



Patient and public involvement: annual review and priorities

**Report from the Trust's strategic lay forum
September 2019**

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1. Welcome

Each year, the Trust's strategic lay forum publishes a review of progress against our patient and public involvement strategy, a summary of activity and impact, and priorities for the coming year.

This report is our third following the adoption of the Trust's patient and public involvement strategy in July 2016. The strategy sets out the ambition and approach to become a genuinely patient-centred organisation and was the first output of the Trust's strategic lay forum.



Involvement is a way of working

Patient and public involvement is about enabling our patients, users, carers and communities to have a voice in our care and wellbeing and working with committed staff to deliver truly patient-centred care.

From a Trust perspective it incorporates all of the activities and ways of working that help us focus on understanding and meeting the needs and preferences of the people who use, or may use, our services. It is not a single function or something offered by a particular department but rather a way of thinking and behaving embedded at all levels of the organisation.

Good progress and ready for the journey ahead

Three years into our strategy, we're pleased with the progress we've made but also aware there is much more to do. Two recent publications usefully frame our ambition. The first is the NHS Long Term Plan, launched in January, and putting patient involvement at the heart of the future direction of travel for the NHS nationally. The second is the Trust's own refreshed organisational strategy, adopted in July following significant lay partner input, setting out an ambition for the Trust to become the most 'user-focused' organisation in the NHS.

We want this report to provide a full picture of patient and public involvement at the Trust – both strong examples of positive change and meaningful collaboration as well as the challenges and barriers experienced by lay partners, patients and staff.

Building a strong foundation for involvement

This report is set out under the four workstreams of the strategy – building involvement infrastructure, awareness, systematically acting on feedback and patient ownership of health and wellbeing. We have focused initially on the first two workstreams and so this is where most progress has been made so far.

Focus for 2019/20

With this solid foundation and clear direction set by national and Trust strategies, we look forward to embedding patient and public involvement further. Our vision is for

patient and public involvement to be 'business as usual' in all parts of the Trust and for it to be consistently high quality and impactful.

Therefore, in 2019/20, the forum is focusing on capturing the impact of involvement so that we can better share the value and insight it creates. We are also doing more to ensure we hear the views and preferences of seldom-heard groups and individuals, including those who haven't traditionally been included in healthcare decision making. We also want to use patient feedback and experience data to actively guide improvements, particularly in response to complaints.

We also look forward to continuing the collaboration around key plans for the Trust this year, particularly implementing the Trust's refreshed organisational strategy and much needed estates redevelopment.

Leading the strategic lay forum

The strategic lay forum was established in November 2015 and first chaired by its founder, Michael Morton, a very experienced and dedicated lay partner who sadly passed away in November 2018. I'm honoured to have been selected to build on Michael's achievements, taking up the position of chair in February 2019. I'm joined by 11 other lay partners as well as senior staff from around the Trust to form the strategic lay forum.

I am really pleased to volunteer my time to develop truly patient-centred care and am very grateful for the commitment, time and dedication of all our lay partners, patients, volunteers and Trust staff in reaching this important goal.



Trish Longdon
Chair of the Trust's strategic lay forum

The Trust's new strategy sets an objective to have a systematic, evidence-based approach to building two-way relationships with as many people as possible, offering a range of engagement and involvement opportunities.

2. Executive summary

This is the third report from the forum following the adoption of the Trust's patient and public involvement strategy in July 2016. While there is still much to do, this review highlights openly the key challenges and barriers, as well as achievements – a positive sign in itself of the progress the Trust has made.

Infrastructure, awareness and engagement

In the past year, we have seen our approach and ambition for patient and public involvement at the core of two important strategy documents: the NHS Long Term Plan published by NHS England and the Trust's own organisational strategy, which include the ambition for the Trust to become the most 'user-focused' organisation in the NHS. This combined with work to develop and embed the Trust vision, values and behaviour, has cultivated a positive and Trust-wide foundation where we expect patient and public involvement to continue to progress.

Lay partners – and the strategic lay forum – were closely involved in the development of the Trust's strategy and directly influenced its content. A small but very significant demonstration of that influence was when one of our three strategic goals moved from 'to help create a high quality integrated care system *for* the population of north west London' to 'to help create a high quality integrated care system *with* the population of north west London'. This small word change hardwired collaboration into our organisation and the collaborative approach further developed specific changes we expect to see to help us deliver that goal.

Other highlights from the past year include achieving the current total of 66 lay partner roles supporting 26 major Trust projects, two Trust-wide reference groups helping to guide communications and digital developments and an increasingly strong and effective strategic lay forum working in collaboration with Trust leaders and senior staff. When including completed projects, we have established a total of 75 lay partner roles since 2016.

We have also continued to embed and develop the strategic lay forum and its wider influence. Last year, we formalised the role of chair and the new role of deputy chair and followed a clear and open process to select, respectively, Trish Longdon and Ceema Namazie. They both attend our leadership forums. The whole strategic lay forum has an annual planning day, involving the Trust chair along with a number of executive directors, to input into Trust business planning. Our chief executive also meets with the chair and deputy chair every six months. These regular meetings help ensure our forum keep well informed and that we collaborate around genuinely shared goals.

In 2018/19, the forum advised and/or fed back on the following projects:

- the 'care journey and capacity' project, looking at how patients move through our hospitals, from A&E through to discharge
- the Trust's vision and strategy
- introduction of physicians associates

- revalidation of doctors
- review of Imperial College London's medical school curriculum
- our quality account
- the leading change through vision, values and behaviours programme
- physiotherapy and HIV inpatient service pathway changes
- revising quality metrics for our estate as part of the PLACE assessments.

We aim to have two lay partners on each major Trust project and now have more diversity amongst our lay partners in terms of age, ethnicity and working status. We have made more effort to engage working-age lay partners who aren't regular patients and those from black, Asian, minority ethnic (BAME) or seldom-heard groups. We also have two 17 year old lay partners contributing to our adolescent 'big room'.

The review highlights some positive examples of how they are impacting our work. We're also working to develop our lay partner community through networking breakfasts and training. Over 50 lay partners attended networking events last year and 14 have taken part in healthcare training courses.

Later this autumn, we will launch the updated and expanded patient and public involvement toolkit for staff. To date, 186 staff have taken part in patient and public involvement training to support quality improvement, delivered by the quality improvement team and the head of patient and public partnerships.

In July, we awarded the first Michael Morton patient and public involvement award as part of our annual 'make a difference' staff recognition awards. The winner and shortlisted projects are highlighted in this report. This new award is now one of five awards presented annually and is a fitting way to remember the first chair of our strategic lay forum who passed away in November 2018. Michael was a very dedicated lay partner and key in establishing the strategic lay forum.

Our National Institute of Health Research biomedical research centre (BRC) also has an advisory panel which provides strategic input into the BRC's research. A lay chair, Sandra Jayacodi, was appointed to lead this panel which is run by the Imperial Patient Experience Research Centre (PERC). PERC also has also been piloting new patient and public engagement methods. Four 'people's research café' events were held throughout the year and 212 people gave feedback directly to researchers in response to their research proposal.

The Trust's involvement team and PERC are also collaborating and working together more, especially around developing the Imperial Health Knowledge Bank (more information is on page 22)

Systematically acting on feedback

We have not focused as much on this workstream to date as we have prioritised actions to establish and raise awareness of the patient and public involvement approach more generally. Good progress has been made with the pilot to use AI to

create real-time sentiment analysis of the friends and family test to guide local service improvements supported by Imperial College and with the coproduction of a patient reported experience measure (PREM) for lung fibrosis. We will be exploring how we can help share and expand these approaches across the Trust.

Patient ownership of health and wellbeing

This is another undeveloped workstream though there are many examples of positive developments across the Trust that need to be shared and pulled together as part of a more proactive strategy linked to our goal around integrated care. Developments include the Care Information Exchange, the neonatal family care app, Connecting Care for Children, Café hab, and many of the nominations for our first patient and public involvement 'make a difference' staff recognition award.

Priorities for 2019/20

The report also summarises the priorities for involvement in 2019/20 as:

- measure the impact of the strategic lay forum and implement an evaluation plan to benchmark lay partner involvement in future years. We will also demonstrate the positive difference PPI makes through promotion and case studies
- further established our lay partner programme, actively promoting the opportunity to people from black, Asian, minority ethnic or seldom-heard groups
- prioritise lay partner involvement in the top 20 strategies and build the lay partner community. We will learn from, and support, all lay partners working across the Trust
- focus our work on issues raised by users and communities through reviewing complaints and patient feedback
- scope a project to reduce health inequalities and involve seldom heard groups.

3. Background

The strategic lay forum oversees the patient and public involvement strategy and sets a clear vision for effective patient and public involvement within the Trust. Its role is to ensure the Trust takes a patient-centred approach to policy, planning and strategic developments. It is led by a lay chair as well as 11 additional lay partners plus senior staff from across the Trust and its key partners – communications, improvement, patient experience, integrated care, governance, quality and safety, Imperial Health Charity and Imperial College London. Along with this annual review to the board, the forum provides quarterly reports to the Trust’s executive committee.

Our patient and public involvement strategy

Our approach to, and priorities for, patient and public involvement cover a wide spectrum of work that strives for collaboration, patient-insight and feedback throughout the Trust, at all levels of decision making.



The vision for the strategy is for:

- all patients to feel that they are understood, heard, and have control and choice over their health and care
- patients, families, carers and local residents to feel encouraged and supported to take an active role in their own health as well as shaping and delivering care
- a core pool of patients, carers and local people to be able to directly influence our organisational strategies and major programmes to help ensure we are making the best use of all of the insight, skills and knowledge available to us.

Patient and public involvement strategy workstreams

To implement the strategy, we have the following four workstreams:

1. Patient and public involvement infrastructure – developing processes, policies and resources
2. Building awareness and engagement – including a ‘keep in touch’/involvement offer
3. Systematically acting on feedback – meaningfully responding to feedback and acting on comments as part of business as usual
4. Patient ownership of health and wellbeing – to support new approaches to care that encourage and enable everyone to stay as healthy as possible.

4. Progress to date

4.1 Infrastructure – developing processes, policies and resources

Strategic lay forum

Throughout 2018/19 we continued to develop the strategic lay forum and its wider influence. It's now recognised as part of our Trust structure and, in addition to the agreed priorities and workplan, the forum has regular opportunity to input into projects and plans and long term Trust developments, such as the Trust strategy and three-year objectives.

Governance of the strategic lay forum

In early 2019, we further enhanced the governance of the forum by selecting a new chair, Trish Longdon, and establishing the role of a lay deputy chair. This role is carried out by Ceema Namazie who has been a lay partner on the forum since early 2016.

Engagement and partnership with senior Trust leaders

Trish Longdon and Ceema Namazie, the chair and deputy chair of the strategic lay forum, now attend the Trust's twice yearly leadership forum, working alongside senior Trust staff to directly shape strategic developments and receive briefings on upcoming plans and challenges.

We also have an established process to engage the forum in annual planning. Each year, in quarter four, we have a day-long workshop involving executive directors and the Trust chair. The agenda covers sessions on the organisational strategy, financial reporting as well as the strategic lay forum's progress and priorities for the year ahead. In February 2019, the Trust's new chair, Paula Vennells, attended and heard first-hand the forum's views on staff morale, integration and use of digital technology.

In addition to the annual workshop, the chair and deputy chair of the forum also meet with the Trust's chief executive, Professor Tim Orchard, every six months.

These regular meetings help ensure a well-informed strategic lay forum focused on achieving shared goals through collaboration. In this way, lay partners on the forum

are able to fulfil the role of a 'critical friend', constructively challenging and supporting Trust staff.

Strategic lay forum input

In 2018/19, the forum contributed to the development of the following projects:

- the 'care journey and capacity' project, looking at how patients move through our hospitals, from A&E through to discharge
- the Trust's vision and strategy
- introduction of physicians associates
- revalidation of doctors
- review of Imperial College London's medical school curriculum
- the quality account
- the leading change through vision, values and behaviours programme
- reviewing the physiotherapy and HIV inpatient service pathway
- revising quality metrics for our estate as part of the PLACE assessments.

While it's a measure of activity, not impact, requests for time on the forum's agenda have increased significantly. This had led to thorough consideration of where the forum focuses its efforts, shared agenda planning and an emphasis on meaningful engagement and co-design. We're careful to avoid tick box exercises or show and tell type presentations where there is limited scope to comment or if the forum is just being involved in successful developments.

Developing our strategy and putting collaboration in our 'DNA'

One consistent area that the forum has been involved in is the development of the Trust's organisational strategy. This was achieved by sharing and co-designing the strategy as it developed over 18 months and continually taking on comments and suggestions as it progressed.

Input and improvements offered by the forum focused on language, articulating what integrated care would feel like for patients and what would actually change, as well as robust challenge around how the Trust works with other providers, CCGs and GPs to deliver integrated care.

A small but very significant demonstration of lay partners' influence was when they ensured one of our three strategic goals moved from 'to help create a high quality integrated care system **for** the population of north west London' to 'to help create a high quality integrated

care system **with** the population of north west London'. This small word change hardwired collaboration into our organisation and the collaborative approach further developed specific changes we expect to see to help us deliver that goal.

Collaborative 'big room' approach to strategy

Flow coaching is a well-known healthcare approach that aims to empower frontline staff to improve care for patients and minimise delays as they move through stages of care, from ward to home. Coaches take part in a year-long training course and, when completed, lead a weekly 'big room' to facilitate improvements.

Big rooms are collaborative open spaces for members of staff and lay partners involved in a particular clinical pathway to develop, test and embed improvements. Each big room starts with the patient story, which is an important way to focus and reflect. We've worked hard to have as many lay partners as possible join big rooms and really pleased that four could take part in the weekly strategy big room. We've also enabled dial in video conferencing and held strategy big rooms in tandem on our other sites to engage as many staff as possible.



More open and transparent strategy development

"Like many trusts, we're working on our organisational strategy to meet the future needs of our patients, communities and local population, and the ambitions set out in the NHS long term plan. To do this, we opened up the process and took a more collaborative approach than ever before. We involved our strategic lay forum, patients and lay partners from the very beginning and through setting up a 'big room' also involved many more staff. Without this collaboration, support, reflection and helpful challenge, I'm very confident we wouldn't be as far along nor as ambitious in the development of our organisational strategy."

Dr Bob Klaber, consultant paediatrician and deputy medical director



Lay partners

Lay partners are members of the public, often patients, former patients or local community members, who volunteer their time to work in partnership at a strategic level with staff to ensure we have listened to, understood and responded to what patients and the community want, need and prefer. They do not represent patient views themselves but are there to ensure relevant patient views are taken into account.

They join our programme and project groups as equal members to provide external points of view and constructively challenge as critical friends.

More diversity and the highest number of lay partners

Including the 12 lay partners we have on our strategic lay forum, we have 66 lay partner roles across 26 projects and programmes. These include projects such as catering and transport tenders, 'big rooms' and improvement and transformation programmes.

We currently have 66 lay partner roles across the Trust on 26 projects. To date we've collaborated with 75 lay partners on active or completed projects.

We aim to have two lay partners on each major Trust project and now have more diversity amongst our lay partners in terms of age, ethnicity and retired, a full time student or employed. Many of our lay partners have been retired professionals looking to volunteer 'with their brain' and we have made more effort to engage working-age lay partners that aren't regular patients or those from black, Asian, minority ethnic (BAME) or seldom-heard groups ensure we have a range of views. We recently introduced two 17 year old lay partners to our adolescent big room that looks at improving the transition when teenagers move from children's to adults' services.

During 2018/19 we welcomed lay partners on many new and transformational projects. These include the:

- end of life project focusing on palliative care
- new invasive procedures committee that reviews first use of new devices and medical procedures in the Trust
- care journey and capacity looking at how patients move through the hospital, from A&E onwards, to receive the right care
- high-value tenders for beds, catering, cleaning and portering, which have a huge impact on patient experience

- men's health, a project looking at how we link and explain health services for men such as urology, cardiology, mental health and fertility to offer more cohesive care for men.

Lay partners can unite us and say things we can't

There are many positive anecdotes and stories about the value lay partners bring. Numerous times Trust staff have fed back that just by lay partners taking part, we change how we think and behave as it is an effective way to unite the Trust and bring external views into the room.

Lay partners see things we don't

"We have lay partners on our end of life project to improve care for people at the end of their lives across the Trust. We've just started working with lay partners and already they bring new perspectives and suggestions we hadn't considered. Working with lay partners requires time and investment as you have to brief them and build a relationship where you can trust and challenge each other but, from my experience, it's invaluable."

Dr Katherine Buxton, consultant in palliative medicine and clinical lead for end of life care

While anecdotes and short case studies are positive, we're aware more needs to be done to evaluate, benchmark and celebrate the positive influence and change lay partners enable. This is why it's one of the key priorities of the forum this year.

Putting the patient at the centre

"I'm the secretariat for our new invasive procedures committee, a group that reviews and approves the first use of new medical devices or procedures in the Trust. It can be a technical meeting with a focus on sophisticated devices and medical terms but by having lay partners in the room and hearing their views, we automatically change our thinking and always consider what these development in medicine, however clinically brilliant, might feel like for patients. It's a simple way for us to see the whole picture."

Trish Bourke, safety and effectiveness team

Developing our lay partner community

We want to continue to build our lay partner community so they feel connected, supported and informed to meaningfully engage and helpfully challenge the Trust. This year the Trust held breakfast networking seminars to create a lay partner community. We offered training and briefings so lay partners can gain a better understanding of Trust priorities and get to know Trust staff leading the projects.



In November 2018 and April 2019, over 50 lay partners and staff attended to hear updates about the Trust, give feedback and take part in relevant training. We introduced lay partners to founding principles of quality improvement and held a workshop for them to feed into and comment on our developing organisational strategy.

The Trust also offered training opportunities for lay partners at The King's Fund and Royal Society of Medicine events, including a relevant short online course. To date, 14 lay partners have taken part in these training opportunities.



Lay partner training and support

“It is early days for me but the induction afternoon was very informative and helpful. I look forward to being more fully involved. The ‘working with patients for safer care event’ at the Royal Society of Medicine was a fantastic immersion.... I’d welcome going to more events like this. I also appreciated being directed to the NHS explained online course.”

Tanya, lay partner

Reviewing and improving lay partner induction

This year we improved our briefing and induction process for lay partners and invested much more time in ensuring lay partners receive thorough briefings and face to face introductions with Trust staff that lead the respective projects they’re joining. We recognise the effectiveness of this collaboration is grounded in the lay partners and Trust staff knowing and trusting each other and this can only happen if they have a good working relationship.

Trust staff also need support, guidance and reassurance that collaboration with lay partners will work. Collaboration like this is a step change in how we work and for the first three years, we quickly engaged lay partners on projects where managers were open and natural innovators in terms of change. Now we need lay partners on all appropriate projects so it becomes business as usual and we continue to encourage the critical mass of staff to incorporate this form of collaboration.

As part of our induction the strategic lay forum chair and Trust involvement lead now also spend more time with Trust managers and meet with them to reflect and support their collaboration with lay partners.



Enabling staff at all levels

“In my role I can see the challenges of involving patients for ward managers and front line staff. They can feel unconfident, it’s a new relationship, and it’s hard to make time amongst other pressures. Everyone agrees it’s good to do but hard to make happen. In our division we set up a working group focused on sharing ideas and support with senior nurses and ward managers. It’s a good way for the division to get corporate support. We’ve identified a few projects, so we’re going to start in a small way and build it from there.”

Jo Fisher, deputy director of nursing for surgery, cancer and cardiovascular

Research

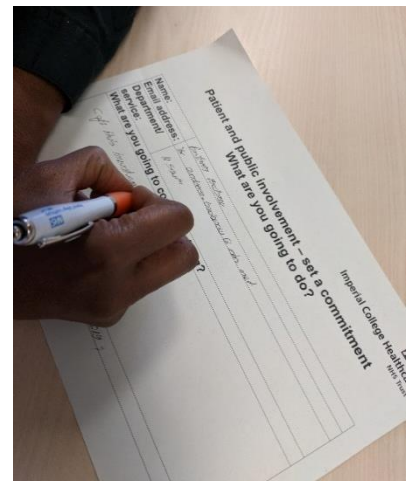
Our NIHR biomedical research centre (BRC) also has a public advisory panel which provides strategic input to the BRC's research, ensuring effective involvement and engagement of patients and the public. A lay chair, Sandra Jayacodi, was appointed to lead this panel this year and represents the panel on the Trust's research committee. This aspect of patient and public involvement is led by the Imperial Patient Experience Research Centre (PERC), funded by the BRC.

PERC has been piloting new and flexible ways of working with members of the public, including a 'people's research café', where researchers talk about their project ideas at the café meetings with the community and ask the public for feedback and advice. Four of these cafes have been held so far, with 212 people providing really valuable input into shaping our research.

The Trust's patient and public involvement team and PERC are building much stronger links and integrated working, especially around the development of the Imperial Health Knowledge Bank (see page 22).

Supporting and enabling staff

This year we continued to offer patient and public involvement training to staff which is led by the quality improvement team. This is a 90-minute session that gives an overview of the principles and practical advice on types of involvement as well as highlights of recent case studies in the Trust. All participants are also now encouraged to make a commitment to take on their own small project to involve patients and the public after their course. Since April 2018, 37 people have completed this short course and 149 completed it as part of a four day quality improvement coaching course.



Staff cite knowledge, confidence and time as some of the barriers and challenges to involving patients. When time and resources are pressured, it can seem like another task. We know there is more to do to build confidence and focus on the value patient involvement brings.

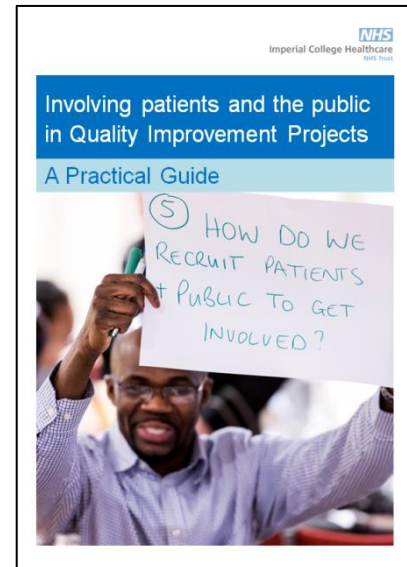
PERC and the Imperial Clinical Trials Unit also provide training on public involvement specifically on research. In 2018/19, they trained 140 researchers and members of the public through 14 sessions co-delivered with public partners. PERC also offers small grants to researchers for public involvement projects.

Involvement toolkit for staff

In February 2018 we published our first patient and public involvement toolkit for staff. It was developed by the improvement team to give practical advice on how to carry out a variety of involvement activities. This was reviewed and updated through co-design workshops with staff and patients to include more case studies, contacts for support in the Trust and advice on where to go for more information. This updated version will be finalised in autumn 2019.

Moving beyond lay partnership

Lay partnership, while bringing significant benefits, is not the only approach required to ensuring we are a genuinely patient focused organisation. It's not a role that suits everyone.



Patient voices need to be heard and their preferences and needs understood, at all levels of the Trust and we need a variety ways of doing this.

Clinic 'walk throughs' to test new ideas with patients and the public

During the year we introduced some simple methods for patients to provide feedback that could easily be used more widely. The hand therapy and plastic surgery team wanted to improve the experience and waiting times for patients with carpal tunnel syndrome. To test the idea of a 'two stop' clinic they organised a 'walk through' of it with patients, members of the public and staff. The benefit of the new clinic will enable patients to have their consultations and nerve tests on one day and then return for their surgery, rather than have various appointments for consultations and diagnostics and wait much longer for their treatment.

The initiative took a few hours to organise and 90 minutes to carry out. It involved the whole team physically walking through the new clinic set up, from arriving at Charing Cross Hospital to leaving the fracture clinic, and raising any concerns or queries they have at each stage. This feedback completely changed the patient information that was prepared. Important points such as including how long patients were likely to spend with each clinician to reduce pre-clinic anxiety were identified. Previous information focused on the condition and treatment however the service found that patients wanted to know about the process, waiting times and what's going to happen when. The initiative resulted in a more streamlined patient-centred process.

“It was invaluable having clinical and admin staff, patients, members of the public and communications support all together to walk through the proposed clinic. Trust staff thought the information was clear and straight forward and it was crucial to get ideas for improvement at the start so we could build them in now rather than unpick things later.”

Joelle Chalmer, clinical lead for hand therapy and quality improvement lead for therapies

“Walk throughs should be embedded as part of any service development. It’s a culture change as we have to be open but is a very effective way of developing patient information.”

Joanne Pitumpe, patient information manager

Trust wide reference groups

We have two reference groups that focus on a particular theme or part of the healthcare journey: a digital group that focuses on how we embrace and use digital technologies; and a communications group, that comments on written communications and patient information.

The digital group has 20 members and met four times this year. It gave useful feedback on how we set up clinicians having mobile access to electronic patient records and what concerns patients would have regarding this. They also fed into the requirements for a supplier tender for Care Information Exchange and provided a patient voice at other meetings and events. Members attend the digital quality improvement big room and digital showcase presentations.



The patient communications group meets annually and has fortnightly email contact to review and feedback on patient information leaflets and wording. Recently the group improved the wording for ‘did not attend’ letters and information about outpatients appointments on our website: <https://www.imperial.nhs.uk/patients-and-visitors/patient-information/outpatients>

We need external views on the language we use

“It is great that we have a way of getting views from patients before publishing documents that affect them. The suggestions from the patient communications reference group have been so useful – they create information that is valuable for our patients. At the end of the day, we run a service for them, and we need to know what they think!”

Chandni Mehta, business manager for outpatient clinics

4.2 Building awareness and engagement

We're aware that if we want patient and public involvement to be an integral part of the Trust, we need to continue to increase its visibility and promote the opportunities for patients and the public to get involved.

Communications to Trust colleagues

In 2018/19 we tailored quality improvement training to include case studies and practical examples of effective patient and public involvement to showcase the valuable insight involvement enables. We also used this opportunity to inform staff about collaboration with lay partners and using the Trust reference groups to provide feedback on written information and the use of digital technology.

The new Trust intranet enabled an effective way to give staff easy access to the patient and public involvement toolkit, contacts, guidance and templates to reimburse patients for expenses. We also promoted our lay partners through our staff twitter account, @imperialpeople.

The head of patient and public partnerships also supported our cancer and surgery division to set up their own involvement project group. This included face to face support and guidance for senior nurses so they can implement local involvement projects.

During the year, the Trust developed a behavioural framework based on our values of being kind, collaborative, expert and aspirational. It articulates desirable and undesirable examples of behaviour and its detailed explanation of collaborative is especially relevant to patient and public involvement. This long-term programme is still underway and is key in supporting a culture change necessary to meet the ambitions set out in the Trust strategy.

In 2019/20 we will continue to promote involvement and patient-centered care to our Trust colleagues and see the further work being carried out around vision, values and behaviour and our Trust strategy as further opportunities to incorporate this goal.

External communications

It's important we share information about all the work that has been done to build the involvement infrastructure at the Trust and share involvement opportunities.

Information about involvement is available on our website and to promote our lay partner opportunities we interviewed and filmed some existing lay partners. This short film will be completed in autumn 2019. It will explain the role and include views and comments from staff about how we collaborate and what it feels like to work with lay partners.

Events are also a great way to engage our public. The lay partner networking breakfasts, outlined on page 14 were an effective way to share news on new projects.

We also held an open day at Charing Cross Hospital in October 2018 to celebrate its 200th birthday. This large-scale event was attended by around 1,000 people and enabled staff to showcase services to the local community. It included activities for children, information on jobs at the Trust, historical and clinical visits giving behind-the-scenes tours and education talks.

As an organisation we know there is more to do in terms of community engagement and we see our Trust strategy as one way to develop it. As part of the strategy, we've set some goals to work with partners and to consider our potential as an 'anchor institute' – an organisation that contributes to the local economy beyond its main function, for example, in terms of employment, purchasing power, offering free use of site facilities. Again this is another opportunity we hope to harness in the coming years.

New staff award for involvement

In July this year, we awarded the first Michael Morton patient and public involvement award as part of our high profile 'make a difference' ceremony for staff. This new award is now one of five awards presented annually and a fitting way to remember the first chair of our strategic lay forum. Michael was very dedicated and passionate about integrated care. He was key in establishing the strategic lay forum and fully engaged in many initiatives within the Trust, fulfilling his role as a critical friend right up until his sad passing in November 2018.

The award was co-designed with our strategic lay forum who endorsed the criteria and the forum's chair and deputy chair, Trish Longdon and Ceema Namazie, were two of the judges. It recognises the hard work, dedication and achievements of staff to improve the outcomes and experience of patients through involving patients and co-producing improvements.

The four finalists

We were pleased there were eight strong award nominations to consider and look forward to this award becoming established as we further embed the principles of involvement. Read more about the winning project and finalists below.

Winner: Café hab

Patients from our inpatient neuro rehabilitation unit reported anxiety about going home, with little to do around therapy sessions and few opportunities to speak with others who have gone through a similar experience. 'Café hab' is a weekly coffee morning at a local coffee shop and was set up to give inpatients practical and real life experience of handling money, ordering food and traveling by public transport again in an appropriately supported way. It also gives patients invaluable opportunity to

socialise with other patients and to work towards individual therapeutic goals. It is now a permanent feature and a well-attended part of our rehabilitation programme.

Runner up: Parkview Olympics – designed by families to reduce childhood obesity in White City

Through GP practices and the Trust's Connecting Care for Children Service, children and families collaborated with healthcare providers and developed their own solution to reduce childhood obesity. Together they created Parkview Olympics, a series of physical activities and informative sessions, to introduce the concepts of health and nutrition to children and teenagers. The initiative connected local sports and food education providers to host the activities and created a low-cost, sustainable annual event.

Friends and family test language analysis

The friends and family test is a short survey patients complete after each appointment or treatment with the Trust. Each month it creates about 20,000 free-text patient comments – a rich source of information but so large it is difficult to analyse due to the time required to read, categorise, and use the comments to drive and evaluate improvements. A cross-organisational team from the Trust, National Institute of Health Research Patient Translational Research Centre and Imperial College London, as well as patients used machine learning to quickly analyse these free text comments into themes for action which are already driving improvements. The project team also included a lay partner who inputted into the analysis approach. While this project is in its infancy, it has potential for the Trust to become more user-focused by being able to rapidly respond to patient feedback.

Airway stenosis

Airway stenosis in adults is a rare and chronic condition which causes the narrowing of the airway and can lead to secondary health issues that require intensive support. We provide the largest service of its kind in Europe, treating over 70 new patients a year. Since early 2016, the multidisciplinary team have been co-designing the service pathway with patients to ensure that we offer the best possible care and support. It has led to more emotional support for patients to deal with this life changing and chronic condition. Patients have also joined clinicians when presenting at national conferences to show the importance of working in partnership.

Systematic approach to engagement by 2023

As outlined in our organisational strategy agreed by the Trust board in July 2019, we will establish a systematic evidence-based approach to building two-way relationships with as many patients and local people as possible.

This will set up a sustainable and long-term approach that will link together our various involvement opportunities, such as attending events, volunteering, fundraising, providing feedback, taking part in research and lay partnership, as a cohesive offer that we will actively promote to our communities. This report covers the limitations of the lay partner role and the premise of this offer will be a co-

ordinated spectrum of involvement and engagement opportunities that appeal to a wide demographic of people.

We have worked closely with Imperial College and the BRC's patient experience research unit on the development of a new initiative, Imperial Health Knowledge Bank.

Imperial Health Knowledge Bank brings together our patients, clinicians and researchers to increase understanding of health conditions, detect diseases earlier, develop new tests and treatments and improve clinical training. It is a database of individuals who are interested in taking part in relevant research studies and who allow us to store biological samples for research and teaching. We have just begun testing different approaches to recruiting patients to the Knowledge Bank to understand what encourages or discourages patients from consenting. We are trying small scale recruitment via a direct approach from consultants in outpatient clinics and from non-clinical 'floorwalkers' approaching patients in outpatient waiting rooms to explain the offer. We are also looking to understand how best to scale up our recruitment approach and to develop a sense of community for Knowledge Bank members, potentially extending to a wider group of patients and local residents who are interested in getting involved in a variety of ways.

3.3 Systematically acting on feedback

When setting this workstream, we were aware it required our previous workstreams of infrastructure and awareness to be well established. It needs both robust processes and an organisational culture of collaboration and transparency where quality improvement can rapidly thrive.

As expected, this workstream is still developing but in 2018/19 we have made positive and sustainable progress on moving towards an integrated approach to use meaningful feedback to identify, prioritise and evaluate improvements.

Our quality improvement programme and vision, values and behaviour work mentioned previously in this report, have been key in setting a foundation so we can systematically act on feedback.

Large-scale feedback from all patient demographics

"As a Trust, we've done a lot to involve our public over the last three years. It's also fantastic to have more lay partners, fledgling projects and transparency about the challenges on what needs to change. However for us to be truly person-focused, we need to refocus the organisation and enable ways to capture large-scale feedback from all patients, not just those already engaged, and use it to inform improvements. If we really do put patients at the centre of our organisation, we won't need a patient and public involvement strategy and eventually I hope we don't. It will just be the way we do things."

Toby Hyde, deputy director of transformation

Friends and family test language analysis

As highlighted last year as part of this workstream, we have further developed the project to use machine learning to analyse the free text comments in the 'friends and family' survey. This project was shortlisted as part of the Michael Morton patient and public involvement award (covered in detail on page 20) and now in place at outpatients at the Western Eye Hospital and A&E and inpatient wards at St Mary's Hospital. This project also won the [Digital Innovation Team of the Year award](#) for their innovative approach to improving patient care through technology from the British Medical Journal.

Effective use of valuable patient feedback

"As an organisation, we collect a huge amount of feedback data and our challenge is to use it effectively to drive improvements based on what matters to patients. For me, as patients have taken the time to feedback, we have an ethical responsibility to use it well and am really pleased the work on sentiment analysis will enable this."

Stephanie Harrison-White, head of patient experience and improvement

Machine learning analysis has enabled us to make waiting areas more comfortable for patients, improve signage at A&E and create a 'ward discharge checklist' so patients avoid having to re-tell basic medical details when moving wards within the hospital.



Patient advice and liaison service (PALS) volunteers

PALS volunteers were developed in late 2017 with Imperial Health Charity and provide an important liaison role and point of contact for patients in wards. They deal with a range of issues for patients including clinical and non-clinical concerns. Some issues are resolved quickly and others are escalated to PALS for further follow up. All

feedback is shared with the clinical teams at the time and through these volunteers issues are resolved quickly effectively avoiding potential complaints.

We have 10 patient support volunteers at St Mary's in surgical, medical and post natal wards and will soon have them supporting patients at Charing Cross and Hammersmith Hospitals later in the year.

Dealing with patient issues

"PALS volunteers are a really effective way of improving patients' experience. They're on wards to deal with or direct any important patient issues. If they're clinical issues, they're escalated to clinical staff, but often PALS volunteers are able to deal with many patient queries or problems such as lost property or information about discharge."

June Parker, patient advice and liaison service manager

Co-designing experience measures with lung fibrosis patients

Patient reported experience measures (PREMs) are a way to quantify patients' perception of their personal healthcare experience. Through a co-design methodology, we developed a PREM which we're using to improve the care pathway and patients' experience of it. At each stage of the care pathway, patients feedback through a statistically robust questionnaire on areas such as empathy from clinicians, communication, how integrated the care was and physical and emotional comfort. This information will be used to improve the overall experience of the service but also to respond individually to a patient when their experience can be improved.

Patients, carers, relatives, support group professionals as well as clinical staff from a range of areas were involved in developing the PREM and this is one of the few services in the Trust using this approach. This work has also been highlighted nationally. We're sharing the developments, methodology and questionnaire with NHS England and their specialised respiratory commissioner to help inform national improvements to act on patient feedback for this chronic and life-changing condition.

Robust way to measure patients' experience

"Our patient reported experience measure (PREM) is an emerging tool to put some real rigor around measuring patients' experience of our care. It will shape our service and quantify the things that really matter to patients. It's already informed changes to improve information to patients and how we measure patients' knowledge of their condition. We will present our data at the European Respiratory society conference this year."

Dr Mel Wickremasinghe, respiratory consultant

3.4 Patient ownership of health and wellbeing

We've continued to develop projects and initiatives that promote patients taking an active role in their health and wellbeing such as Café hab and Parkview Olympics covered on page 20. These are projects that move away from the historical patriarchy of medicine where traditionally patients have been compliant and follow instructions given to them by clinicians. Patient ownership aims to share information and power so that members of the public have agency and control over their health.

A related, and perhaps further developed, concept of this is shared responsibility for health where patients and clinical staff both have duties to agreed health goals. In developing the system changes to meet the future health demands, [The King's Fund](#) argues that this cultural shift is one of the biggest challenges facing the NHS and explains that a patient's knowledge of and their capability to self-manage their own condition, in particular chronic conditions, affects their health outcomes.

While this is an integral part of our patient and public involvement strategy and we support the innovative projects below, we know more needs to be done to establish a working culture where the below examples are the norm. It's a long-term goal and one the whole healthcare system is facing. We are confident however we have the right foundation, values and strategy to achieve this as part of our vision of 'better health, for life'.

Patient ownership is our long-term goal

"This goal is in line with our vision 'better health, for life' and while ambitious, something we're working towards. It's great to have trailblazing projects and we need to share and spread the basics of involvement across the Trust to build a foundation for this area to thrive."

Jo Fisher, deputy director of nursing for surgery, cancer and cardiovascular

As a major healthcare provider in north west London, we are also part of the Hammersmith and Fulham Integrated Care Partnership which aims to deliver integrated care for nearly 200,000 people living in the area. With our five other partners, we have developed three clinical workstreams looking at integrated pathways for children, adults and older adults. Since the very beginning of these workstreams, users and lay partners have been embedded on each one as part of the governance structure.

Further development of the Care Information Exchange

This online system funded by Imperial Health Charity provides secure access to medical records, blood tests, radiology results, appointment and clinic letters, future appointments and discharge summaries, empowering patients as they have access to and more control over their health records. It was launched in 2015 and last year

the number of patients able to see their appointments, test results and letters increased from 5,000 to 25,000. As part of our Trust strategy work, we are now leading work for it to become 'business as usual' and used consistently across our services.

Involving families in neonatal care

We were the first Trust in the UK to implement a model that integrates families in the care of their premature babies on our neonatal wards. Parents are trained by the multidisciplinary teams to tube feed, change nappies and take basic observations and take an active role in rounds by feeding this information back to the team. This is also supported by a mobile app featuring information and guidance. Putting parents at the forefront of their premature baby's care has been found not only to reduce anxiety in parents and their baby, but can also benefit the baby's medical progress and development. This approach has shown to reduce hospital stays for babies born at less than 30 weeks' gestation, by an average of two weeks. It also encourages babies to suck feed earlier, breastfeeding rates on the unit are high, and the baby's development is faster.

Resuscitation classes for parents and children

Our children's services team share important first aid training to increase public knowledge of these lifesaving techniques. In June 2019 three doctors went to a primary school in Willesden to give first aid and resuscitation training to over 100 year five and six children. It was so successful, they'll return next year to run a class for parents, sharing an important life skills that will stay with these communities. The team also hold monthly baby resuscitation classes for parents at St Mary's Hospital. Evaluation has shown that 92 per cent of the 217 parents reported feeling very confident using the skills.



5. 2019/20 priorities

With continued progress in all of the workstreams as part of the patient and public involvement strategy, we're confident positive and sustainable improvements are being made. We're aware it's a long journey to achieve the vision agreed as part of the strategy but one that has already shown enormous value and very significant learnings.

In 2019/20 the strategic lay forum will:

- measure the impact of the strategic lay forum and implement an evaluation plan to benchmark lay partner involvement in future years. We will also demonstrate the positive difference PPI makes through promotion and case studies
- further established our lay partner programme, actively promoting the opportunity to people from black, Asian, minority ethnic or seldom-heard groups
- prioritise lay partner involvement in the top 20 strategies and build the lay partner community. We will learn from, and support, all lay partners working across the Trust
- focus our work on issues raised by users and communities through reviewing complaints and patient feedback
- scope a project to reduce health inequalities and involve seldom heard groups.

We will also continue to build integrated working with Imperial Patient Experience Research Centre, particularly around involvement in clinical research.