NHS Blood and Transplant

Board Meeting in Public

Tuesday, 01 December 2026

Title of Paper	Patient and Donor Engagement Final Report and Recommendation	**Agenda No.**	3.8
Nature of Paper	☒ Official	☐ Official Sensitive	
Author(s)	Professor John Forsythe; Jessica Jones; Independent Co-Chairs, Patient and Donor Engagement Policy Working Group		
Lead Executive	Rommel Ravanan- Chief Medical Officer		
Non-Executive Director Sponsor	N/A		
Presenter(s) at Meeting	Professor John Forsythe and Jessica Jones Independent Co-Chairs, Patient and Donor Engagement Policy Working Group		
Presented for	☒ Approval ☐ Information ☐ Assurance ☐ Update		
Is there a plan to communicate this to the organisation?	☐ Yes ☐ No ☒ Yet to be determined Organisation is already aware of the PDE work		

Executive Summary

This paper provides The Board with a detailed report and recommendations from the organisation-wide Patient and Donor Engagement Policy programme.
The programme has drawn on 1,104 survey responses from patients, donors, families and staff, alongside internal and external discovery work, the Lived Experience Advisory Panel, Working Group and the collaborative event held on 30 September 2026. The evidence identified considerable existing strengths and commitment across NHSBT, but also significant variation in how consistently engagement is embedded, how early people are involved and whether contributors receive feedback about the impact of their involvement. Five broad themes emerged: leadership, governance and accountability; supporting and recognising staff; meaningful and accessible opportunities for involvement; communication, feedback and demonstrating impact; and creating a culture of genuine partnership. These themes are underpinned by 10 recommendations.

A significant risk arises from the expectations this programme has created. Patients, donors and families have contributed extensively, and important progress has been made in rebuilding trust and strengthening relationships. However, this engagement has created legitimate expectations of meaningful change. Failure to translate the findings into tangible improvements risks undermining that trust, reinforcing existing scepticism and, critically, driving further disengagement among the very communities NHSBT most needs to reach, hear from and work alongside.
Sustained improvement will require visible executive leadership, directorate-level ownership and a willingness to embrace changes in organisational culture and practice.

The Board is asked to

1. **Note** the evidence gathered and findings, including existing strengths and areas requiring improvement.
2. **Discuss** the recommendations and their implications for NHSBT.
3. **Recognise** that achieving the programme's ambition requires changes not only to governance, processes and staff support, but also to organisational culture and attitudes towards lived experience.
4. **Acknowledge** its collective and individual responsibility for modelling openness to constructive challenge, respect for lived experience and willingness to improve existing practice.
5. **Approve** recommendations

Previously Considered by	
3 November 26 - Executive Team	
Recommendation	
The Board is recommended to approve the recommendations, and provide full support for national policy implementation	
Risk(s) identified (Link to Board Assurance Framework Risks)	
See exec summary for details of risk	
Strategic Objective(s) this paper relates to:	
☒ Modernising One NHSBT ☒ Optimising Donor Experience and Meeting Demand ☒ Campaigning & Identity ☐ Data, AI and Interoperability ☐ New Treatments	
Appendices:	N/A

Patient and Donor Engagement Policy

1. Background and ambition

The programme was commissioned to establish a more consistent, meaningful and coordinated approach to patient and donor engagement across NHSBT, recognising the different needs and experiences of patients, donors, donor families and the communities it serves.
The emerging ambition is for NHSBT to become an exemplar of patient and donor engagement across the NHS, ensuring lived experience routinely and meaningfully informs services, policies and organisational decisions.
This builds on considerable existing strengths. The review has encountered committed staff, effective involvement and strong relationships with patients, donors and families. However, engagement is not consistently embedded across NHSBT. Opportunities to contribute, staff support and feedback to participants often depend on individual teams and relationships.
The challenge is therefore not simply to increase engagement activity, but to ensure it is purposeful, influential and accountable.

2. Evidence and emerging findings

Three organisation-wide surveys received 1,104 responses:

- 173 patients and family members; 554 donors and donor family members; 377 NHSBT staff.

These substantial but self-selected samples should not be interpreted as representative estimates of wider populations. Nevertheless, they offer valuable insight into recurring experiences, organisational strengths and opportunities for improvement.
The evidence highlights a distinction between the quality of individual interactions and the consistency of organisational follow-through.
Among donor and donor family respondents who had previously provided feedback, 85.3% rated the respect they received highly. Yet only 25.6% recalled being told what happened as a result. The equivalent figure among patient and family respondents was just 18.8%.
One donor respondent summarised the expectation:
“Tell me what has changed as a result, and if no change why.”
The staff survey offers a similar perspective. Although 93.9% of respondents understood the benefits of engagement to their work, only 34.4% agreed that patients, donors and families were involved sufficiently early to influence decisions. Time and capacity were frequently identified as barriers.
The principal challenge is therefore not an absence of goodwill, but ensuring staff have the organisational structures, expectations and practical support needed to engage consistently and effectively.
The review also identified differences between patient and donor populations in what they wish to influence and the practical and emotional barriers they encounter. An organisation-wide policy must establish common expectations while retaining flexibility in how engagement is undertaken.

3. The collaborative event: 30 September 2026

The collaborative event brought together patients, donors, donor families, NHSBT staff and external contributors to explore how engagement could be strengthened.
Designed around genuine discussion rather than a traditional conference format, participants worked in smaller groups, combining lived experience and professional expertise.
Feedback was overwhelmingly positive. Participants valued open discussion, direct contact with NHSBT colleagues and senior leaders, and feeling that their experiences were taken seriously.
One participant commented:

“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.”

However, a consistent message was that the event must be a starting point, not an achievement in itself. Contributors emphasised that success would be measured by whether their contributions led to meaningful action and visible improvements.

As participants observed:

“the real measure of success will be how the feedback is used and translated into meaningful action”

“acting now, and visibly, is clearly key”

The positive response demonstrates what NHSBT can achieve through partnership but should not be mistaken for evidence that sustained organisational change has already occurred. Listening matters, but what follows determines whether engagement has been meaningful.

4. Themes

The evidence identified five interconnected areas for improvement, which underpin the recommendations.

4.1 Organisational leadership, governance and accountability

Meaningful engagement must become a consistent part of NHSBT's core business, rather than depending on particular individuals or teams.

The emerging direction is towards clearer organisation-wide leadership, directorate accountability and regular Board-level oversight, ensuring engagement informs relevant planning and decision-making processes and has demonstrable impact.

4.2 Supporting, developing and recognising staff

Staff need confidence, resources and organisational support to engage effectively, particularly in sensitive or complex circumstances.

Proposals focus on practical guidance, access to experienced colleagues, sharing good practice and recognising those already demonstrating excellent engagement. This should build on existing expertise without creating unnecessary bureaucracy or relying excessively on mandatory training.

4.3 Creating meaningful and accessible opportunities for involvement

Patients, donors and families need clear opportunities to contribute, including early enough to genuinely influence decisions.

The emerging approach considers a standing organisation-wide lived experience advisory structure, supported by a wider network of contributors able to participate according to their interests, circumstances and availability.

Accessibility, representation, appropriate remuneration and relationships with successful existing arrangements will be important considerations.

4.4 Communication, feedback and demonstrating impact

The evidence identified a significant need to improve communication with those contributing their experiences and views.

Emerging proposals include clearer routes for involvement, more consistent communication about opportunities and mechanisms for recording, responding to and tracking contributions.

Crucially, contributors should receive meaningful feedback explaining how their views were considered, what changed and, where appropriate, why suggestions were not taken forward.

4.5 Creating a culture of genuine partnership

Perhaps the most fundamental challenge identified through this work is the need for a shift in organisational culture and attitudes towards patient and donor engagement.

The review has found that meaningful engagement is not always recognised as integral to good decision-making. At times, lived experience is regarded as something to be consulted, managed or

accommodated, rather than as valuable expertise that should help shape organisational thinking and priorities.

This is not universal. We have encountered staff across NHSBT who demonstrate genuine curiosity, humility and respect in their relationships with patients, donors and families. Their commitment provides an important foundation for improvement. However, the organisation cannot continue to rely on individual attitudes and relationships to determine the quality and influence of engagement.

Genuine partnership requires a willingness to listen without immediately defending existing practice, recognise that professional expertise does not provide every answer, and welcome perspectives that challenge established assumptions. Patients, donors and families may identify problems less visible from within the organisation, and their experiences deserve serious consideration, even when uncomfortable to hear.

This extends beyond engagement processes to the attitudes and behaviours that determine how people are treated and how their contributions are received. A policy can establish expectations and provide structures, but cannot, in itself, deliver the necessary change in mindset. That requires leadership and a willingness across NHSBT to reflect critically on established ways of working.

5. Implications for NHSBT and its leadership

The emerging findings present a significant opportunity to build on NHSBT's existing strengths. However, the changes required extend considerably beyond establishing a central engagement function, producing guidance or creating new advisory structures.

This is particularly relevant to the Executive Team. The commitment demonstrated by the Chief Executive in commissioning and supporting this work provides a strong foundation, but meaningful and sustained change cannot depend on the Chief Executive alone, nor can responsibility be passed to a central team.

Every executive leader must take ownership of what these findings mean for their directorate, including the behaviours, expectations and priorities that shape how staff work with patients, donors and families.

This requires leaders to consider whether engagement is genuinely valued within their areas of responsibility, whether staff have the time, resources and support to undertake it effectively, and whether the organisation is prepared to listen and respond when the messages it receives challenge established assumptions or practices.

It also requires openness to the possibility that some current approaches, however well-intentioned, may not be delivering the involvement or influence that patients and donors should reasonably expect.

The Board and Executive Team have a particular responsibility to model the culture they wish to establish. Staff take their cues from leaders. If engagement is visibly endorsed but deprioritised when operational pressures arise, or if constructive challenge is met with defensiveness rather than curiosity, it will be difficult to establish meaningful partnership as an organisational expectation. Conversely, when leaders demonstrate openness, humility and a willingness to act, they enable others to do the same.

There is also a significant risk associated with the expectations this programme has created. Patients, donors and families have invested considerable time and trust, and important progress has been made in rebuilding relationships. However, that trust depends on what happens next. Failure to translate their contributions into visible improvements risks reinforcing existing scepticism and driving further disengagement among the very communities NHSBT most needs to reach, hear from and work alongside.

The report and recommendations should not be interpreted as criticism of the many NHSBT colleagues who already demonstrate excellent practice. Their commitment illustrates what is

possible. The challenge for leadership is to ensure that such practice is recognised, supported and becomes the norm rather than the exception.

The September event offered an encouraging demonstration of NHSBT's willingness to listen and work collaboratively, with the participation of senior leaders particularly valued. However, as contributors themselves emphasised, the true measure of success will be whether that commitment is sustained and translated into meaningful improvements throughout the organisation.

The report and recommendations provide a framework for action, but their effectiveness will depend on NHSBT's leaders championing the necessary cultural change, demonstrating the behaviours they expect from others and ensuring meaningful partnership becomes part of everyday business.

6. Next steps

Final report and proposed recommendations presented to NHSBT Board in December 2026, with subsequent governance and approval stages to be confirmed.
Approved recommendation to be written into national policy.
Further work will address implementation arrangements, organisational ownership and assessment of impact. Continued involvement of LEAP, the Working Group and wider patient and donor contributors will help test proposals and keep the final approach grounded in lived experience.

6. **Discuss** the five broad themes and their implications for NHSBT.
7. **Recognise** that achieving the programme's ambition requires changes not only to governance, processes and staff support, but also to organisational culture and attitudes towards lived experience.
8. **Acknowledge** its collective and individual responsibility for modelling openness to constructive challenge, respect for lived experience and willingness to improve existing practice.
9. **Support** continued development of the final report, policy and implementation proposals, recognising the need for visible leadership and ownership across all directorates.