Building meaningful patient and donor engagement across NHS Blood and Transplant

Patient and Donor Engagement Policy Working Group

Co-Chairs: Professor John Forsythe and Jessica Jones

Acknowledgements

This work has depended on the remarkable generosity, candour and commitment of patients, donors, donor family members and others who have shared their experiences. Some contributed while living with illness, bereavement, work and caring responsibilities. Their willingness to help NHSBT get this right should never be taken for granted. It deserves to be repaid through action, transparency and lasting improvement.

We offer particular thanks to members of the Lived Experience Advisory Panel (LEAP), who contributed insight and constructive challenge throughout, and to the Patient and Donor Engagement Policy Working Group, whose members brought together lived experience and organisational expertise.

We also acknowledge staff across NHSBT who gave time and thought to this work, alongside the colleagues already building excellent relationships with patients, donors and families. This report is intended to strengthen and spread their good practice, not overlook it. We thank the external organisations and partners who shared learning, and NHSBT leadership for commissioning a review willing to consider where the organisation can do better.

Foreword | Frances O'Callaghan, Chief Executive

Introduction from the Co-Chairs

NHS Blood and Transplant touches lives at moments of extraordinary generosity, vulnerability and hope. Every donation, treatment and decision involves people whose experiences deserve to shape the services that affect them.

Our review has made us optimistic about what NHSBT could achieve, but not complacent about the work required. We met staff who demonstrate compassion and judgement far beyond formal

expectations, and contributors who described constructive relationships that have made a real difference. We also heard from people who could not find a route to contribute, were approached once policy decisions were already largely made, or who shared insight or experiences but never discovered what happened as a result.

We acknowledge both realities. NHSBT has not always got engagement right. Recognising this does not diminish the good work already being done, or the people doing it. It is the necessary starting point for making those strengths consistent across the organisation.

We believe that NHSBT has the opportunity to become an exemplar across the NHS, not through engagement for its own sake, but by making the expertise of patients, donors and families a natural part of service improvement and decision-making. That ambition can only be realised in partnership with people with lived experience and the committed staff who serve them.

We thank NHSBT's leadership for commissioning this work and for being willing to hear constructive criticism. Above all, we thank the patients, donors, families and staff who have made the evidence impossible to ignore. It is their contribution that must now be carried into action.

Thanks also go to Sophie Seymour, Naomi Jones and Rachel Worgan for their help in getting to this stage.

[SIGNATURE PLACEHOLDER: Professor John Forsythe, Independent Co-Chair]

[SIGNATURE PLACEHOLDER: Jessica Jones, Independent Co-Chair]

Executive summary

This report proposes an organisation-wide framework for meaningful patient and donor engagement, building on good existing practice while addressing inconsistency, inadequate feedback and insufficient organisational accountability. The key test is whether lived experience genuinely influences NHSBT's decisions, policies and services.

The central finding of this review is not that NHSBT fails to listen. It is that attentive, respectful encounters are not consistently linked to involvement at the right time, reliable follow-through or demonstrable organisational change. Strong individual relationships and weak organisational processes can coexist.

The evidence includes 1,104 self-selected survey responses: 173 from patients and families, 554 from donors and donor families and 377 from staff, alongside 27 discovery meetings with people from a wide range of interests and with expertise in this subject. The findings were considered through LEAP and Working Group discussions and at the collaborative event on 30 September

2026. These are substantial sources for understanding recurrent experiences, though the survey samples cannot be taken as estimates of the views of everyone NHSBT serves.

Among donor and donor-family survey respondents who had given feedback, 85.3% rated respectful treatment highly (8–10 out of 10). Yet only 25.6% said they were told what happened afterwards. The corresponding proportion among patient and family feedback-givers was 18.8%. The consequence is significant: contributors may feel respected in the moment while being left uncertain whether their contribution mattered. This erodes trust and means NHSBT cannot reliably demonstrate the value of engagement.

We therefore recommend clear senior scrutiny and accountability; practical support for staff seeking to undertake effective engagement, alongside recognition of those already doing this to a high standard; earlier and more accessible opportunities for involvement; preparation, advice and guidance for patients, donors and donor family members taking on representative roles, including how to manage confidential information and the responsibilities of such roles; a standing lived experience structure linked to a wider contributor network; and a tracked requirement to acknowledge, consider and explain the outcome of contributions. The policy must establish these as core organisational expectations, with flexible methods for different services and groups.

The collaborative event held on 30 September 2026 brought together patients, donors, donor families and NHSBT staff to explore how meaningful engagement could be strengthened across the organisation. Feedback was overwhelmingly positive, with participants particularly valuing the opportunity for open discussion, the willingness of senior leaders to listen, and the sense that their experiences and perspectives were being taken seriously. For many, the day demonstrated what genuine partnership could look like.

However, participants were equally clear that the success of the event would not be determined by the discussions themselves, but by what happened afterwards. The positive feedback should be welcomed but must not be mistaken for evidence that lasting organisational change has taken place. The real measures of success will be whether people see tangible improvements in practice, whether staff are supported and empowered to deliver them, and whether NHSBT can demonstrate to its Board, patients, donors and families how lived experience has influenced decisions and brought about meaningful change.

1. Purpose, evidence and limitations

The review examines how patients, donors and families influence NHSBT’s work across blood, blood products, organ and tissue donation and transplantation, and stem cell services. It is about the role of lived experience in policy, service design, governance and improvement. It is not

intended to duplicate routine service communication, clinical decision-making or complaints processes.

Three surveys were considered alongside internal and external discovery discussions, the contributions of LEAP and the Working Group, and a collaborative event that brought staff and people with lived experience together. These approaches were deliberately complementary: surveys identified patterns; discussions with patients, donors, donor families, NHS bodies and international comparator organisations provided context; and the event allowed participants to test the direction of the proposed policy.

The samples quoted are self-selected and experiences differ within the broad respondent categories. Percentages refer to the relevant question respondents, and some findings concern only those who had previously given feedback. Comparisons are descriptive, not proof of causation or of population-wide differences. Quotations illustrate individual experiences, rather than the frequency with which a view was expressed.

2. The issue is not a lack of goodwill: it is the distance between contact and influence

An honest assessment must begin with what NHSBT already does well. People described kindness, compassionate treatment and staff who took additional trouble, over and above their stated role, to respond to their circumstances. Among donor and donor-family respondents who had provided feedback, 85.3% rated respectful treatment 8–10 out of 10, and 75.0% rated feeling listened to in that range. These findings are not incidental good news. They show that the people of the organisation possess the human skills and experience needed to build an exemplary approach. This deserves celebration.

“They are sensitive to bereaved families and show compassion and respect to donor families”

Donor and donor-family survey, anonymised free-text response

Such relationships can create trust that takes years to establish and moments to lose. The danger in designing an organisation-wide approach would be to discount what these colleagues have already achieved or replace responsive local relationships with a distant central process. NHSBT should instead identify, support, recognise and share that expertise across roles and grades.

The weaknesses sit alongside these strengths. Less than half of respondents in either lived experience survey reported knowing that NHSBT seeks their views (42.4% among patients and families, 40.0% among donors and donor families). This suggests opportunities are insufficiently

visible, particularly to people without an established connection or an individual willing to invite them.

Even where someone can take part, the invitation may come too late. Engagement that asks people to comment on decisions already effectively settled risks becoming a sham consultation without giving people meaningful influence. This is not simply a problem of perception: it can deprive NHSBT of insights that would have changed its plans and delivered services closer to the needs of the populations it serves. In the staff survey, only 34.4% agreed that people were involved early enough to influence decisions.

The practical implication is that NHSBT must make early consideration of lived experience a normal part of relevant planning and decision-making. The central expectation should be consistent across the organisation, but the method must remain proportionate and suited to the people and service involved.

3. NHSBT must close the gap between listening and doing

The sharpest shared finding concerns what happens after somebody contributes. Of respondents who said they had given feedback, 13 of 69 patient and family respondents (18.8%) and 56 of 219 donor and donor-family respondents (25.6%) said they had been told what happened. These figures have conditional denominators, but the pattern is striking: NHSBT is frequently unable to demonstrate to the person involved that their time and insight led to consideration, action or an explanation of a different path.

Not every suggestion can or should result in change. Decisions must reflect evidence, safety, resources and competing responsibilities. But a reasoned response is different from silence. If a person is invited to share a painful experience and then hears nothing, the organisation may unintentionally reinforce the view that engagement is primarily a request for personal testimony rather than a partnership in improvement.

“People feel taken for granted. Feedback is powerful. Tell us how you are using it.”

Mentimeter response, 30 September 2026 event

This is more than a communications problem. It is an accountability problem. A person needs to know who has received their contribution, whether it has been considered, what decision followed, and why. Staff need a manageable means to record, direct and close that loop. Senior leaders need to know where feedback repeatedly identifies issues and whether those issues are being resolved.

We therefore propose an organisation-wide response and tracking mechanism, supported by clear ownership and reporting requirements. Its purpose must not be the creation of another bureaucratic system. It is to make something fundamental reliable: when NHSBT asks people to contribute, it takes responsibility for telling them what happened.

4. Meaningful involvement must reflect different lives and different relationships with NHSBT

A uniform policy should not mean a uniform form of engagement. Patients and families most often prioritised influencing improvements to services (80.9% placed this among their top three areas for involvement), whereas donor and donor-family respondents frequently identified public awareness campaigns (60.6%) and improving the donor experience (59.1%). These are differences of focus, not differences in the importance of either perspective.

Awareness also varies. Among patient and family respondents, 36.5% of solid organ transplantation respondents knew NHSBT sought their views, compared with 52.6% of blood-related respondents. The implication is that NHSBT cannot rely on one generic invitation or assume that people who care about its work know how to take part.

In the donor and donor-family survey, 51.2% selected the possibility of involvement feeling difficult, too personal or upsetting. For people living with illness or grief, access is as much about choosing the right moment and offering genuine control as it is about remote meetings, travel and expenses. This will of course be very individual, and the main requirement of staff is humanity.

“Don’t try to engage with people when they are at an acute stage of illness or grief. Timing is everything”

Mentimeter response, 30 September 2026

NHSBT should create a standing advisory body with transparent appointments and regular renewal of membership to balance accumulated experience with fresh perspectives. There should also be a network of people able to contribute occasionally. That combination allows sustained scrutiny without reducing involvement to a small circle of established voices. For the standing group, it must also be accompanied by appropriate remuneration, flexible routes to participation and sensitivity to individual circumstances.

The existing research-focused involvement arrangements have widened beyond research topics in response to need and developed valuable expertise. This should not be displaced casually. Whether an organisation-wide structure grows from them or operates alongside them requires a

deliberate decision with current contributors and affected teams. The essential test is access, influence and accountability, rather than the name of the group.

Meaningful participation also requires preparation. People asked to join advisory groups or act as representatives may be new to NHSBT governance, unfamiliar with organisational language or uncertain about what they can legitimately share. NHSBT should offer a clear induction, accessible information about the role and decisions they may influence, and practical guidance on confidentiality, information handling and speaking from lived experience without being expected to represent every patient or donor. Such support should equip contributors to challenge constructively without making professional expertise a prerequisite for being heard.

5. Staff commitment must be matched by organisational permission and support

The staff evidence challenges a simplistic explanation that colleagues do not understand or value engagement. In the survey, 93.9% understood its benefit and 84.0% supported a more consistent organisational approach. Many already invest considerable energy in involving people. What is less consistent is their ability to make that ambition work amid competing demands.

Time or capacity was the most frequently selected barrier (45.7%). Staff also described the need for clearer expectations, resources and confidence in sensitive conversations. Asking everyone to engage more without addressing these barriers risks adding another expectation to already stretched teams and producing formulaic activity rather than thoughtful involvement.

The response should be supportive and practical: accessible guidance, experienced advice, case studies, coaching where helpful, and tailored support for teams beginning significant work. Engagement should be integrated into project planning and routine responsibilities, rather than confined to mandatory online training. Managers must make space for it.

Existing excellence should be recognised in tangible ways. Expertise to help those staff who feel under-confident already exists in the organisation but is not used to best effect. A network of champions across directorates, disciplines and grades would allow colleagues to learn from those who have already demonstrated good practice. People working directly with patients, donors and families may be particularly valuable sources of experience. Recognising them also sends a necessary message: partnership is skilled work, not an optional extra.

6. The September event showed what is possible, not what has yet been delivered

The collaborative event on 30 September brought patients, donors, donor families, staff and partners into a shared discussion about how NHSBT could involve people more meaningfully. Feedback collated afterwards was strongly positive about the atmosphere, honesty and willingness of senior leaders to listen. Contributors referred to the “opportunity to speak openly and honestly”, a “welcoming, inclusive event”, and “creating a safe enough place for so many real feelings and perspectives to be shared”. These comments are evidence of an encouraging experience on the day.

“I have felt really listened to as a donor family. I’m so impressed that this is authentically shown from the very top. It isn’t tokenism.”

Mentimeter response, 30 September 2026; respondent self-identified as donor family

The important qualification in the post-event feedback was equally clear. People were glad to have been invited, but they were not offering an unconditional endorsement of NHSBT’s future approach. As one participant put it, “the real measure of success will be how the feedback is used and translated into meaningful action”. Another observed that “acting now, and visibly, is clearly key”. A further contributor wrote: “I look forward to reading the event report and seeing how the discussions from the day help shape the next stage of this work.”

These are not criticisms of the event. They are a clear statement of its purpose. An event can be moving, inclusive and well run without changing a single decision. NHSBT therefore needs to resist the temptation to regard the day as the successful completion of engagement. The test will be whether the discussions that led to the recommendations in this report are acted upon across directorates and whether participants and the wider community can see the results.

This requires an explicit account to everyone who contributed: what NHSBT heard; which recommendations and policy commitments followed; which issues require further work; and what will be reported back, by whom and when. Where action is not possible, the explanation matters. It should be straightforward enough for participants to recognise their contribution and honest enough to acknowledge where their requests have not been adopted.

It also requires leadership beyond the project team. The event benefited from visible support from the top of NHSBT. Its credibility will rest on that support being translated into expectations and resources across the organisation, including areas not present or prominent in the room.

A related concern, raised by LEAP members and staff alike, is that this report and the review it represents could become a “one hit wonder”, without a permanent change in how NHSBT undertakes engagement. We acknowledge the senior executive commitment to prevent that outcome, but a systematic approach, continuing monitoring and clear oversight are needed to withstand staff turnover and changes in organisational priorities.

7. Our ambition and the change in approach it requires

We propose that NHSBT aims to become an exemplar across the NHS in how lived experience shapes decisions, services and priorities. This is ambitious but grounded in the expertise already present among its staff and communities. It should not be achieved through more engagement as an end, but through clearer influence, more equitable access and demonstrable follow-through.

The organisational acknowledgement required is threefold. First, what NHSBT does well is real and worth protecting. Second, excellent individual relationships have too often existed without reliable organisation-wide routes to influence and feedback. Third, a policy will not solve this on its own: culture, leadership, resource and practical arrangements must reinforce one another.

One of our key fears is that the policy and actions arising from this report could become another bureaucratic or “tick-box” exercise, adding vacuous work to already stretched staff. The recommendations below therefore seek to give the principles a practical form, with a clear focus on influence and accountability rather than activity for its own sake. They are proposed directions for decision, not claims that implementation arrangements have already been agreed.

8. Recommendations

Recommendation 1. Establish clear leadership, responsibility and accountability at every level of NHSBT

Why this follows from the evidence: *Meaningful patient and donor engagement cannot depend on the commitment of individual staff members or teams. It must be embedded within NHSBT’s organisational structures, with clear responsibility for delivery, executive leadership and Board oversight. Without these arrangements, the remaining recommendations risk becoming isolated initiatives rather than delivering sustained organisational change.*

We recommend that NHSBT establishes a clear and enduring framework of accountability, with three connected elements:

Leadership and organisational delivery, reporting to executive level.

An organisation-wide patient and donor engagement lead should be appointed, with a clear reporting route to a designated executive sponsor. The lead should provide strategic coordination, expertise and support, while each directorate retains responsibility for embedding meaningful engagement in its own work, decisions and services.

Board oversight. A Board Non-Executive Director to be nominated to champion patient and donor engagement, providing scrutiny and challenge, and ensuring that progress remains a sustained organisational priority.

Transparent reporting and demonstrable impact. NHSBT should publish an annual account of patient and donor engagement, demonstrating how lived experience has influenced decisions, shaped services and delivered improvements, rather than simply reporting activities undertaken. This should support regular Board scrutiny of progress and areas requiring further action.

These arrangements will underpin all the recommendations that follow. Responsibility for meaningful engagement must extend throughout NHSBT, supported by central expertise and reinforced through executive leadership and Board accountability. Success should be measured not by the structures established, but by whether meaningful partnership becomes a consistent and demonstrable part of how NHSBT operates.

Recommendation 2. Make early involvement a routine part of relevant planning

Why this follows from the evidence: Engagement that starts too late cannot genuinely shape the choice being made and can create an adversarial environment between staff and lived experience representatives.

NHSBT should require proportionate consideration of lived experience before relevant policies, service changes and programmes are settled, with practical support to identify participants and record how views informed decision points. Meaningful involvement is already an established expectation in many publicly funded research processes; equivalent discipline should inform relevant organisational decisions.

Recommendation 3. Give staff practical advice, capacity and confidence

Why this follows from the evidence: The strong motivation reported by staff needs organisational permission and means to be effective.

NHSBT should create a central support resource for individuals and teams, including accessible advice, examples, guidance and tailored support for sensitive situations; ensure managers account for time and capacity.

Recommendation 4. Give patients, donors and donor families practical advice, capacity and confidence

Why this follows from the evidence: *Opportunities to contribute cannot be genuinely equitable if people are expected to understand complex governance arrangements, confidentiality requirements or the responsibilities of representative roles without preparation or support. People with lived experience should be equipped with the knowledge, guidance and confidence to participate meaningfully, while retaining the independence and distinct perspectives that make their contributions valuable.*

NHSBT should provide accessible induction, clear role descriptions and ongoing guidance for patients, donors and donor families undertaking formal representative or advisory roles. This should include an understanding of relevant governance and decision-making processes, how their contributions can influence decisions, expectations around confidentiality and handling sensitive information, and access to a named contact for advice and support.

Particular attention should be given to involvement in policy development, where representatives may contribute to discussions involving sensitive information, emerging proposals and options that are still under consideration. People with lived experience should be supported to understand why it is important that the organisation can explore the full range of appropriate options openly and confidentially before decisions are reached, including options that may ultimately be discounted.

Previous experiences where expectations around scope, remit and confidentiality have not been clearly understood or jointly agreed have left some staff reluctant to involve people with lived experience. Clarity and mutual understanding from the outset are therefore important for both sides, enabling representatives to contribute confidently and independently while ensuring that sensitive discussions can take place openly and constructively.

Preparation and support should strengthen genuine partnership, not professionalise lived experience, restrict legitimate challenge or dilute the value of the perspectives people bring. The level of preparation *should be proportionate to the nature and responsibilities of the role*, with a lighter-touch, flexible approach to informal or occasional involvement. These arrangements are intended to enable participation, not introduce additional bureaucracy, unnecessary requirements or barriers to engagement. No one should be excluded from contributing simply because they have not undertaken formal induction or training where this is not necessary for the nature of their involvement.

Recommendation 5. Recognise and share existing excellence

Why this follows from the evidence: Improvement will be more credible and achievable if it builds on colleagues who already do this exceptionally well.

NHSBT should establish a supported network of engagement champions across different levels and functions; share positive examples and recognise skilled work with lived experience partners.

Recommendation 6. Establish sustained lived experience advice

Why this follows from the evidence: Continuity and constructive challenge need a recognised place in governance but should not undermine arrangements that already work.

NHSBT should create a transparent standing organisational advisory structure with a defined remit, recruitment, refresh and access to decision-makers. Determine with existing groups whether to extend research-centered structures or add a complementary body.

Recommendation 7. Widen the routes into participation

Why this follows from the evidence: NHSBT should not hear only from people who already know whom to contact.

NHSBT should develop an opt-in, securely managed wider network; offer occasional and sustained forms of involvement; advertise through varied organisations and communities; enable contributors to raise their own agenda items.

Recommendation 8. Remove practical and emotional barriers

Why this follows from the evidence: An opportunity to contribute is not genuinely accessible if people cannot reasonably or safely take it up. Barriers may be practical, financial or emotional, particularly for those living with serious illness, bereavement or other difficult circumstances.

The very nature of NHSBT's work means that the issues can be emotive, challenging, deeply personal and passionately felt. People often have an enormous personal investment in the

outcomes, and the stakes can be exceptionally high. Meaningful engagement must recognise this human reality, including the impact that difficult conversations can have on both contributors and staff. When people share deeply personal, sometimes painful experiences, that openness must be met with more than a sympathetic hearing. They need to know their courage and emotional investment have been worthwhile, and that their contributions can make a meaningful difference.

However uncomfortable some of what we hear may be, it is essential that patients, donors and families have the space to share their experiences openly and honestly. It is NHSBT's responsibility to listen, reflect and respond constructively, rather than allowing difficult conversations to become barriers to future involvement. Equally, staff should feel supported in navigating sensitive or challenging exchanges, recognising the humanity and legitimate pressures on all sides.

Creating an environment in which people feel able to speak openly, and staff feel equipped and supported to listen and respond, is fundamental to genuine partnership. This must become an ingrained part of NHSBT's culture and everyday practice, rather than depending on the confidence, resilience or commitment of individuals.

NHSBT should establish consistent recognition and expenses arrangements, using the National Institute for Health and Care Research (NIHR) payment guidance for public contributors as a recognised benchmark, reflecting the approach adopted across wider health and care organisations. This should include appropriate recognition of time, prompt reimbursement of expenses, flexible timings and formats, accessibility support and sensitive approaches to illness and bereavement. Staff must also have the time, confidence and support to make meaningful engagement a routine and achievable part of their work.

Recommendation 9. Create reliable feedback and transparent communication

Why this follows from the evidence: A respectful conversation without follow-through is an incomplete engagement process, while poor visibility of opportunities and outcomes prevents people from understanding or testing NHSBT's commitment between events.

NHSBT should record, acknowledge, direct and close significant contributions and suggestions, with named owners, proportionate response standards and explanations where changes are not made. It should also make opportunities easy to find, publish examples of what did and did not change, and offer two-way open discussions with leaders on questions substantially shaped by contributors.

Recommendation 10. Set a culture of partnership from the top

Why this follows from the evidence: Structures will not endure if constructive criticism is routinely met with defensiveness or treated as outside the business of NHSBT. Defensiveness among staff has caused distrust and, at times, alienation. We have had to work doubly hard to keep some patient and donor representatives on board, because of the attitudes they have encountered, which left them feeling their voices were not always wanted. It should be made clear that such an approach undermines the professionalism of the organisation and is not tolerated. This does not mean we don't recognise navigating engagement with a diverse group of people with vastly different lived experience can present real challenges and is not an easy task to undertake. It is vital patients, donors and families can give their unvarnished views.

NHSBT should require leaders and staff to demonstrate respect, a willingness to consider and discuss new ideas, an openness to challenge and a recognition of lived experience as expertise.

9. From report to demonstrable change

Board approval and publication are important milestones, but neither is evidence that NHSBT has become more responsive to lived experience. An implementation programme should identify an executive sponsor, accountable owner for each recommendation, resources, milestones, and a way for people with lived experience to test whether the changes are working. It must include directorate responsibility rather than leaving delivery to a small central engagement team.

The measures should answer practical questions: Were contributors involved before decisions were fixed? Were they given a meaningful response? Can NHSBT show where a decision or service changed because of their insight? Was that change sustained and visible beyond one programme? Are more people, including those previously absent, able to participate? Do staff feel better equipped to work with them?

The initial implementation plan should include a specific post-event account to participants, with a route for challenge if the account does not reflect what was said, and a later update on progress. An annual report should make the evidence of change accessible to the Board and the public.

10. Conclusion

NHSBT has been offered, and will continue to be offered, something of considerable value: time, candour and expertise from people with direct experience of its work, alongside the commitment of staff who want the organisation to succeed. The generosity of that offer is particularly striking when

it comes from people dealing with serious illness or bereavement. It creates a responsibility that extends beyond thanks.

This review must never be seen to portray NHSBT as an organisation without strong relationships or compassion. It contains many examples of both. It argues that those strengths need to be made reliable across the organisation, rather than unevenly dependent on particular people or programmes. It asks NHSBT to recognise that listening matters most when it informs decisions, is followed by action or a reasoned explanation, and is visible to the people who contributed.

The September event showed a real appetite to work together. Its contributors were encouraging and hopeful, but they were also clear about the terms on which that hope will be justified. The next test is not whether another event can be equally successful. It is whether patients, donors and families can see NHSBT working differently as a result. That is how trust will grow, and how NHSBT can begin to earn its ambition to become an exemplar across the NHS.

Appendix A. Members of LEAP and the Working Group

Lived Experience Advisory Panel (LEAP)

Andrew Foster

Amarachi Obi

Charlotte Vockins

Emma Armstrong

Hayley King

James Mackay

Jamie Reed

Judy Coutinho

Louise Prashad

Prafula Shah

Primrose Granville

Sonsare Zabadi

Stephanie George

Patient & Donor Engagement Policy Working Group

Andrew Broderick

Andrew Foster

Charlotte Vockins

Claire Claydon

Dapo Odumeru

Ella Poppit

Gerrard Hartland

Jag Sidhu

Johannes Muller

Katie Barrowclough

Keren Locke

Maxine Spivey

Olive McGowan

Prafula Shah

Primrose Granville

Stephanie George

Tiffany Jones

Torkwase Holmes

Appendix B. Comparative survey data used in the narrative

Patient and family survey: n=173. Donor and donor-family survey: n=554. Staff survey: n=377. Percentages are descriptive and draw on the August 2026 survey reference; denominators vary by question. The feedback-outcome questions apply only to respondents who said they had given feedback.

Measure	Patients/families	Donors/donor families
Awareness that NHSBT asks for views	42.4%	40.0%
Previously given feedback	40.1%	39.8%
Previously involved in improving services	35.3%	16.5%
Told what happened after feedback	18.8% (13/69)	25.6% (56/219)

Appendix C. Quotations and Event Report

Survey quotations are anonymised verbatim entries drawn from the final survey material. Mentimeter quotations are selected open responses from 30 September; individual roles are not

inferred unless explicitly given in the text. The short extracts of post-event feedback have been taken from written feedback from attendees.

Patient and Donor Engagement
Event Report

30 September 2026 | Draft for participant review

This report reflects what participants told us at the NHS Blood and Transplant (NHSBT) Patient and Donor Engagement event on 30 September 2026. It is deliberately a draft. We are returning it to the people who took part so that you can tell us where we have captured the discussion accurately, where we have missed something, and where anything needs to be corrected or added.

The aim is not simply to report an event. It is to make the process itself participatory: to check the account with those who contributed before the learning becomes part of the evidence used to shape recommendations for how NHSBT should involve patients, donors and families in the future.

Thank you

Thank you to everyone who gave their time, experience, challenge and ideas to the day. The discussion depended on people being willing to speak candidly, including about experiences that had not worked well, as well as sharing examples of what NHSBT already does well.

Particular thanks go to Sophie, Rachel and Naomi, whose work made the event possible, to Lisa for supporting the Mentimeter throughout the day, and to all of our speakers for helping to set the tone and frame the discussions. We also want to recognise the members of the Lived Experience Advisory Panel (LEAP) and the Patient and Donor Engagement Policy Working Group, whose time, insight and challenge have shaped this work throughout.

The day and its purpose

The event brought together people with lived experience and NHSBT staff to consider a central question: what would need to change for patient, donor and family insight to shape NHSBT's services, decisions and organisational work consistently and meaningfully? The day was designed around discussion rather than presentation, with participants working at mixed tables and contributing through facilitated conversation and Mentimeter in real time.

The discussion moved through three connected issues: what makes involvement feel worthwhile; when and how people should be involved; and what NHSBT needs to put in place so that good engagement is reliable across the organisation rather than dependent on individual teams or people.

The tone was constructive but demanding. Participants did not argue that NHSBT lacks committed people or examples of good practice. Several described positive personal contact with NHSBT and the passion of individual staff. The stronger challenge was that good experience is not yet consistent, joined up or sufficiently visible in organisational decision-making.

> *"My personal contacts with NHSBT are almost invariably good. The personal passion is clear. Find ways to utilise this better in the changes you make."*

Who contributed

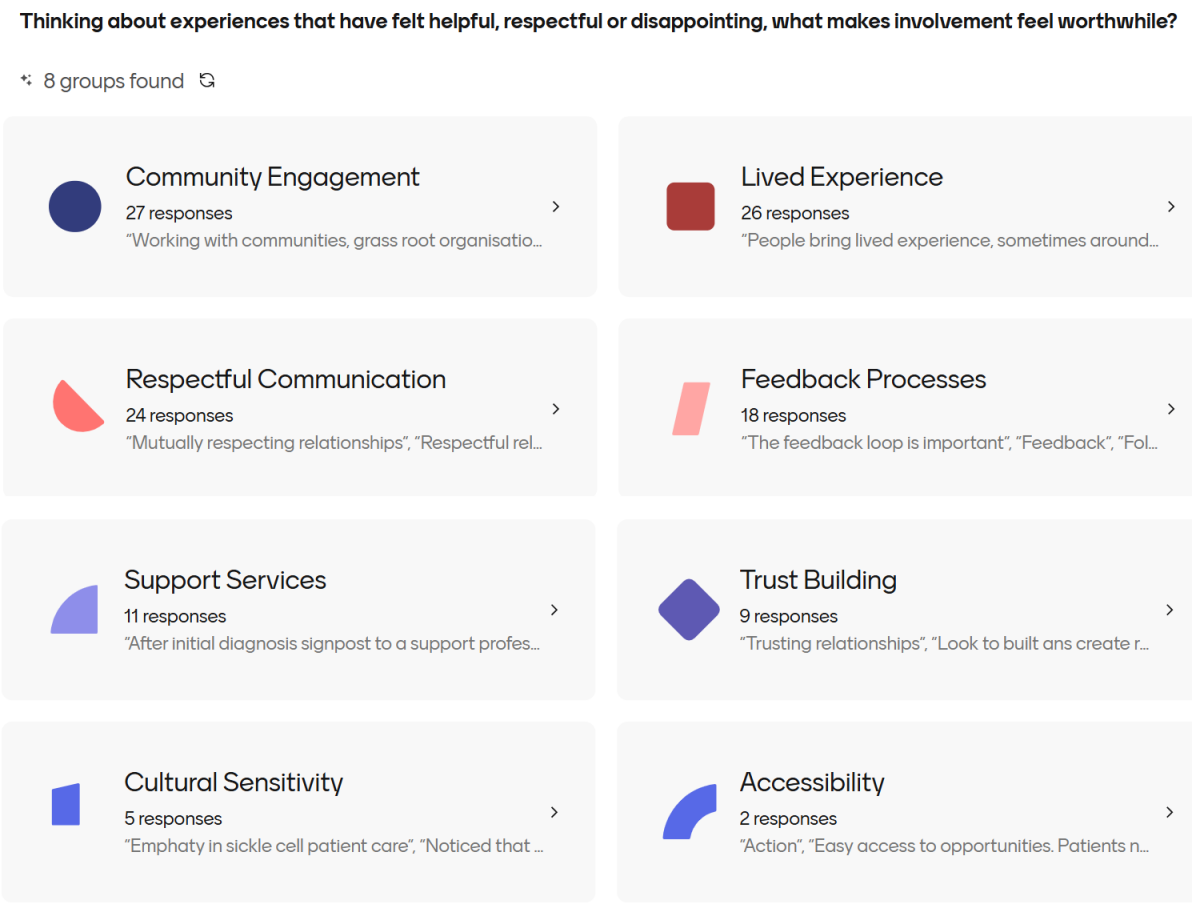
Mentimeter responses show participation across different parts of NHSBT's remit. Seventy-four people answered the question about the area of NHSBT with which they had engaged: 33 selected solid organ transplantation, 24 blood donation, 10 receiving blood or blood products (including plasma), 6 stem cell transplantation and 1 tissue transplantation. Seventy-seven people also marked where they had travelled from across the UK. Response numbers varied by question, with up to 86 people responding to individual questions.

These figures describe participation in the live Mentimeter questions rather than a complete demographic profile of everyone in the room. They should therefore be read as context, not as a claim that every NHSBT community was represented equally.

What we heard

1. Involvement is worthwhile when people can see that it mattered

Across the early discussion, participants repeatedly linked meaningful involvement with being listened to, respected and able to see what happened as a result. Giving people an opportunity to speak was not regarded as sufficient in itself. People wanted evidence that their contribution had entered the work, influenced a decision or prompted an action, with follow-up afterwards.



Selected Mentimeter illustration: grouped themes from the discussion about what makes involvement feel worthwhile.

> *"For me, involvement feels worthwhile when I can see that my contribution has been genuinely listened to and has influenced something, even if the outcome isn't exactly what I suggested."*
>
> *"People bring lived experience, sometimes around very personal and difficult issues, [and] need to feel that their experience is valued rather than being treated as just another piece of info."*

Trust, communication, authenticity, action, respect, community and co-collaboration were prominent in the word and short-phrase responses about meaningful involvement. The emphasis was relational as well as procedural: people wanted NHSBT to work with them, not simply collect information from them.



Selected Mentimeter illustration: words and short phrases participants associated with meaningful involvement.

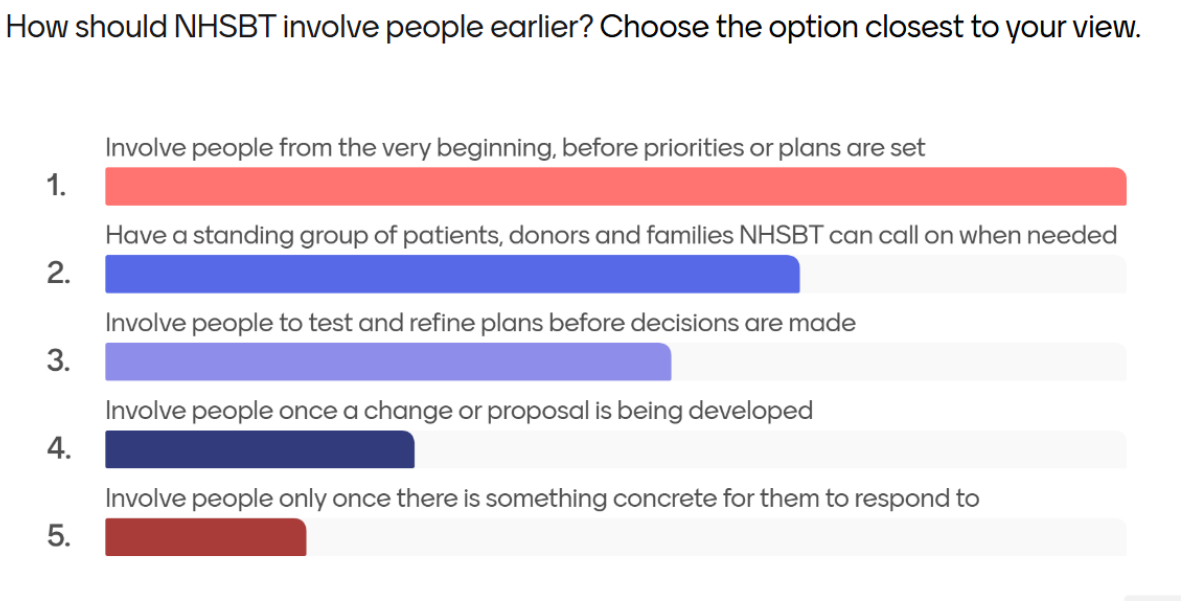
2. The clearest message was to involve people earlier

This was one of the strongest findings of the day. When 86 participants ranked five possible approaches, 60 placed “involve people from the very beginning, before priorities or plans are set” first. A standing group of patients, donors and families that NHSBT could call on was also strongly supported, particularly as a second-choice approach.

The discussion suggests these should not be treated as alternatives. Early involvement requires NHSBT to have relationships and routes already in place, rather than trying to find people only after a proposal has been developed. Participants described a need to involve lived experience before assumptions harden into plans, while still using people later to test, refine and challenge.

> *“Not be frightened of inviting feedback.”*
>
> *“Involve the people with lived experiences.”*
>
> *“Ensure that the information is succinct, clear and simple to understand by everyone including those from underserved communities.”*

There were some responses favouring involvement later in development, which is important not to erase. However, they were a clear minority in the ranking exercise: only 3 people ranked involvement once a proposal was being developed first, 5 ranked testing and refining plans before decisions first, and 1 ranked involvement only once there was something concrete to respond to first.



Selected Mentimeter illustration: views on when NHSBT should involve people in shaping work.

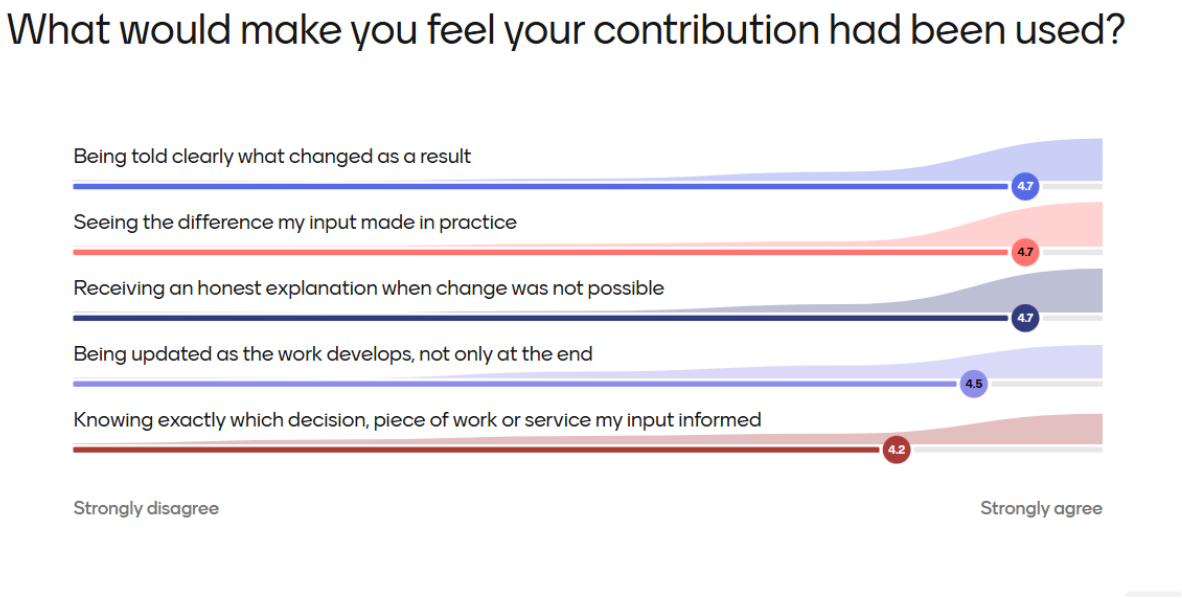
3. Close the loop, including when the answer is no

Participants were highly consistent about what NHSBT should do after people have given their time and insight: acknowledge it, thank people, explain what happened, demonstrate impact and keep people updated. “Close the loop” appeared repeatedly in the free-text responses.

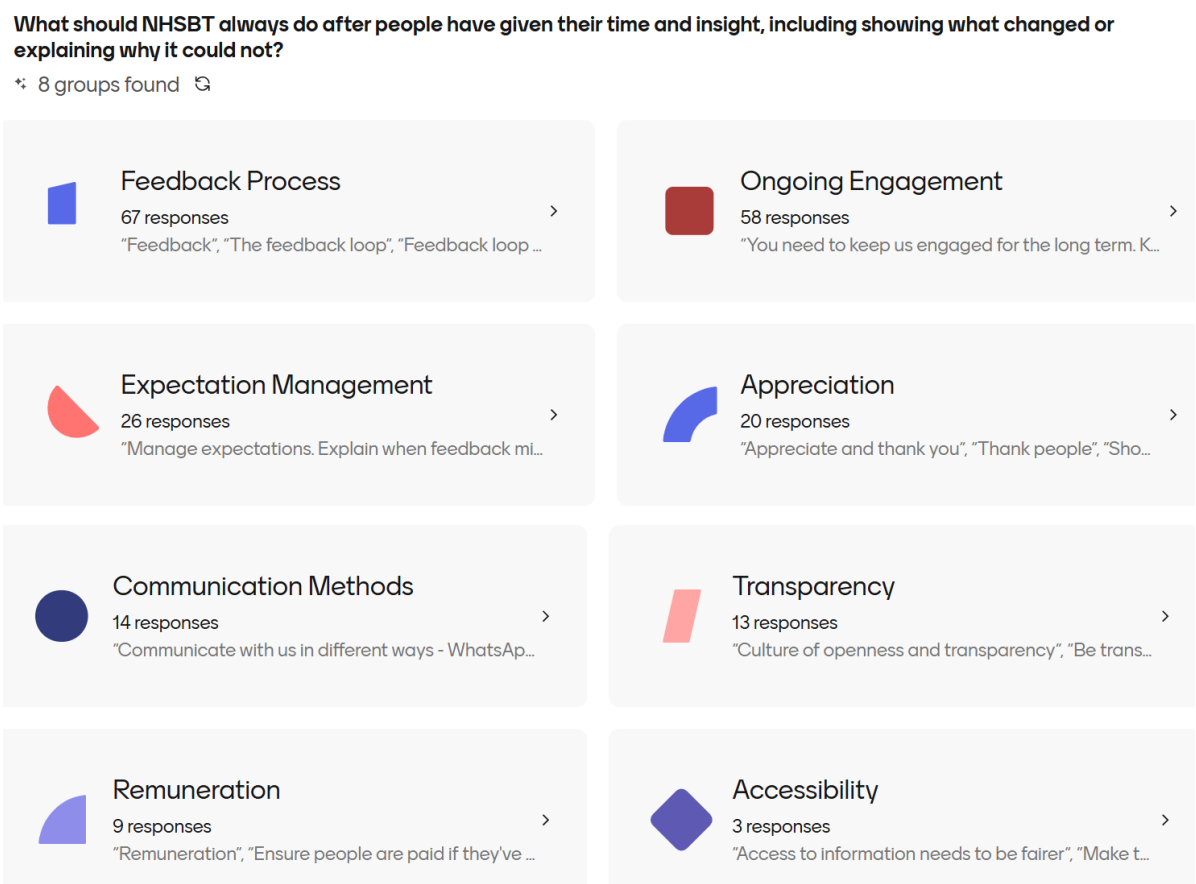
> *“Commit to formally feeding back and then do so.”*
>
> *“Give feedback… You have to implement this rigorously and consistently.”*

The scaled question showed the same pattern. On a five-point scale, the highest-rated statement was receiving an honest explanation when change was not possible (weighted average 4.74). Being told clearly what changed and seeing the difference made in practice both scored 4.69, while being updated as work develops scored 4.45. Knowing exactly which decision, piece of work or service the input informed scored 4.19.

That distinction matters. Participants were not asking NHSBT to accept every suggestion. They were asking for transparency, respect and closure: show what changed where possible, and explain honestly where it was not possible.



Selected Mentimeter illustration: what would make people feel their contribution had been used.



Selected Mentimeter illustration: grouped themes on what NHSBT should always do after people have given their time and insight.

4. Consistency matters as much as individual examples of good practice

A recurring concern was variation across NHSBT. Participants described different teams engaging in different ways, unclear routes into the organisation, silos and an experience that could depend too heavily on the individual member of staff or part of NHSBT encountered.

> *"Be consistent and accountable. Too many different teams in NHSBT have a hand in it. Too much variation. People dealt with in different ways."*
>
> *"The same core commitments everywhere."*
>
> *"One clear front door."*

Participants were not asking for every engagement activity to look identical. Participants also asked for flexible, age-appropriate, language-appropriate and culturally relevant methods. The consistency sought was in the underlying commitment: early involvement, respect, accessibility, feedback, accountability and follow-through, wherever people encounter NHSBT.

5. Partnership means reaching beyond the people NHSBT already hears from

Participants repeatedly raised representation, community reach and the role of charities, advocates and established community networks. There was concern that NHSBT can rely too heavily on its existing contacts and formal channels, while communities and organisations already trusted by people are not always used effectively.

> *"Trust charities and support groups to be part of the communication of awareness network. Go looking for the dots and join them up. NHSBT does not have all the dots."*
>
> *"We need to use the already existing community advocates to reach the people we aren't managing to."*

Suggestions included community ambassadors, work with schools, colleges, universities and primary care, better use of young people to reach young people, culturally relevant communication, and greater trust in lived-experience voices rather than relying principally on corporate messaging or high-profile influencers. Reimbursement was also raised as an equity issue, so that taking part is not limited to those who can afford to contribute their time.

6. Participants want visible ownership, resources and accountability

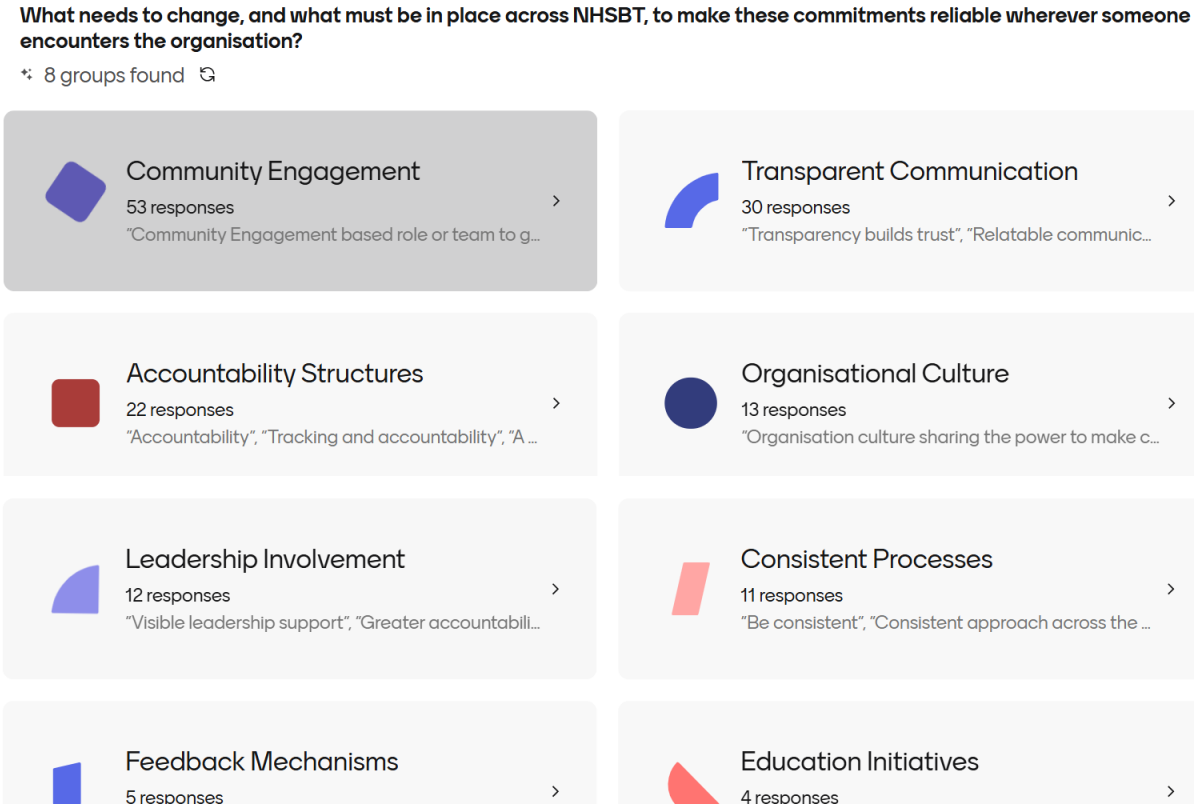
The final part of the day moved from principles to what would make them reliable. The strongest language was about action, accountability, culture, trust, resources, leadership and follow-through. Participants asked who owns this work, how it is reported, what resource sits behind it and how progress will be made visible.

"Each exec owning a bullet point on the action plan and being accountable. NHSBT said they are going to do XYZ and this is who is in charge of delivering that and communicating progress."

"Who at Board level owns this policy, what is its budget, and what goes to the Board each year?"

"NHSBT needs to put the resources (money and people) to support proper engagement activity."

In the final word-cloud question, "action" was the dominant response, alongside accountability, trust, culture change, communication, resources, consistency, commitment, funding and representation. Participants also suggested practical mechanisms such as named owners, timeframes, tracking and public reporting, an annual engagement report, and Board-level oversight.



Selected Mentimeter illustration: grouped themes on what needs to change across NHSBT to make these commitments reliable.

7. Culture and power were part of the conversation

Some of the challenge went deeper than process. Participants spoke about organisational culture, hierarchy, defensiveness, silos and the need for NHSBT to become more comfortable with challenge. There were calls to “shift the power”, flatten hierarchies, bring frontline staff into senior spaces and senior leaders closer to frontline experience, and create safe, non-judgemental spaces in which both staff and lived-experience contributors can be candid.

> *“We need to get comfortable with being uncomfortable.”*

> *“Be honest and take criticism not as an affront but as an opportunity to change.”*

These comments were not universal descriptions of NHSBT, and the report should not present them as such. They are nevertheless an important part of what was said and sit alongside positive comments about committed staff and good personal relationships. The challenge for the work is to understand how those strengths can become more dependable organisational practice.

The emerging picture

Across the day, a consistent picture emerged: involvement should start earlier, continue through the work and be more accountable. Participants want NHSBT to build relationships before it needs an answer; involve people while priorities and options are still open; make participation accessible to a wider range of communities; tell people what happened to their contribution; and make responsibility for doing this visible inside the organisation.

There is also a warning against turning engagement into another layer of process. Participants asked for frameworks, governance and reporting, but the repeated words “action”, “trust”, “authenticity” and “culture” show that a technically correct system will not be enough if people cannot see behaviour and decisions changing.

What happens next

This report is the first step in reflecting back what we heard on the day. We are sharing it with participants so that you can tell us whether we have captured the discussions accurately, and whether anything important is missing or needs to be corrected.

Once that feedback has been considered, the findings from this event will be brought together with the other evidence gathered through this work, including our surveys, discovery conversations, research and the contributions of people with lived and professional experience.

We will then work with members of the Lived Experience Advisory Panel (LEAP) and the Patient and Donor Engagement Policy Working Group to turn that evidence into a set of recommendations for NHSBT. These recommendations will be presented to the NHSBT Board in December.

Once the recommendations have been considered and approved, we will make sure that the final report is shared with everyone receiving this report. It will also be made publicly available, so that patients, donors, families, staff and anyone engaging with NHSBT can see what was heard, what was recommended and what NHSBT has committed to do.

That will not be the end of the work. In many ways, it will be the point at which the real change begins. Improving how people are involved across a large and complex organisation will not happen overnight. It will require sustained leadership, clear ownership, resources, cultural change and continued challenge from the people NHSBT serves.

The important test will be whether, over time, people can see a meaningful difference in how NHSBT listens, involves, responds and acts.

Over to you: have we heard you correctly?

This is not intended to be the last word on the event. It is our first account of what we heard, and we want the people who contributed to test it before we use it as evidence in the next stage of the work.

When you read it, please consider:

- Does this report reflect the main messages you heard and contributed to on the day?
- Is anything important missing, understated or given too much weight?
- Have we represented areas of disagreement or different experience fairly?
- Is there anything you would correct, clarify or add?

We will consider the feedback received and revise the account. The validated learning from the event will then sit alongside the wider evidence gathered through the Patient and Donor Engagement workstream and help inform the recommendations developed for NHSBT.

Question	Headline result	Responses
Area of NHSBT engaged with	Solid organ transplantation 33; blood donation 24; receiving blood/blood products 10; stem cell 6; tissue 1	74
How should NHSBT involve people earlier?	60 ranked involvement from the very beginning first; 17 ranked a standing group first	86

What would make you feel your contribution had been used?	Honest explanation when change was not possible 4.74/5; told what changed 4.69; see difference in practice 4.69; updates during work 4.45; know exactly what input informed 4.19	72
Single most important condition for making this stick	Action was the most recurrent response, with accountability, trust, culture change, communication and resources also prominent	73