



Imperial College Healthcare
NHS Trust

Strategic lay forum annual review 2023

August 2023

Trish Longdon, Chair
Shanaka Dias, Co-deputy chair
Ed Lowther, Co-deputy chair

Contents

Welcome	3
1. Patient and public involvement	3
What is the strategic lay forum?	4
The lay partner role.....	4
What is co-production?	5
2. 2022/23 priorities	5
Progress and challenges - highlights	6
User focus and patient centredness	6
Integrated care	7
Health and healthcare equity.....	10
Redevelopment.....	11
Inclusive research.....	12
Lay partner programme development.....	12
3. 2023/24 priorities	13
User focus and patient-centredness	14
Integrated care.....	15
Health and healthcare equity.....	16
Lay partner programme development.....	17

Welcome

Each year, the Trust's strategic lay forum publishes a review of progress against our aims, with details of patient and public involvement activities and impact over the past year. The review also sets out our priorities for the year ahead.

The report is set out in three sections:

- The Trust's approach to patient and public involvement
- 2022/23 priorities – highlights of progress and challenges
- 2023/4 priorities.

1. Patient and public involvement

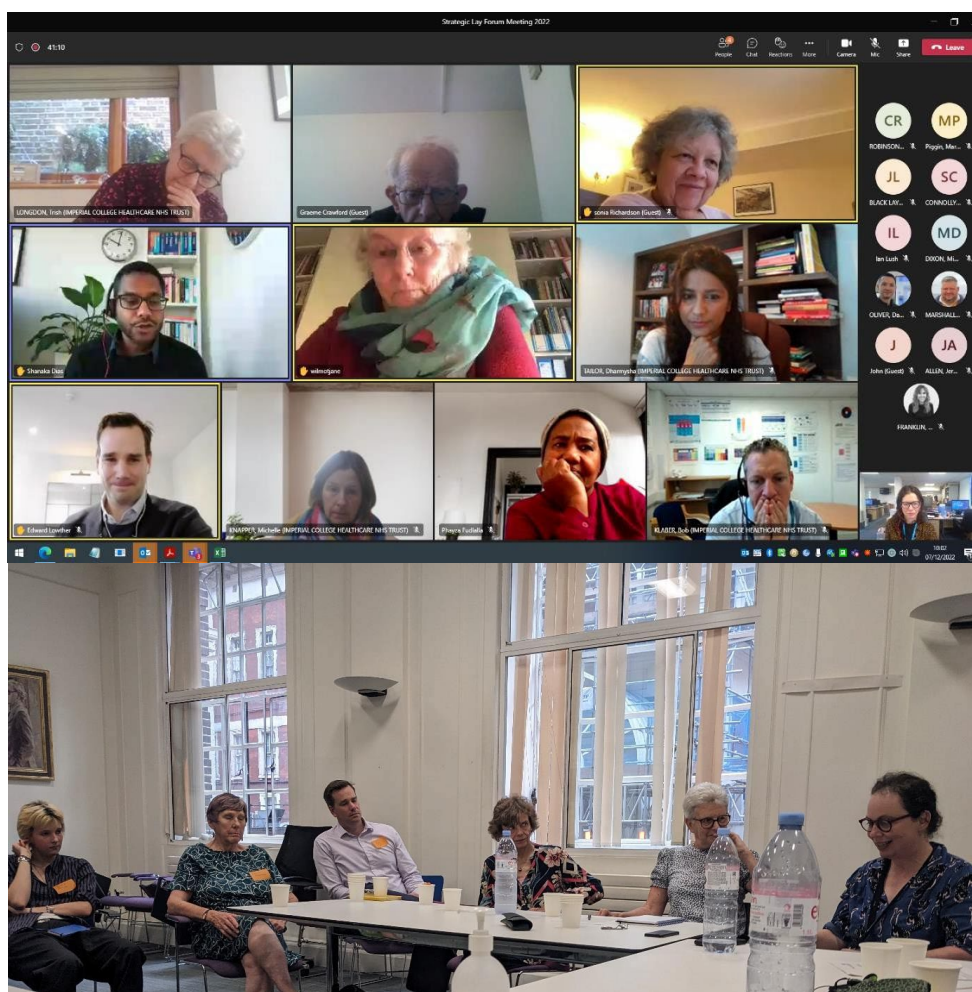
The below framework sets out the areas in which we support the Trust to deliver the vision for patient and public involvement and user-focus.

'Involvement' is a way of working and includes all of the activities that help us focus on understanding and meeting the needs and preferences of the people we serve. It is not a single function or service run by one team but a way of thinking and behaving that should be embedded at all levels of the organisation.



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 was established in November 2015 and consists of up to 20 lay partners, senior Trust staff and patient and public involvement leads at Imperial College and Imperial Health Charity.
- It meets every six weeks and oversees the Trust's involvement strategy, provides advice and feedback and makes sure that the Trust's plans and initiatives are shaped by the needs and preferences of the relevant patients and local communities.



The lay partner role

- We currently have 33 active lay partners who co-produce strategies, programmes and plans with Trust colleagues, working on specific projects, programmes or groups.

- Some are also members of the strategic lay forum.
- Their role is to ensure that Trust plans and developments are patient-centred, and that the Trust has listened to, understood and responded to what patients and our communities want, need and prefer.

What is co-production?

Co-production means Trust staff working with patients, carers and local communities in an equal partnership to design and develop our services and developments. It means engaging with patients and other partners at the earliest stages in the design and development of plans in an inclusive and accessible way.

2. 2022/23 priorities

Each year, the strategic lay forum inputs into the Trust's annual business plan at an away day involving senior leaders of the Trust. For 2022/23, the following priorities were fed into the Trust's business planning process.

- User focus and patient centredness – championing tools and ways for the Trust to become more patient-centred, supporting the development of a user insight function.
- Integrated care – as one of the Trust's strategic aims, we encouraged the Trust to move from this being a series of dedicated projects and people to a patient-centred vision of primary, community, acute and social care connected around the patient. We wanted it to become our systematic 'way of working', with visible Trust leadership and accountability.
- Health and healthcare equity – we supported the coordination of this area of work and reporting and measurement at board level. We have a dedicated slot each forum meeting to follow up on, understand and support this critical area.
- Redevelopment– ensuring the proposals and plans for the redevelopment of St Mary's, Hammersmith and Charing Cross hospitals are codesigned with the Trust's diverse communities.
- Inclusive research – we advocated closer working with Imperial College London and other research bodies to ensure research is relevant to all our patients and based on our communities' needs and preferences. For example, the pandemic had highlighted how little we knew about the disproportionate impacts of a pandemic on our diverse and more vulnerable communities.

- Continued support for improving the patient appointment booking system – this remains the main source of patient complaints and had worsened during the pandemic as virtual appointments were made and procedures and treatment were cancelled. We committed to continuing to raise this as an issue which requires collaboration at the north west London level and to advocate for Trust improvement in all projects, particularly the outpatient transformation proposals, in the meantime.
- Improving our lay partner contribution – to reinforce our lay partner community following Covid and implement the recommendations in the lay partner impact evaluation such as increasing the number and diversity of our community and the support, training and learning available to lay partners.

Progress and challenges - highlights

User focus and patient centredness

The forum supports the overall goal of the Trust to be the most user focused NHS organisation and acknowledges the current challenging environment, including significant operational and financial pressures, long waiting lists, industrial action and staff who have been working hard to deliver high quality patient care in difficult circumstances.

In 2022/23, we contributed to key strategic projects at the Trust, challenging them to be user-focused, inclusive and to integrate and align them with existing priorities, such as health equity. We also believe we helped to break down silos within the Trust and supported an overall cultural change to put patients at the centre of all our care. One key development that we are supporting is the creation of an integrated user insight and experience function. Other key developments include:

- **Outpatient transformation** Outpatients is a vital area of patient care. Feedback from patients told us that there is considerable room for improvement, including connecting care between GPs, Trust specialists and the patient and creating patient rather than provider centred pathways. We believe we need to dramatically improve the failing appointments system, make our digital systems intuitive and user friendly, significantly improve our communications and patient information and make sure that all our changes take particular account of the needs of our seldom heard and vulnerable communities. The lay partners involved in the project challenged the Trust to ensure these concepts were strategic aims of the overall programme and

supported colleagues who wanted more Trust-wide input into this programme. This programme has been refocussed and we welcome the leadership of Dr Amrish Mehta and his commitment that lay partners will be members of its programme board and that a strategic vision will be co-produced with patients and local communities to guide the programme longer term. We are currently working with the programme leadership to ensure that the patient voice is included in the governance of the programme.

- **‘What matters to you?’:** This is an approach to encourage and enable meaningful conversations with patients about their care, rather than just asking ‘what is the matter with you?’. It is about embedding shared decision making in all our treatment and care. We worked with committed nursing staff who piloted this approach in 2022. The results were encouraging but the strategic lay forum remained concerned that the approach had not been embraced by all staff and was not a core part of the Trust culture. We asked that the pilot be extended, and a patient measure of success be developed. We were disappointed that, despite some support, this did not happen last year. As part of our role as a ‘critical friend’, we did not give up but prioritised this initiative again this year. We are delighted that a pilot involving six wards is now planned for autumn 2023 and that we are involved in the co-design.
- **Patient safety partners:** Through co-design with our safety improvement colleagues, we developed the role of patient safety partner (PSP) and supported their recruitment. Since the induction of the first PSPs in November 2022, we have set up ways to work with them to share learnings and support each other. Six PSPs are now embedded in safety improvement projects and activity across the organisation. They are having an impact in many ways, including but not limited to:
 - Ensuring we consider groups that are seldom heard and/or from deprived communities
 - Offering a patient perspective on how we compassionately engage patients and families in investigations following a safety incident
 - Co-designing patient safety communications and literature to best suit the needs of patients
 - Elevating the voice of patients by co-designing and participating in our upcoming world patient safety day event
 - Using their links into the community to share learning.

Integrated care

This is care that is connected around patients, with teams of people from a range of services (and, in the longer term, a range of providers) working with patients and their

carers to co-design and produce care and treatment to achieve the outcomes they seek. This is a long-standing theme of all our work and has proved difficult to progress. We challenged the Trust to have more visible Trust leadership and accountability for the vision and delivery of care integrated around patients. Although progress in 2022/23 was slow, we are now working to embed a patient vision of integrated care in the outpatient transformation programme and are pleased to see an increasing focus on more formal partnerships and relationships to support integrated care, especially within our three main boroughs. Last year we also supported the embedding of the principles of integrated care in a number of other projects or developments, including:

- **Acute programme board/Acute provider collaborative:** There were two lay partners on the Acute Programme Board since it was established, and these roles are transferring to support the new acute provider collaborative structures that are currently being established. Through these roles, lay partners have helped to consider many new and innovative proposals for improving patient treatment and care and we sought to assure that the relevant patient voices, including seldom heard communities, were the basis of each development. We fed in that patients valued consistent access, quality and service between hospitals and geographical areas and sought assurance that patient voices were equally available and heard in all Trust providers. However, we are disappointed that we do not yet have a coordinated way of sharing patient and community voices across the collaborative. We are pleased that one of the priority workstreams established by the acute provider collaborative executive quality group aims to align and progress improvements in user focus and insight. A workshop involving staff from across the collaborative and lay partners kicked off exploration of what common, user focus measures could be developed. More work is being done this year and we hope the Trust will use these measures generally in its quality assessments in the future.
- **Community diagnostic centres:** A lay partner was involved in the development of the north west London community diagnostic centre programme. These centres aim to speed up access to diagnostics, closer to home. A key requirement therefore was to make sure that these centres were located to better serve communities in most need. Through our involvement, we were assured that decisions on these centres were made with patient experience and increasing equity at their heart. We have suggested that this approach be used as a model for similar developments.

- **North West London Elective Orthopaedic Centre**

Olivia Freeman, a lay partner, worked on the development of the north west London elective orthopaedic programme, one of the collaborative's first initiatives. She is a lay partner with several years' experience on the strategic lay forum. She joined the programme board in August 2022. Olivia kindly shares her detailed views and experience of this project here:



I have been interested in the concept of an elective orthopaedic centre since it was first mooted and have followed the development of a similar programme in Epsom. When I joined the programme board, there was a preferred location - Central Middlesex Hospital (CMH). There are pros and cons to this location. CMH is a modern hospital but the major thing against CMH is its location between very busy main roads and the distance from the tube and trains. It is well served by buses. I have been able to focus on transport issues from the patient point of view.

At programme board meetings, everyone was very welcoming and helpful, particularly the then chair. I was the first lay partner that some board members had come across. The regular monthly meetings were held online. There was a certain amount of terminology to learn but I soon found that I was able to ask about things that I didn't understand, make suggestions and ask other questions in relation to the patient journey.

Although I did not join the board at the beginning, I did join before the development and submission of the full business case (FBC) and before a major 18-week public consultation.

My input was respected and quoted during board meetings. My additional input was specifically requested by the transport, digital and communications (for the consultation) workstreams. My main input to the FBC was to ensure that ongoing measurement of patient outcomes was included.

Using the risk register, I identified the areas that would need specific patient involvement. Some have been adopted, for example a patient transport group has been set up. Patients are also involved in the provision of clear and concise patient

information literature and communications to avoid confusion – this is of key importance.

Since approval of the FBC, the programme board has become a shadow programme board, which is run by London North West University Healthcare NHS Trust who will manage the elective orthopaedic centre. This was another learning curve, and I was eventually formally asked to join the shadow board. I have requested a deputy as I think that, going forward, it would be beneficial to have other lay and patient input.

I have recently been able to review the draft partnership agreement and highlight the importance of obtaining patient consent to share personal data across Trusts and also to make it clear to patients who will respond to complaints and also stressed that continued lay/patient involvement is essential.

Of all the lay projects that I have been involved in so far, this has been the most interesting and the most rewarding. It is likely that there will be more pan north west London projects and here are a few thoughts to bear in mind:

- continue collaborating across north west London for patient benefit*
- ensure that research and insights on patient preferences from all projects are shared with other initiatives*
- there should be patient or lay involvement at the beginning of all pan north west London projects – at present it is unclear who will co-ordinate this as each trust has its own system of patient involvement.*

Health and healthcare equity

Improving health equity and reducing health disparities have always been important areas for the forum. We have previously raised concerns about the lack of Trust-wide leadership in this area and so were pleased to see Dr Bob Klaber take this on and begin to develop a focused work plan. We supported a number of specific developments, including:

- Reducing ‘do not attends’:** we supported a key project to understand and address the reasons why a disproportionate number of people who do not attend their outpatient appointments are from ethnic minority or deprived communities. Members of the strategic lay forum are on the project group for this work and we supported the recruitment of members from diverse local communities to take part in the engagement events. We have also asked that any solutions to address inequity are codesigned with patients from those groups and proposed that substantial patient engagement in the work is essential.

- **Improving the patient interpreting service:** Following the pandemic and in the light of the views of local black, Asian and minority ethnic community groups, we asked that the Trust supported a review of the patient interpreting service – which they did. Local community representatives were involved from the start. We voiced our concerns about delays to this work. The report explaining the challenges and recommendations was not completed until early 2023. We are satisfied that this report outlines the issues and the impact it has on patients and communities who do not speak English as a first language. However, we are very concerned that the resource needed to support this programme of work had still not been identified by July 2023. We understand this is now being resolved but will continue to raise our concern until there is clear way forward.
- **Listening to staff and patients to understand and address discrimination:** The forum heard in detail about the Trust’s programme of work to understand and address racism and discrimination experienced by staff at the Trust led by the equality, diversity and inclusion team. We suggested that this approach needed to be extended to patients, visitors and our communities. However, we were clear that this piece of work needs to be co-designed with patients, not simply inherited from the work undertaken with and for staff. We are pleased that this programme will now include patient engagement and lay partners are included on the project steering group.

Redevelopment

The redevelopment of Trust sites is both an urgent and complex project with many financial and political drivers. The forum has, for a number of years, supported and been involved in the plans for redevelopment, particularly for St Mary’s. During this time, we have challenged the Trust to make sure plans are co-designed so that they reflect the genuine needs and preferences of the diverse local communities and are updated following the long delays we have endured. An involvement charter and a summary of patient preferences has also been co-designed, but the delays and uncertainty over the redevelopment meant that the Trust needed to be agile to reopen involvement when the go ahead was given.

This year, we continued to input into this project by:

- Reviewing and commenting on planning and business cases. We were concerned that these cases did not have the user focus we expected from all Trust programmes and those concerns were heard and acted upon.
- Supporting the Trust during 2022, when much of the year was hampered by uncertainty and it was difficult to share information, given that the involvement needed to be purposeful and have an impact. Our main focus was on how, as a lay forum, we might helpfully make the case for funding for the redevelopment without moving into campaigning, with potential risk to the Trust's impartial political positioning.

Inclusive research

The strategic lay forum includes colleagues from Imperial College London and its Patient Experience Research Centre. It has been valuable to share insights, coordinate engagement with local communities and to work together on our shared goal of enabling inclusive and accessible research that is responsive to our communities' needs throughout its life cycle – from setting priorities, research design, the research itself and its review and publication. This positive relationship is key as the Trust and College together carry out research as a Biomedical Research Centre (BRC). The partnership was awarded this status again in October 2022.

Throughout the year we:

- Contributed to the bid for the BRC and helped to establish the governance and patient and public involvement and engagement approach so that it was inclusive and hears from diverse and local voices.
- We promoted the role of community partner on the BRC programme. Some of our lay partners now fulfil this role enabling us to share knowledge and information and learning.

Lay partner programme development

After a period without face-to-face meetings during Covid, we have reinvigorated our lay partner learning events, providing training and networking opportunities for lay partners to strengthen the community and provided opportunities to share learning.

We are building our training and support for lay partners who can now take part in quality improvement training and, over the last four months, three have taken up bursary places to attend healthcare training and conferences offered by The King's Fund.

We currently have 83 lay partner roles filled by 33 lay partners across 54 projects. We recruited no new lay partners in 2022 because we didn't have enough resource to make sure new lay partners could be properly supported and inducted.

Of the 33 individual lay partners, ten are from black, Asian or minority ethnic backgrounds, ten are under 40, and 19 are female.

We now have two deputy chairs. This has proved invaluable in increasing our skill base and widening our perspectives. However, the fact that both deputy chairs are in full time employment means that we have had to increase our support and sharpen up our systems.

With the recruitment of our community engagement manager, we now have dedicated support for the lay partner programme and a plan to address the findings and recommendations set out in the lay partner evaluation that was completed in 2020. We now have more diversity amongst our lay partner community, have streamlined the process to take part and enhanced the support to lay partners through regular conversations with lay partners and the introduction of buddies.

A remuneration scheme, in line with Imperial College London and NHS England recommendations, is in place to ensure that all members of our community can participate as a lay partner, irrespective of their income or circumstances.

3. 2023/24 priorities

The following priorities were developed at the forum's annual planning day in January 2023 and fed into the Trust's wider business planning process for 2023/24.

We have set out our priorities under four themes:

- User focus and patient-centredness
- Integrated care
- Health and healthcare equity
- Lay partner programme development.

In doing that, we also felt it important to acknowledge that the Trust is dealing with a huge number of issues, including operational and financial pressures, long waiting lists and staffing challenges (morale, shortages and industrial action). We have worked to ensure that our priority areas are therefore proportionate, will not take lots of extra time and resources and support existing programmes already underway.

We know staff must feel valued, supported and recognised as there is a direct correlation between engaged staff and quality of care and they are crucial to deliver any strategic aims or plans.

User focus and patient-centredness

All plans and policies must have patients and communities at their centre and the Trust should understand and act on what matters to individual patients. Following the pandemic, the focus has understandably been on reducing backlogs and waits for patients. This focus on targets has detracted from our focus on patient and person-centred care. We support the renewal of this focus across the Trust with care being built around patients' and communities' wants, needs and preferences.

We support:

- A pilot to systematise a 'what matters to you?' approach, linked to the ward accreditation and 'pathway to excellence' programmes. 'What matters to you?' is an approach to care and treatment based on each patient's wishes and goals. This facilitates shared-decision making for care and treatment based on what is important to a patient. The pilot will be fully evaluated, with the support of the improvement team and include the development and testing of a patient-centred measure. The learning will enable the Trust to decide on whether and how to roll this approach out further.
- All Trust leaders living out their commitment to 'user focus' and a renewal of emphasis on the Trust's aim to be the most user centred in the NHS.
- The Trust's establishment of a Trust-wide user insight function to enable the Trust to understand and work with patients and communities to build their wants, needs and preferences into all plans and programmes. We support the Trust's plans to make this approach 'business as usual' and link the knowledge and understanding which exists across the Trust to deepen and make the intelligence we have more accessible. We look forward to learning from the insights this reveals.
- A consistent Trust-wide approach to 'end of life' care, with this care being everyone's responsibility based on improvements co-produced with patients and communities.
- Making sure that all digital developments are simple and accessible to patients as well as integrated with existing apps and approaches. We are aware, for example, that there are many apps and online routes to book, change or confirm appointments or manage specific conditions and treatment. We know these are confusing to users. We plan to spend this year understanding the digital approaches available to users with a view to encouraging a user

strategy which ensures our digital development meets the needs and wishes of our users, are joined up and intuitive.

- All information, letters and self-care instructions for patients and carers being clear, consistent, up to date, available to patients with additional needs and shared in a timely way. Enabling us as patients to fully understand our condition or treatment ensures we can care for ourselves effectively. As we increasingly use digital and virtual forms of contact to promote health and wellbeing, we must make sure that we identify and work with those who experience digital poverty or who cannot or choose not to use digital forms of access to ensure equal and easy access.

Integrated care

For many years we have promoted the need for health and social care to be integrated around patients. Patients should not have to navigate complex and fragmented organisations. We support the development of a single, patient-owned, healthcare record shared with all healthcare partners.

Integrated care is one of the Trust's three strategic aims. There are many initiatives and successes, for example to improve the discharge process and work to develop the financial approaches for greater integration between primary and acute care. But there seems to be no Trust-wide or north west London wide vision or strategic approach to move the work from a series of projects to 'the way we all work'.

We support:

- The development of a shared vision of what care connected by GPs and acute specialists, integrated around patients, would look like, as part of the outpatient transformation project. For example, this might include changing the referral process fundamentally by enabling each patient to have a timely (virtual) consultation between themselves, their GP and the acute specialist at which the next steps are discussed, and a shared decision reached and agreed. This vision should be co-designed with patients and staff and provide the long-term aim for transformation work. The development of a consistent approach to collaboration and involvement across north west London and the integrated care system to ensure that the patient voice is heard and care is consistent for all residents.
- We have lay partners on north west London acute sector developments and observed that there are differences in how patient involvement and insight work is understood and carried out. We support effective ways to maximise the patient voice within this new way of working and will continue to participate in north west London-wide programmes.

- We support processes amongst north west London collaboration partners that ensure learnings and patient insights from specific projects are systematically shared. For example, insights on patient transport, equity and staffing would be relevant to many north west London developments.
- We welcome clarity on how lay, patient and user involvement will be incorporated into operational collaborative developments such as of the community diagnostic centres and elective orthopaedic centre. This will need to guide key issues, such as the handling of complaints, as well as clinical pathways.
- The development of a single appointments system across all the providers in north west London. This is a necessity for truly integrated care and will help address the main source of patient complaints. The work on why people from disadvantaged communities are overrepresented amongst those who 'do not attend' their appointments has found that failures in the appointments system account for over half of these unused appointments. The creation of the acute provider collaborative provides a real opportunity for north west London to take the lead on this very complex initiative. In the meantime, we support the work the outpatient transformation project is undertaking to improve the Trust's own appointments administration.

Health and healthcare equity

Access to all healthcare services must be available to individuals and communities in an equitable way regardless of their status under the nine protected characteristics and economic disadvantage. The Trust should be able to share clinical decision-making with all patients and communities and ensure that care and treatment is sensitive to each individual's culture, language, faith or other needs.

We consistently encourage trusted relationships with seldom heard communities and have a dedicated slot on the agenda of every strategic lay forum meeting to understand and support the Trust's work.

We support:

- The analysis which demonstrates that patient groups that do not attend procedures and treatment are significantly overrepresented in certain minority ethnic communities and those from the poorest areas. We supported the co-designing of actions to address this with people from these communities and have encouraged the inclusion of patient-focused measures to assess the impact of these actions on individuals from these communities. We will be supporting and monitoring progress throughout the year.

- Work to overcome the barrier to access and understanding provided by our current patient information and letters. Patients who do not have English as a first language have told us how hard it is to understand the letters and messages they receive and how difficult it is to plan and reschedule appointments.
- The Trust's decision that the project to review and improve patient interpreting will be co-designed with the appropriate communities. The project has now completed its first stage and we support continued co-design with our local non-English speaking groups as we move to the next stage.
- The development of a clear framework for patients and visitors on our approach to reducing discrimination in all forms. We have worked with staff network representatives to learn about the work they have been leading on race equality and to identify learning. Over the next year, we will be exploring the synergy between the work undertaken by the Trust on issues of equality and diversity for its own staff and extending it to patients and communities.
- Inclusive and consistent co-production with patients, users and communities on the redevelopment of our hospital sites, as soon as we have approval to progress these vital developments.
- The development of research focussed on our communities' needs, to address the issues raised by the pandemic and subsequently which have user/public involvement from the affected communities throughout the life cycle of the research – from setting the priorities to research design, access to the research itself and its review and publication. We have agreed to set joint goals with Imperial College London and are considering with them how we can better co-ordinate research involvement and engagement and enable greater diversity amongst those who take part in research trials.
- Further work, particularly on prevention and wellbeing, which supports community public health. By linking with the community engagement programme and the patient interpreting improvement project, there is potential to use existing programmes to promote greater health awareness and prevent poor health.

Lay partner programme development

In addition to our input into Trust business planning, we will continue to support the development of our lay partner community. We welcome the fact that this year we have additional staff support so that we can increase the number, diversity and effectiveness of our lay partners.

This year we will:

- Increase the size of our lay partner community to meet the increasing requests for lay partner involvement from staff and be strategic about where we offer lay partner support across the Trust.
- Increase the diversity of lay partners.
- Provide better support for lay partners and more systematically shared learning between us.
- Link and collaborate with other, similar roles such as patient safety partners and patient representatives, so that our knowledge is shared as widely as possible.