where only "the loudest voice and those with the most resources" get their agenda prioritised. National Voices was cited as one such example.

4. Accessibility implementation and the role of frontline staff

Participants highlighted that frontline staff – particularly reception and administrative teams – are central to patients' day-to-day experience of general practice and play a critical role in delivering reasonable adjustments and creating inclusive environments. However, participants felt that these staff members are often overlooked in training and improvement work, despite being "the ones that actually make most of these adjustments in practice, beyond more technical stuff related to actually delivering the hands-on care".

Patient-facing staff were seen as having the potential to serve either as "blockers" or as "allies" in embedding accessibility as part of business-as-usual. The lack of consistency in training and support for administrative staff was seen as a key barrier, with adjustments often being improvised on the spot but not recorded or escalated. This meant adjustments often did not become routine practice and wider system issues remained unaddressed.

In terms of how VCSE organisations support accessibility implementation, participants found that centring the lived experiences of patients can be more effective than simply providing written guidance. One attendee described how people with lived experience delivering training sessions at GP practices – sharing the emotional impact of unmet needs – created lasting change: "when you do engage on that emotional level with people … they're more likely to advocate [for change] within their system as well."

Multiple attendees highlighted the lack of inclusive systems to date, including poor implementation of existing guidance, such as the Accessible Information Standard and the Equality Act 2010. Examples included the unavailability of hoists to support physical examinations in people with mobility needs, and GP practices not routinely capturing communication needs (e.g. language or format). Several participants argued that ICBs could play a key role in driving systemic change by setting expectations and monitoring performance against these standards, rather than relying solely on individual goodwill. The consensus was that systematic implementation would improve patient experience and reduce inefficiencies.

5. System complexity and navigation

Participants highlighted system complexity happening at two levels: the healthcare system that patients and carers must navigate to access care, and the organisational system that VCSE organisations must navigate to contribute to quality improvement.

In regard to accessing care, fragmentation of care pathways emerged as a significant barrier, particularly for people with intersecting needs. One participant described how sight loss and mental health represent "discrete" care pathways with "no sort of crossover between the various points where there could be," despite mental health being a "huge problem" for people losing their sight. This structural separation fails to reflect the reality that "people have more than one issue that they're dealing with," requiring them or their carers to coordinate between services that operate in isolation.

VCSE organisations face parallel challenges when attempting to engage with improvement initiatives. One participant described "struggling to understand the health system and where to tackle, like, where would be the best entry point" to amplify community voices, noting they "keep coming across boards and networks, and platforms" that "sometimes are speaking about the same thing, but they're not coordinating with each other." The suggestion was made for system mapping to help organisations target their efforts effectively rather than "duplicating stuff or starting again each time."

These parallel experiences of fragmentation suggest that improving quality and access requires addressing system complexity at both levels simultaneously.

Recommendations

These recommendations were co-developed during the roundtable discussion, drawing on BRACE's research findings and participants' lived experience. They are primarily aimed at commissioners, general practices, ICBs, and improvement leads seeking to embed inclusive, patient-centred approaches to QI.

1. Engage meaningfully.

Not all projects require co-design – but all involvement should follow good practice. Even feedback can be meaningful when designed effectively. Avoid tokenistic co-design and don't use limited engagement as a justification to shut-down further learning and development.

2. Ensure genuine representation.

Actively seek out and specifically include marginalised groups, including unpaid carers, LGBTIQ+ communities, disabled people, and people from minoritised communities, rather than assuming existing patient reference groups are representative.

3. Prioritise accessibility and reasonable adjustments systemically.

Ensure reasonable adjustments are embedded throughout both service delivery and quality improvement processes, with proper recording and flagging systems so patients don't have to repeatedly explain their needs (as required by the Accessible Information Standard).

4. Engage and train frontline staff.

Include reception and administrative staff in training, engagement, and improvement initiatives, recognising their crucial role in implementing adjustments and shaping patient experience.

5. Support VCSE capacity.

Provide adequate payment for VCSE organisations and individuals contributing to quality improvement work, recognising this as skilled work requiring proper resourcing. Consider in-kind support (staff time for research, direct access to care providers) to build organisational expertise.

6. Prioritise what matters to patients.

Expand success metrics beyond access data (e.g. number of appointments) to include lived experience outcomes, equity of access for different groups, and whether reasonable adjustments are consistently provided.

7. Build relationships.

Commissioners and policymakers should allocate time and resources to build relationships and trust with communities, recognising this as valuable work.

8. Connect with VCSE infrastructure.

Require sustained engagement with local, regional, or national VCSE umbrella organisations to ensure comprehensive rather than piecemeal involvement.

Appendix A: Attendee briefing

Overview

This roundtable supports the ongoing evaluation of quality improvement (QI) programmes in general practice being conducted by the Birmingham, RAND and Cambridge Evaluation Centre (BRACE).

BRACE's research examines how system-level QI initiatives are organised, commissioned and delivered to improve access to primary care, and how these programmes involve general practices, partners, and communities.

Integrated Care Boards (ICBs), established in 2022, were designed to bring NHS organisations, local authorities and community partners together to improve population health and reduce inequalities. They are expected to enhance access and quality across local systems, but how they do this in practice is not yet well understood. This research therefore examined how different ICBs perform this 'bridging' role between national policy and general practice.

Across three ICB sites of different sizes, researchers conducted 32 semi-structured interviews with ICB staff, commissioners, and primary care stakeholders, and hosted two focus groups with patient representative groups.

The study identified a range of QI initiatives, including implementation of the modern general practice access model, participation in the general practice improvement programme (GPIP), peer learning networks, and targeted work for underserved groups.

BRACE's findings suggest that ICBs tend to play three overlapping roles.

- Transactional: translating national policy and funding into local delivery and coordination
- Relational: building trust, partnerships and shared priorities across practices and communities
- Developmental: supporting learning, data capability, and innovation spread

While BRACE's findings suggest that ICBs can and do act as critical connectors and enablers of system-wide improvement, many are still developing trusting relationships with GPs, and struggling to meaningfully involve patients and organisations in QI design.

This roundtable will reflect on these findings and explore how QI initiatives can develop a clearer focus on patient outcomes as a quality measure and develop recommendations on how commissioners and GPs can more appropriately involve patients and communities.

Discussion Part One

The first part of the discussion will review evidence from the BRACE project to understand how the findings reflect your own understanding of the needs of patients in general practice and where further research might be needed.

Key questions include:

- From your organisation's perspective, does BRACE's finding that patient involvement in improvement is often limited to feedback rather than co-design reflect what you see in the communities you work with?
- BRACE found that ICBs often prioritise national targets over building ongoing relationships with patients and communities. Does this reflect your local experience, and what helps or hinders ICBs to connect effectively with your organisation or the people you represent?
- BRACE's research suggests that most improvement programmes measure success through access data rather than lived experience. How well do the measures you see in use reflect the realities your communities face when seeking primary care?

Discussion Part Two

The second part of the discussion will focus on how QI initiatives can strengthen their focus on patient outcomes and provide recommendations on how commissioners and GPs can more effectively involve patients and VCSE organisations in designing and evaluating improvement work. We are particularly interested in any relevant examples of good practice from your own work.

Key questions include:

- From your organisation's perspective, which outcomes should general practice improvement programmes prioritise? How can these better reflect the needs of people who are least likely to access or benefit from primary care?
- What makes patient and community involvement in improving access to general practice genuinely meaningful? What would need to change for this to become the standard, not the exception?
- How can VCSE organisations work with ICBs and general practices to build trusted improvement partnerships? What kinds of support would make this collaboration effective and sustainable?