

Patient and public involvement annual review

Patient and public partnerships team and the strategic lay forum

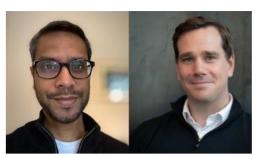
March 2025

Contents

Strategic lay forum co-chairs' welcome and introduction3
1. Background4
What is the strategic lay forum?4
What is a lay partner?4
How does the strategic lay forum work?5
Other aspects of patient and public involvement5
2. Strategic lay forum focus and achievements in 20246
What we mean by 'deep dives'6
Deep dive 1: How the Trust seeks and responds to patient feedback
Deep dive 2: The appointment and booking process and how to reduce waits7
Deep dive 3: Preventing ill health, exploring relevant developments including partnerships and integrated care initiatives7
Deep dive 4: Cancer care, including the Trust's cancer care improvement programme prompted by patient feedback8
Impact of deep dives8
Other strategic issues raised by the strategic lay forum in 20249
3. Wider patient and public involvement focus and achievements in 2024
Developing the lay partner programme10
Patient safety partners10
Diversity and inclusion of lay and patient safety partners11
Training, support and development12
Our first patient voice remuneration policy12
Community engagement13
4. Priorities for 2025
Strategic lay forum input into Trust business planning13
Person-centredness13
Integrated care14
Equity in health and wellbeing15
Strategic lay forum developments16
Developing a lived experience panel16

Strategic lay forum co-chairs' welcome and introduction

We assumed our roles as co-chairs of the strategic lay forum in January 2024, marking the beginning of a year filled with both challenges and achievements. Our aim has been to build on the tremendous work and energy of our predecessor, Trish Longdon, in



collaboration with Trust leaders. We remain committed to providing a supportive voice to the Trust, helping to embed and sustain the principles of patient-centred care and equity, especially now as it faces challenging times.

With this in mind, the forum has focused its efforts on issues that are central to patient-centred care and require a cross-organisational approach. Over the past year, we conducted detailed explorations ('deep dives') into four such cross-cutting topics (see section 2), aiming to connect thinking and initiatives across the Trust and with key external partners. We also continued to contribute to the Trust's wider patient and public involvement activities. This report summarises our work in these two broad areas over the past year and sets out our priorities for 2025/26.

We know that the year ahead will be especially challenging for the NHS, given the difficult financial climate. This will inevitably place pressure on all areas of the Trust's work. However, we believe that patient and public involvement becomes even more vital when difficult decisions must be made. It is essential that we share both the challenges and the process of finding solutions with our patients and local communities wherever possible.

Collaboration is at the heart of the strategic lay forum. We are grateful for the support of the deputy chairs, Phayza Fudlalla and Stephanie Nash for their time, energy and teamwork and to the wider forum, lay partners and staff for their commitment to involvement and co-design.

As we look forward, our ambition is unequivocal: for the Trust to become the leading example of patient-centred care in England, recognised nationally for its unwavering commitment to meaningful patient and public engagement.

Shanaka Dias and Ed Lowther Co-chairs of the strategic lay forum

1. Background

What is the strategic lay forum?

The strategic lay forum is at the core of patient and public involvement at the Trust, setting and championing a clear vision for effective patient and public involvement. It works to ensure every aspect of the Trust's work and thinking understands and responds to the needs and preferences of patients and local communities, actively looking through an 'outside/in lens' rather than through our internal service and project structures.

It was established in November 2015 and now consists of 14 lay partners plus a core and changing group of up to 10 senior Trust staff and representatives from Imperial College London and Imperial Health Charity. It meets every six weeks and oversees the Trust's involvement strategy and provides strategic advice and feedback, especially to ensure key developments are 'user-focused' from the start.

Many of the lay members are also involved as lay partners or patient representatives on projects or programmes run by the Trust and/or core partners. For example, one of our co-deputy chairs is a member of the steering group for the NIHR Imperial Biomedical Research Centre and two are also patient safety partners. Some are also members of local community or patient groups. In this way, forum members often help to 'join the dots' on patient journeys and experience across the wider health and care sector as well as across the Trust.

While individual forum members are not expected to represent any particular group, we have been working to ensure that, collectively, they are reflective of our patient and local populations. Currently, of our 14 lay forum members, six are from black, Asian or minority ethnic backgrounds, four identify as disabled and four are a patient or carer for someone at the Trust.

The strategic lay forum takes a particular interest in reviewing and supporting:

- ensuring patients and local community needs and views are central to decision-making at all levels
- integrating care around patients
- improving health equity.

What is a lay partner?

Lay partners are individuals who operate at a strategic level with a remit of ensuring Trust plans and developments are person-centred, and that the Trust has listened to, understood and responded to what our diverse patients and local communities want, need and prefer. They may be current or past patients or live in the local community and, while they may draw on their own experiences and knowledge to help inform their work, they do not represent the views of any particular group.

How does the strategic lay forum work?

Topics for review and input - including deep dives - are agreed by the forum in collaboration with the director of engagement and experience. They are prompted by new developments and insights, both internal and external to the Trust. For each topic, relevant members of staff and/or partners prepare reports or presentations and join the lay forum meeting for discussion. All major new programmes are expected to be presented to and discussed at the forum to help ensure they incorporate an effective approach to patient and public involvement.

While the strategic lay forum is not a formal part of the Trust governance structure, its views and advice are summarised in a regular insights and experience report that is taken through the Trust's quality governance fora. It also brings an annual report to the executive management board and the Trust's standing committee. There are many other points of contact with the senior leadership team too, including a bimonthly meeting between the co-chairs and co-deputy chairs and the chief executive and co-chairs/co-deputy chairs' attendance at the Trust's leadership forum meetings.



"Being part of the strategic lay forum has enabled me to input into how patients are cared for, including ensuring it is inclusive, for everyone. And it's brilliant the meetings are hybrid and so accessible. As a disabled person, I can always take part." Maria Stoeva, member of the strategic lay forum

Other aspects of patient and public involvement

The patient and public partnerships team, part of the Trust's engagement and experience division, supports the strategic lay forum, lay partner programme and a range of other patient and public involvement activities and developments. This includes the development of patient representatives and lived experience representatives as well as community engagement. The patient and public partnership team also works closely with the medical directors' office who support our patient safety partner programme.

2. Strategic lay forum focus and achievements in 2024

The focus of our four deep dives over the past year is set out below, along with the key insights and opportunities that came out of discussions.

What we mean by 'deep dives'

For each deep dive topic, the strategic lay forum asked the relevant staff leads to cover the following information in their report or presentation and this was also pursued through the discussion at the forum:

- What are we planning to achieve this year/longer term?
- Are we drawing sufficiently on patient, carer and family needs and views in our understanding of the problems and the potential solutions?
- If not, what are the barriers and solutions?
- Where are the potential opportunities/challenges in terms of:
 - integrating care around patients
 - ensuring patients' needs and views are central to decision-making at all levels
 - o improving health equity?
- What's happening across north west London/the wider NHS?
- What are we missing, in terms of priorities and actions?
- How can patients and local communities help?

Deep dive 1: How the Trust seeks and responds to patient feedback

In April 2024, we looked at the different ways patients provide feedback to the Trust (including via friends and family test, complaints, PALS and other surveys) and how the Trust responds. We covered developments underway to triangulate and share insights from feedback and to be more responsive and accessible. The lay forum asked that the Trust looks to:

- Reduce complexity and improve accessibility of making a complaint.
- Address underrepresentation of specific groups in feedback and complaints data.
- Review the language regarding feedback and insights as part of the 'improvement for all' programme.
- Develop new metrics to measure experience and link them to projects.
- Change the culture around complaints and feedback, encouraging and supporting clinical staff to have the initiative, power and resources to address and resolve issues as quickly as possible.
- Find easier ways for staff to receive compliments and thanks.

Deep dive 2: The appointment and booking process and how to reduce waits

We brought together senior managers and clinicians from outpatients, surgery and waiting list management so that we could consider the end-to-end process for patients. The lay forum concluded that:

- We need to understand the entire 'life cycle' of care, from GP to final treatment. We should systematically capture insights and opportunities to make improvements, including on communications, ensuring patients know what is happening and what the timelines are likely to be. We need to consider the holistic patient experience, rather than each team only considering their bit of the cycle. They also felt this was a better way to identify efficiencies. The forum noted that this is the approach being used in the outpatient transformation programme and felt that it should be extended to all types of planned care, including surgery.
- We should engage GPs more in the booking process so they can support their patients.
- There is scope for more involvement and co-design in the theatre efficiency programme.
- We need to focus more on health inequities and consider greater support for patients who miss their appointments. The forum also raised concerns about the current North West London ICS 'access policy' where patients can be discharged back to their GP if they miss one appointment.

Deep dive 3: Preventing ill health, exploring relevant developments including partnerships and integrated care initiatives

After presentations on our emergent approach, the forum concluded that:

- The Trust should focus on the drivers of health/ill health that it can control, supporting developments that use our regular service contact with patients to support healthier behaviours, such as the Trust's new smoking cessation support for inpatients and preparation and recovery from surgery programmes.
- The Trust should look at how it reports on and evaluates its progress towards delivering its vision of 'better health, for life'.
- The Trust's collaboration with partners offers enormous benefit and value to communities, through sharing information or supporting the development of more joined up services. For example, social service provision in north west London wide is very fragmented which makes it harder to ensure patients have the support they need out of hospital. The forum also saw big potential in the community partnerships being established, such as with the Paddington Development Trust and via Imperial Health Charity's community programme.

Deep dive 4: Cancer care, including the Trust's cancer care improvement programme prompted by patient feedback

Insights from the discussion included:

- The importance of both patient and staff experience in determining care quality and areas for improvement. It is crucial to understand this across the different tumour pathways and where and how they should differ.
- Staff engagement is crucial to improvement. Even though the cancer review has very senior leadership support, wider staff buy-in, as well as sufficient resource and time for improvement, are critical dependencies.
- Any insights, learnings or innovative approaches should be adopted by other and future improvement programmes.
- We must evaluate the success of this programme and be sure that the patient experience has improved, with another call to develop proper patient experience metrics.
- Quality care depends on clear patient information in the right type of language. We need to ensure information is consistent, detailed for the right cancer group and not relying on clinical language.
- It is important to provide holistic care and support the whole patient after a serious illness, for example mental health support to help manage adverse effects of treatments.

Impact of deep dives

There was a consensus across the lay partners and staff that the deep dives provided a helpful format to connect teams and build a shared understanding of challenges and opportunities in key cross-cutting areas. Although, it was also clear that it is tricky to pin down whether and how the insights and conclusions from the deep dives are applied and help produce further improvements.

"It's always helpful to get other perspectives. The appointments and waiting list deep dive was a good opportunity to connect across the Trust and challenge ourselves to think holistically about patients. I'm not sure we implemented any immediate changes but the discussion reinforced the need to keep prioritising patient communications and information, which is the focus of both the theatres and outpatient programmes. We're looking at how we can collaborate further with the work on patient access, waiting well, and equity. One area is how we can incorporate this two-way feedback into existing governance more. Another report to committee might not be answer; instead clarity at each 'deep dive' topic about which programme/committee/steering group the feedback would go to, this is where we could improve."

David Woollcombe-Gosson, Divisional head of productivity and development for the Division of surgery and cancer

In January 2025, at its annual planning day, the lay forum decided to continue with the deep dive approach, now looking to refine the focus. The first topic for the next round of deep dives will be 'reducing the number of patients who do not attend their appointments'.

Other strategic issues raised by the strategic lay forum in 2024

Other key issues explored include:

- Ensuring that West London Children's Healthcare, managing children's services across both Imperial College Healthcare and Chelsea and Westminster Hospital, has a clear home and strong voice with the other clinical divisions of the Trust. Since children's services were moved into West London Children's Healthcare, it's not always easy to see how they are affected or involved in Trust-wide programmes such as outpatient improvement or redevelopment.
- Patients who 'do not attend' their appointments and addressing the health inequities that are likely to act as both a driver of missed appointments and a consequence. With the pressure to reduce waiting lists and existing problems with the appointment and booking process, the strategic lay forum decided to make this area a topic for a future deep dive.
- Reviewing the Trust's patient and public involvement strategy. First developed in 2016, the strategy needs a full review, especially to reflect key developments since then, including a refreshed organisational vision and strategy; changes in organisational culture, value and behaviours; the development of user insight and experience, community engagement, equity, diversity and inclusion, and health inequities focus and functions.

3. Wider patient and public involvement focus and achievements in 2024

Developing the lay partner programme

Since the lay partner programme was established in 2016, we have collaborated with 219 lay partners on 144 different projects or developments.

We currently have 40 active lay partners who, between them, are involved in the following projects or developments:

- artificial intelligence steering group
- Care Information Exchange
- Connecting Care for Children
- Paddington Life Sciences digital inclusion workstream
- north west London digital healthcare information exchange board
- end of life care steering group
- elective orthopaedic programme board
- patient interpreting improvement steering group
- improvement for all implementation board
- NHIR Biomedical Research Centre
- new invasive procedures committee
- nursing and midwifery research committee
- outpatient improvement programme
- GP forum
- acute provider collaborative planned care board
- green plan advisory group
- infection prevention and control committee
- cancer improvement programme
- north west London perioperative care improvement.

Patient safety partners

In addition to our lay partners, we have five patient safety partners who are supported by the medical directors' office as part of our safety programme. The role is a way of involving patients, carers and other lay people in our governance, management and planning to improve patient safety and reduce harm. Two patient safety partners sit on our strategic lay forum.

The role was developed in collaboration with the lay partner programme and both programmes benefit from very collaborative working across the patient and public

involvement and medical directors' office teams, including sharing resources, recruitment approaches, training, policy development and reporting.

The main difference between the roles is that patient safety partners have enhanced training and support to enable them to take part in confidential serious incident review meetings. They provide a crucial patient-focused view in these meetings. They are also involved, between them, in a range of safety projects and developments:

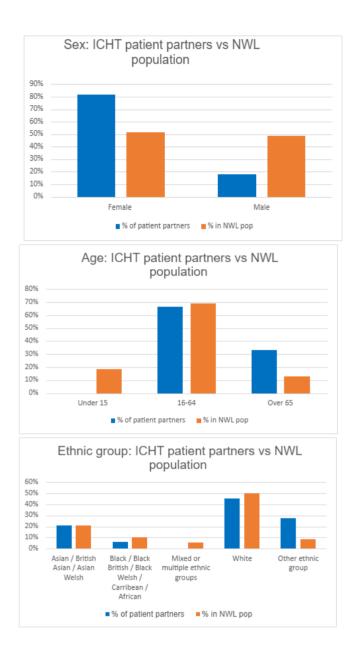
- safety improvement group
- improving involvement of patients and families in learning responses
- patient interpreting improvement steering group
- ward accreditation programme committee and visits
- hand hygiene steering group
- medicines safety group
- anticoagulant group
- new invasive procedures steering group
- deteriorating patients steering group
 - Martha's rule
 - Call for concern
- reducing falls with harm steering group.

"By involving lay partners in the 'Call for Concern' work they drew our attention to importance of inclusive language and how we might need to amend our support and presence in emergency department areas, where patients can deteriorate very quickly. By them just being involved, we maintain a patient-lens." Robert Latchford, safety improvement lead

Diversity and inclusion of lay and patient safety partners

By the strategic nature of their work, lay partner and safety partner roles are not for everyone. Within these constraints, we have put significant effort into becoming more inclusive and ensuring we make progress towards equitable representation across protected characteristics. For example, we have worked with local community groups to identify and support potential new partners, and we are putting more resources into training and support more generally.

Here is the current breakdown of lay and patient safety partners by sex, age and ethnicity:



Training, support and development

We hold quarterly events to help build a community of empowered lay partners. The events provide opportunities for information sharing, networking, peer support or training. A group of lay partners have also been part of the first phase of our quality improvement training. This year, three lay partners attended The King's Fund course on community engagement.

Our first patient voice remuneration policy

We have developed our first remuneration policy to help ensure we are able to be as inclusive as possible in patient and public involvement, doing what we can to remove barriers of direct and indirect financial costs. The policy has drawn on all we have learnt from remunerating lay and patient safety partners so far to help us establish a

consistent and fair approach across the Trust. The policy is expected to be finalised in April 2025.

Community engagement

Community engagement focuses on building two-way, trust-based relationships with our communities, directly with individuals and via community leaders and organisations. Building on our principles of community engagement co-designed with community groups in 2022, we have taken forward a range of developments in the past year, in partnership with community organisations, including:

- Developing a shared approach to community organisation contact management and relationship building across the Trust, other health and care partners and Imperial College London.
- Built on the strong relationships we fostered with 11 local community groups that took part in our 'engaging for equity and inclusion' listening events in late 2023. This work aimed to better understand what we can do to be an inclusive and antiracist organisation and since then have recruited four new members to the strategic lay forum form these groups, improving the diversity of the forum and establishing longer term relationships.
- We were able to use the same contacts and known community groups to review our NHS Equality Delivery System submission in late 2024 that assessed the need, access and outcome/experience of some of our services.

4. Priorities for 2025

Strategic lay forum input into Trust business planning

The strategic lay forum acknowledges the uniquely challenging year financially that the Trust and the whole of the NHS faces in 2025/26 and wants to play its fill role in helping the Trust make the best possible decisions on where and how to save costs and become more efficient. Patients and local communities are often very well placed to identify poor processes and ways of working that, if tackled, would release savings as well as improve patient care and outcomes.

We want to continue to help the Trust to focus on three key themes as it looks to make significant changes this year – evidence shows that these approaches, implemented effectively, help deliver financial efficiencies as well as better care and outcomes.

Person-centredness: We want care to be tailored to the needs of individual patients and urge all services and teams to make sure they are gathering and using feedback and insights from their patients and local communities, making special efforts to reach all groups.

Areas for note and particular focus:

- We want to ensure the Trust is innovative in the ways it listens to patients and communities, particularly seldom-heard groups, and how it acts on the feedback. We held a 'deep dive' on this in April 2024 and plan to return to this topic in 2025.
- We recognise that, for the Trust to respond to insights and feedback, it needs an engaged and empowered workforce who have enough time and resources to drive improvement. This is why we support the improvement for all programme as well as initiatives to promote staff wellbeing and inclusion. wellbeing and the EDI listening work.
- Digital transformation and AI are here to stay and, if implemented effectively, can transform care positively. But we must ensure its use is inclusive, safe and proportionate. Patients are currently expected to navigate a wide range of apps and digital portals as part of their care. This can be extremely difficult, especially for those that experience digital poverty or have a lack of skills or confidence in this area. With the move to align care pathways and reduce service variations across north west London, we also want to see a more consistent digital experience for patients.
- In particular, we would like to see digital transformation have a focus on enabling safer and more personalised care and better two-way communications. This includes supporting everything from language preferences to building stronger relationships and improve health. We are keen to learn more about the Trust's plans for implementing a 'customer relationship management' system and further development of its electronic patient administration system.
- We are aware that transitioning from children's care to adult care can be a daunting time and so want to have a focus on supporting developments in this area and making sure that all major Trust developments include full consideration of children's needs.

Integrated care: We have long championed the need to integrate care around patients and helped to set this as one of the Trust's three strategic goals.

Areas for note and particular focus:

- We are encouraged by the development now of integrated neighbourhood teams in north west London and ask that the Trust looks at they can play their full role in this approach, alongside other health and care partners.
- We also urge the Trust to embed the principles of integrated care in outpatient transformation. The programme offers a great opportunity to co-design processes and ways of working that support genuinely joined up care, especially across primary and secondary care.

• We encourage the Trust to work even more closely with other trusts in northwest London, especially in terms of patient and public involvement.

Equity in health and wellbeing: Healthcare must be available to individuals and communities in an equitable way regardless of their status under the nine protected characteristics and economic disadvantage.

Areas for note and particular focus:

- We will continue to offer support to all health equity and access initiatives, such as interpreting improvement and smoking cessation.
- We want to focus particularly on how we can further support efforts to reduce the number of patients who' do not attend' appointments. We are keen to explore collaborations with partners to understand the underlying issues and to make sure we are maximising opportunities to link with wider work, such as outpatient improvement, cancer improvement and the development of integrated care.
- We understand the Trust wants to better prepare and support patients for surgery, including preparing patients to be ready for 'last-minute' booking opportunities. It's essential that access to all of these appointments and opportunities is equitable and we help minimise barriers to patients in terms of their own resources and support networks.
- We want to offer support to the Trust's equality, diversity and inclusion work, and especially ensuring the delivery of its new anti-racism and antidiscrimination commitments. We are especially interested in seeing improvements in access to equipment and adjustments to support disabled patients and staff and training for staff. We also want to ensure feedback about making improvements for LGBTQI+ patients has been acted upon.
- We know there is significant pressure on the Trust's maternity services and that further change is likely. We want to help ensure there is no adverse impact on health inequities and to encourage greater involvement of the Maternity and Neonatal Voices Partnership.
- We want to have a special focus on digital poverty in relation to health equity.
- It's crucial that the full life cycle of research, from setting research priorities to benefiting from the outcomes, is inclusive to open to our diverse communities.

The strategic lay forum receives updates from Imperial Biomedical Research Centre and one of its co-deputy chairs is a member of the BRC steering group. We recognise, more generally, the growing importance of life sciences for the Trust, including the expansion of Paddington Life Sciences. We will keep a special focus on this area of work.

• We also want to ensure the Trust gets good input from all parts of our diverse communities in its redevelopment schemes.

Strategic lay forum developments

In terms of our own improvements, we will focus on:

- Refreshing the Trust's patient and public involvement strategy. First developed in 2016, the strategy needs a full refresh, especially to reflect key developments since then, including a refreshed organisational vision and strategy; changes in organisational culture, value and behaviours; the development of user insight and experience, community engagement, equity, diversity and inclusion, and health inequities focus and functions.
- Reviewing our terms of reference and ways of working to ensure we are as effective as possible.
- Building relationships with a wider group of Trust leaders to help understand their challenges and develop shared goals.

Developing a lived experience panel

We are exploring establishing a lived experience representative panel to complement the work of our strategic lay forum and lay partners and to help support services to establish and/or work with their own groups of patient representatives. This work draws on learning from other trusts, including those in the North West London Acute Provider Collaborative.