# Imperial College Healthcare NHS Trust - patient and public involvement strategy

## Introduction

In November 2015, the Trust Board gave the go ahead to develop a strategy to enable more effective patient and public involvement. The agreed approach was clear in its aim to encourage and enable involvement in all aspects of our work to help us develop an organisational culture where everyone is attuned and responsive to our patients' needs as a matter of course.

Since the November board meeting, we have made some immediate improvements in our involvement approach, and have worked with patients, carers and local people to develop our longer term strategic vision, implementation work streams and action plan. In this document, we present both a summary of progress since November 2015 and our proposed five-year patient and public involvement strategy and implementation plan – for input and approval.

## Progress so far

### *Strategic lay forum*

We established our first strategic lay forum, under the chairmanship of Michael Morton, in November 2015. The forum now has 12 lay representatives with a wide range of backgrounds and experience. The connections our representatives bring with them, such as with the 'whole systems' work across north west London as well as with other strategic health and care developments, has been particularly helpful. The forum meets bi-monthly with senior staff members from communications, quality improvement, governance, patient experience and the Charity – and others, as required.

The strategic lay forum role is to help establish a clear vision for effective patient and public involvement across the Trust and to use that to guide and oversee the further development and implementation of the Trust's patient and public involvement strategy. It seeks to increase and enhance the role of patient and public involvement at all levels of the Trust. This includes the development of the strategic lay forum itself, looking to clarify and enhance the role of lay members in decision making, setting priorities and system collaboration. The forum also provides advice and feedback on the development and implementation of Trust strategies and major initiatives, especially with regard to ensuring they are appropriately shaped by the needs and preferences of patients and local communities. Significant improvements to two projects – the proposed changes to acute medicine and chest pain pathways and the phase 1 redevelopment of St Mary's Hospital – have already been achieved through the advice and support of the strategic lay forum.

### *Co-production of our involvement strategy*

With the strategic lay forum – and over 30 other patients, carers and local people identified through requests to service leads and partner organisations - we have run two 'co-design' events to produce our longer-term involvement strategy and implementation plan.

*Internal 'stock-take'*

We have been progressing an internal 'stock take' of patient and public involvement activities. We interviewed a number of clinical directors and followed up on a number of leads for staff who undertake or who have an interest in involvement activities. While there is a significant amount of involvement activity, it is generally undertaken on an *ad hoc* basis, there is a lack of clarity in terms of accountability for involvement, there is little oversight or evaluation, and the information and insights gathered are not shared.

There are, though, a number of service-specific patient fora (for example, in paediatrics, renal and haematology); good examples of involvement in specific improvement projects (such as the project to improve cancer patient experience run in partnership with Macmillan or the redevelopment of the St Mary's paediatric intensive care unit), and at least eight formal programme or project boards or committees that include lay representatives (including the Hammersmith and Fulham integrated health programme board, outpatients redesign project group, care information exchange project board). This internal 'stock take' will continue as part of the proposed strategy implementation.

Through the 'stock take', we also aimed to gauge interest and ideas for involvement activities amongst staff, primarily at a service and project level. Generally, there was a genuine commitment to involvement and a desire to have a more structured and consistent approach. The barriers appeared to be a lack of resource, no clear accountabilities, a sense that specialist skills were required and a lack of an agreed involvement infrastructure (for example, around the payment of expenses or how to 'recruit' patients fairly).

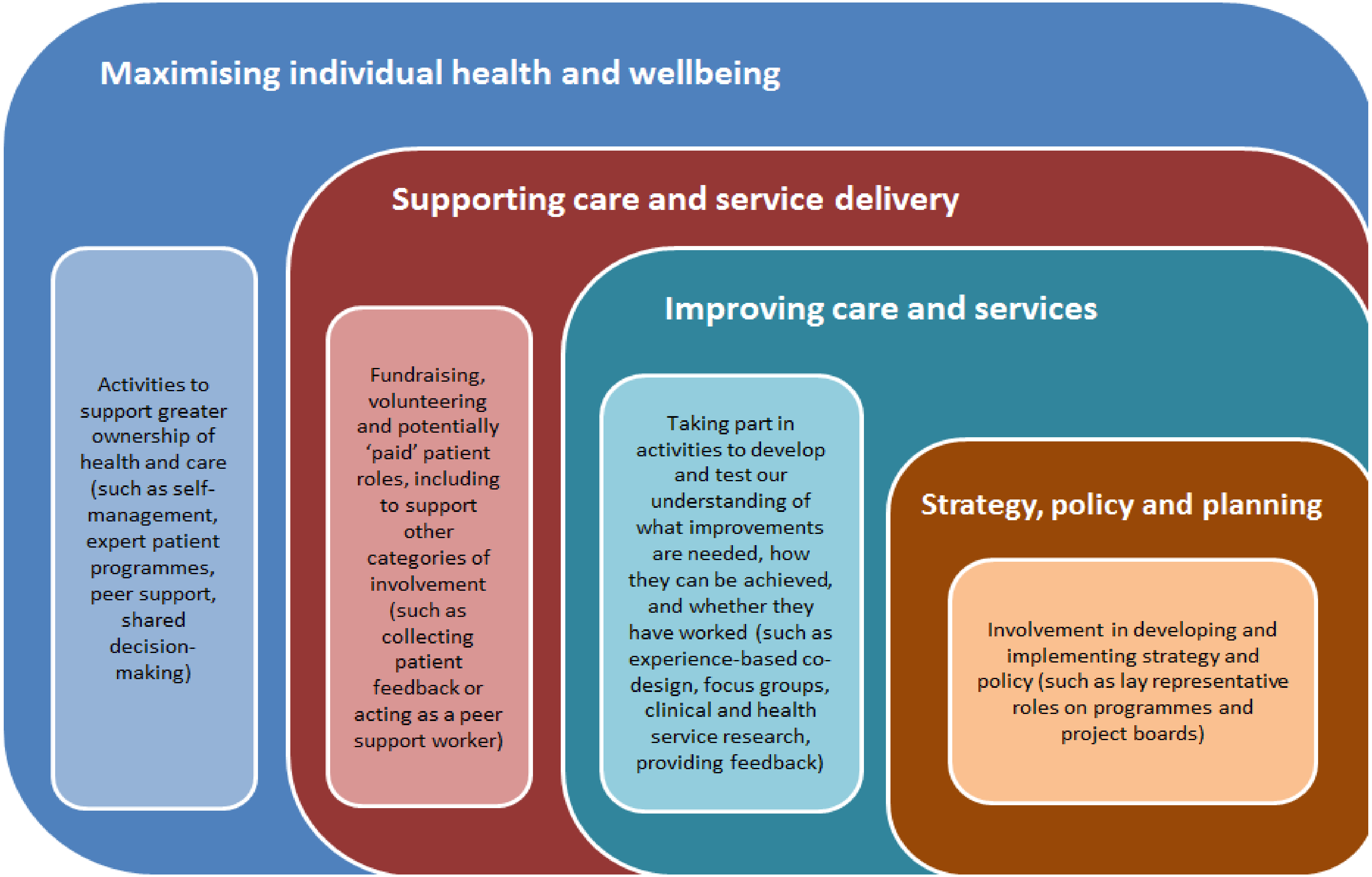
*Quality improvement*

The quality improvement (QI) programme, which was established at the end of September 2015, has a specific aim of supporting staff to deliver QI projects that are co-designed with patients, service users and local people wherever possible. A specific example of this has been the development of QI sprints. The idea behind these events came from paediatric emergency department consultant Dr Fran Cleugh, who first applied a 'hackathon' method developed in the USA in 2013 to support junior doctors in launching improvement projects. An adapted model is now employed by the QI team alongside a service design tutor from the Royal College of Art – in an intense, one-day facilitated workshop, teams of clinicians, patients, designers and other professionals investigate a problem that healthcare staff are facing in their daily working lives, generate ideas and come up with pragmatic solutions. The most recent QI sprint in July 2016 involved 56 participants. They looked at how to move to paperless outpatient clinics, how to increase awareness around self-administration of medication and how the existing poster campaign 'What matters to me' can be turned into a sustainable project.

*External links*

We have been exploring and building links between our involvement strategy and key partners, including Imperial College and the Patient Experience Research Centre, local commissioners and Imperial Health Partners, the academic health sciences network for north west London.

## Our five-year plan



**Maximising individual health and wellbeing**

Activities to support greater ownership of health and care (such as self-management, expert patient programmes, peer support, shared decision-making)

**Supporting care and service delivery**

Fundraising, volunteering and potentially 'paid' patient roles, including to support other categories of involvement (such as collecting patient feedback or acting as a peer support worker)

**Improving care and services**

Taking part in activities to develop and test our understanding of what improvements are needed, how they can be achieved, and whether they have worked (such as experience-based co-design, focus groups, clinical and health service research, providing feedback)

**Strategy, policy and planning**

Involvement in developing and implementing strategy and policy (such as lay representative roles on programmes and project boards)

Through discussions within the strategic lay forum and with involvement leads in partner organisations, the involvement ‘stock-takes’ and the two strategy co-design events, we have developed a vision for patient and public involvement for the Trust. There was a strong consensus that the **strategic framework** presented to the Board last November, setting out four broad categories of involvement, was broadly the right one, with a few tweaks for improved clarity, as proposed above.

We wanted to be clearer about what all of this involvement is intended to help achieve, and drafted a **five-year vision**, as proposed below, that links directly to our own overarching promise of ‘better health, for life’ and to the emerging sustainability and transformation plan for north west London. Both our promise and the STP look to help us and the wider NHS make the essential shift from care being reactive and crisis-driven to being proactive and health and well-being focused, and ensuring, regardless of provider, that patients feel that their care is joined-up, consistent and tailored to their individual needs. In this way, we will be able to address the three ‘gaps’ set out by in the NHS *Five Year Forward View* – in health and wellbeing; care and quality; funding and efficiency.

Through the patient and public involvement strategy, and other transformational programmes, our vision is for:

- all patients to feel that they are understood, heard, and have control and choice over their health and care so that it meets their specific needs.

- as many patients, families, carers and local residents as possible to feel encouraged and supported to take an active role in their own health as well as in shaping and delivering the care we provide to help ensure it better reflects patients’ needs.

- a core group of patients, carers and local people to be able to directly influence the development and delivery of our organisational strategy to help us ensure we are making the best use of all of the insight, skills and knowledge available to us.

There were also five **key principles** that emerged about how we should think about and position involvement in our Trust in order to achieve our vision:

- *We need to actively find out what patients, carers and local people want and avoid making assumptions* – that includes not expecting representatives on project groups or boards to be representative of the views of all patients. There are tried and tested ways of gathering insight and understanding of patients – or of customers, clients and citizens – and we need to be as structured and systematic as we can in using evidence-based approaches and drawing on best practice, including the use of socially and culturally sensitive mechanisms for increased involvement of seldom heard patients and groups. There was a strong consensus amongst staff, patients and lay representatives that gathering and using patient insight needs to go beyond the current friends and family test (FFT). We also need to go out to talk with our patients on their own ‘ground’ – we heard of a great example of a local women’s community group really valuing one of our specialist consultants visiting them to discuss pre-conception care and management of diabetes in pregnancy – they said it made them feel ‘listened to’.

- *We should look to make involvement business as usual for everyone* – it shouldn’t be considered as a central ‘function’ but a way of working embedded in everything we do. As such, it needs to be part of many other functions, including: governance, service change and delivery, safety and quality improvement, patient information development, customer care, patient feedback, communications, complaints, patient data gathering and sharing, health improvement. The central function that is required can be characterised as one that seeks to establish the right soil and growing conditions for involvement to flourish everywhere in the Trust. All staff need to be open and committed to seeking patient and public involvement and to have the knowledge and confidence to systematically gather and use patient and wider input to make improvements.

- *We need to think north west London-wide* – recognising that patients, carers and local people don’t ‘belong’ to one NHS organisation. We should look to integrate or align our involvement activities and approaches wherever possible in the same way that we are looking to integrate and align our services with key partners, especially across the north west London sustainability and transformation plan footprint.

- *We must learn to share and draw on what works and what doesn’t* – there are some very developed and effective PPI approaches within many of our service areas, we can learn a lot from these activities and draw on the expertise and support of the patients and staff involved. The issue is that they generally sit in silos – which means that no else knows about them and we tend to have a whole range of service/disease-specific initiatives (eg various passports) that the patients have to co-ordinate, and also lots of duplications and gaps when seen from a patient’s perspective. There are also other players in our health system (for example, the CCG-led teams working on ‘whole systems’) who are more advanced in their development of involvement approaches and we need to avoid ‘reinventing the wheel’.

- *We must find ways of systematically measuring and evaluating the outcomes and impacts of involvement activities* – we need to be able to evidence the positive impact of involvement, for example, in business cases. We particularly need to beyond measuring the outputs of involvement to measuring the outcomes and impacts.

To achieve our five-year vision, drawing on our key principles, we have identified four main areas for development– translating in to **four work streams**. The first two work streams are required to support and enable all categories of involvement activity while the remaining two are intended to achieve a major shift of approach within specific categories of involvement - systematically and proactively acting on feedback in order to improve our services; and developing an organisation-wide strategy for supporting individual ownership of health and wellbeing.

We have been exploring with Imperial Patient Experience Research Centre, part of the Biomedical Research Centre, how we can develop an 'involvement test bed' to encourage and enable innovative approaches to involvement to support the four work streams, and how we can establish a robust evaluation approach to the impact of the whole involvement strategy.

The four work streams are:

**Patient and public involvement infrastructure**

Within five years, we want to have a full complement of processes, resources, and policies to support diverse patient and public involvement led by clinical and corporate directorates, and to ensure it is delivering demonstrable improvements in health and care, fairly and efficiently. We want the patient voice to be clearly present in our organisation, including lay representatives directly involved in planning and decision making.

By the end of 2016/17:

- We will have two lay representatives on all of our key initiative programme or project boards or committees.
- Lay representatives will be appointed through a new selection and development process, managed by the communications department and supported by the QI team and potentially partner organisations in north west London. The process, drawing on an approach developed by the north west London whole systems lay partners advisory group, will involve establishing roles specifications, and running facilitated development/selection days in order to create a pool of potential lay representatives. The pool will be kept informed and matched with lay representation opportunities as they arise. We will also establish a process for identifying and co-ordinating lay representation opportunities across the Trust, and potentially linking in with other north west London organisations, as appropriate.
- We will co-produce an involvement charter to clearly set out expectations and responsibilities for staff and patients, carers and local people taking part in any involvement activities.

- We will co-produce a remuneration policy, looking to align with similar policies for partner organisations across north west London and drawing on existing good practice. The NHS England guidance will be a key source of guidance but we need to understand in more detail how this will work in a provider organisation and what the potential impact would be.
- We will develop immediately an expenses policy with the intention of ensuring all patients, carers and local people who attend involvement activities for the Trust are reimbursed for reasonable travel and child care/carer expenses. We will ensure this is aligned with the development of the Charity's volunteering policies.
- We will work in partnership with the Charity and with information governance to have an aligned, or ideally joint, 'customer relationship management' system in place to manage all of our 'non-clinical' patient, carer and local resident contacts.
- We will launch a programme of training sessions on patient and public involvement for service and care improvement (included for all QI-supported projects) open to all staff
- We will launch a suite of involvement resources – checklists, toolkits – available to all staff via the Source (and all QI-supported projects via the pilot collaborative hub)
- We will establish and begin to implement an evaluation model, in partnership with Imperial College and potentially other partners.

*Involvement test bed*

- New community ophthalmology service – working with the service team to help establish a new service, with patient and public involvement structures and processes embedded from the start.

**Building awareness and engagement**

Within five years, we want to be seen as a leading organisation in terms of the positive impact of our patient and public involvement approach. We want to have tens of thousands of patients, carers and local people choosing to be kept up to date on the Trust's work and opportunities for involvement and regularly providing valuable feedback. We want thousands to be more actively involved through a diverse range of activities.

By the end of 2016/17:

- In partnership with our Charity, we will develop and launch a revised 'membership' offer, with a new marketing programme. As a minimum, we will offer everyone interested in keeping involved, an e-newsletter with updates on the Trust and a round-up of specific involvement opportunities.
- We will be asking all new patient contacts via email to allow us to contact them to keep them involved in our work and opportunities for them to shape what we do and/or to become a 'member'.

- In partnership with our Charity, we will establish ‘involvement hubs’ on all of our sites, areas to promote our new ‘membership’ offer and all the ways of being involved.
- We will establish an involvement network open to all Trust staff, to help raise awareness of opportunities, resources and support available and to encourage the sharing of ideas and best practice.

*Involvement test bed*

- Maternity and St Mary’s A&E service pilots – clinicians/volunteers encouraging patients to ‘sign up’ at key stages of the patient journey to be kept involved with the Trust and its work (and/or to become a ‘member’).
- Patient/staff pair pilot – partnering patients with staff within two or three services to champion and facilitate involvement approaches and activities, identifying and helping to unblock barriers as well as replicable successes.

**Systematically acting on feedback**

Within five years, we want the vast majority of our patients and all staff to be engaged with the systematic gathering of meaningful feedback and insight – as well as *ad hoc* feedback and ideas gathering - that is analysed and used at all levels of the organisation to identify, shape, prioritise and evaluate improvements. We want this feedback and insight to be easily available for all of our audiences to see and to use for themselves.

By the end of 2016/17:

- We will have undertaken scoping and discovery work to establish an integrated programme of work in this area, drawing on a number of QI-supported projects underway.

*Involvement test bed*

- Paediatric service ‘what matters to me’ development
- Maternity services piloting ‘whose shoes?’ patient involvement in improvement methodology
- Others to be determined
- Explore the Northumbria NHS Foundation Trust example of publishing regular quality ratings about all services

**Patient ownership of health and wellbeing**

Within five years, we want the vast majority of our patients with on-going health conditions and as many other local people as possible to be actively engaged with us – and other health partners - in maximising their own health and wellbeing. We want thousands of patients and local people to be part of delivering the support to make this possible.

By the end of 2016/17:

- We will have undertaken scoping and discovery work to establish a co-ordinated approach to maximising health and wellbeing as part of the work of the integrated health directorate and the development of the wider clinical strategy.

*Involvement test bed*

- Developing 'practice' champions in paediatrics
- Self -administration of medicines QI project
- Others to be determined

## Implementation management and oversight

- A senior overall 'lead' for each of the four involvement categories:
    - strategy – Director of communications
    - improvement – Associate medical director (quality improvement)
    - delivery – Chief executive, Imperial College Healthcare Charity
    - wellbeing – Director of integrated health programme
- Additional senior involvement from patient experience and governance and divisional leadership and from the BRC Patient Experience Research Unit.
- Reporting into strategic lay forum bi-monthly and half-day co-ordination and planning sessions quarterly,
- Reporting to executive transformation committee quarterly and to Trust board annually.
- A project manager, funded jointly by communications, the Charity and QI, has been appointed to run the implementation programme on a fixed term contract from July to March, to be reviewed as part of the 2017/18 business planning round.

## Resources

The first two work streams will be funded from within existing budgets of communications, the Charity and QI, and we are exploring external and partner funding or resourcing opportunities. Scoping work for the other two work streams will be used to understand their resourcing requirements.

## Risks

The key risks are:

- not achieving sufficient awareness, engagement and support for the proposed involvement approach
- not ensuring staff – and patients where appropriate – have the training, resources and support – to enable effective involvement activities
- not being able to evaluate and evidence the impact of involvement activities.

This would exacerbate the mismatch between the expectations of our patients and local communities in terms of their ability to inform and shape what we do and how we work and, more generally, the responsiveness of our services to their needs. In turn, this makes successful change and improvement very difficult to achieve.

The strategy recognises these risks and includes a major focus on building awareness and engagement at all levels of our organisation as well as on establishing a programme of training and a suite of resources. We are also working closely with the BRC Patient Experience Research Unit to establish robust evaluation and establishing an effective co-ordination and governance structure for the work.