

# Patient participation strategy 2017-2022

Working with patients  
to discover, develop  
and deliver the best  
eye care



Moorfields  
TEER

Restart Step 1/5 Step

You have  
arrival.

Please take a seat in the  
area and wait for your name



# Foreword

In our 2017 strategy 'Our Vision for Excellence', we articulated our purpose to "work together to **discover, develop and deliver** the best eye care."

As part of this, we developed a quality strategy which sets out our aims to deliver outstanding patient care.

Patients and carers are an integral partner in us achieving our vision and ambition for excellence in everything we do.

The need for a patient participation strategy has arisen because we want to shift the relationship with patients as part of responding to the changing external context and our ambition to be a world-class healthcare provider.

It is about identifying where and how patient participation can help Moorfields meet its strategic aims and improve health outcomes.

To maintain our reputation as a world-class eye hospital well into the future, we need to consider how working with patients can help us achieve our vision for excellence.

There is significant evidence that healthcare that is produced by staff and patients working together leads to better health outcomes overall. We already work with and involve patients across Moorfields in a variety of ways, which is delivering some great results. However, there is an opportunity to build a more systematic approach and share learnings with each other to build on good practice.

This document, therefore sets out practical steps to realise our vision by outlining how we will encourage and support patients to participate in all of Moorfields' work. We describe how we will improve patient experience, undertake effective and meaningful engagement and work in partnership with patients, involving them across all our work.



**David Probert**  
chief executive



**Tracy Lockett**  
director of nursing and  
allied health professions

# Our vision

Moorfields will work with patients as partners in discovering, developing and delivering the best eye care.

## We will:

- **involve** as diverse a group of patients and carers as possible and give them different ways to participate.
- **ensure** that patient participation is meaningful rather than tokenistic.
- **develop** the skills, knowledge and confidence of staff and patients and encourage them to co-produce wherever possible and feasible.



# What is patient participation?

It is important to define what we mean by patient participation and related terms.

Below are some clear definitions which Moorfields will adopt and use to describe patient participation in the future.

Patient participation is where patients actively take part in healthcare, including a spectrum of activity from shaping individual care and giving feedback on their experience to working alongside healthcare practitioners to design service improvements.

## There are three main types of patient participation:

<b>1. Patient experience</b>	<p>Patients giving feedback, enhancing our understanding of our performance as a trust.</p> <p><b>Example methods:</b> surveys, focus groups, storytelling.</p>
<b>2. Patient engagement</b>	<p>Taking time and/or creating opportunities to give patients a deeper understanding of their condition or care and the wider work we do.</p> <p><b>Example methods:</b> seminars, research days, newsletters and articles.</p>
<b>3. Patient involvement</b>	<p>Working alongside patients to shape and develop our work across clinical, education &amp; research, and service provision.</p> <p><b>Example methods:</b> workshops, co-design processes, co-production, formal patient board roles, patient reviewers.</p>

# Why is patient participation important?

Patient participation is not just a 'nice to have'.

There is a significant body of evidence demonstrating the link between participation and better health outcomes. It is also a focus of the NHS's plans set out in the 'NHS Five Year Forward View' (NHS England, 2014).

Patient participation is about designing patient experience, engagement and involvement as a means of both increasing patients' knowledge, skills and confidence in managing their health and improving the overall design of healthcare itself.

## Through patient participation, we aim to develop:

### Active patients

Patients who play a significant part in managing their own care, participating in and shaping the care around them, based on their lived experience. Active patients have the knowledge, skills and confidence to better manage their health and therefore achieve better outcomes.

### Responsive healthcare

Where hospital services are continually shaped by patients' experience of their condition by involving patients in the design and delivery of services.

## Case study:

# Active patients

In 2016, Moorfields patient Elaine Manna was invited to participate in a seminar with Moorfields and DeepMind, a company that conducts research into artificial intelligence and its application in healthcare settings.

Elaine was invited by her Moorfields consultant, Pearse Keane, to talk to delegates about her experience of age-related macular degeneration (AMD), her treatment and the impact of vision loss on her life.

Elaine spoke powerfully about the fear of losing her sight, the feelings of isolation that come with it, and the importance of patients being given hope via medical research.

Not only did Elaine's insights provide valuable learning for practitioners, they also gave her a sense of empowerment and control over her situation. Elaine gained knowledge and confidence in the process of being invited to participate by telling her story.

“My confidence had dropped right to the floor when I was diagnosed. [After the talk] I came away with wings on my feet; my confidence level was sky high. From stumbling down this dark path, there's a glow. I feel hopeful, for myself and for future generations in this field that DeepMind Health are offering and for generations to come. As a patient, I felt valued and respected to be asked to tell my story. They gave me a voice. It meant so much and I will always be grateful to them.”

Since then Elaine has gone on to contribute to health journal articles on DeepMind, participate in patient and service improvement workshops, and support other patients experiencing AMD and other sight threatening conditions. She also raised over £2,000 for Moorfields Eye Charity by doing a skydive.





## Case study:

# Responsive healthcare

### Patient pagers

Sometimes responsive healthcare is about simple interventions, rather than large service improvements. The patient pager system at Moorfields City Road is an excellent example of an intervention that was developed in collaboration with patients.

The patient experience team understood from consistent patient feedback that waiting times were an issue for City Road's busy outpatient clinics. But by working with patients to understand their concerns, they also found out that patients were frustrated with waiting, partly because they were worried that they would lose their place in the queue if they left their seat.

The idea of a patient pager was a relatively simple intervention that would ensure patients felt more freedom to leave the waiting area to visit the lavatory or go to the coffee shop during their wait; giving them more confidence that they would be seen and not lose their slot.

### Working with the Accessible Information Standard patient forum

As the trust began work to meet the requirements of the accessible information standard (AIS), an AIS patient forum was established to review, contribute to and advise on implementing the patient pager project across all Moorfields network sites. The forum members have a wide range of visual impairment and communication needs and their involvement has proved invaluable in providing a patient perspective to the work of introducing the AIS to the trust.

The AIS patient forum has worked with the trust AIS implementation committee on a number of projects, including joint design of the AIS patient questionnaire, advice on the types of equipment used by patients with sight loss, suggestions regarding pharmacy labelling, guidance on braille and other formats and reviewing the patient self check-in kiosks.

# How are we doing today?

There are many excellent examples of involving patients in research, education and shaping healthcare across the Moorfields network.

## These include:

**Research days** organised by the NIHR Biomedical Research Centre at Moorfields Eye Hospital NHS Foundation Trust and UCL Institute of Ophthalmology.

**Dedicated glaucoma surgery seminars** running at St Ann's Hospital.

**Work to improve patient pathways** in glaucoma and medical retina services.

**'Patient as teacher' sessions** run as part of the undergraduate education programme.

However, these are isolated pockets of good activity, limited to a handful of active patients at present. There is an opportunity to create more systematic and structured opportunities for patients to participate throughout the trust.



## The cultural shift

As we worked with staff and patients to develop this strategy, we identified the necessary shift in mindset and culture that was needed to create opportunities for participation across Moorfields.

This cultural shift will not be an easy one to make, as it will sometimes challenge the structures and systems we already have in place.

But it is a necessary shift for all of us to make to enable us to create a culture of working together to discover, develop and deliver the best eye care.

From	To
Lists of symptoms	People with conditions
Recipients	Participants
Passive	Active
Wanting to be served	Willing to help
'Us' and 'Them'	Working together



# What will we do?

## 1

**We will train staff to feel equipped to work with patients more systematically, both in their day-to-day work and on dedicated projects.**

We know that there is a lack of shared experience among staff of what patient participation looks like, why it matters and how it helps them in their work. As a result, many projects and processes are completed without involving patients at all, and those that do often don't involve a full spectrum of patients with relevant experience of a service or clinic.

### We will:

**Communicate to all staff** that patient participation is important to everyone, should be locally driven and does not fall exclusively to the patient experience function.

**Establish training for staff** at Moorfields about patient participation, starting with a few key groups before rolling it out to other staff and teams. The training will include:

- Why patient participation matters
- How to do it
- How to evaluate it

**Establish methods** for sharing success and best practice, celebrating and supporting those who are doing it well.

**Roll out training** via digital and other tools to ensure it reaches across the network.



### How will we know we are successful?

#### We will:

- **record** the number of staff who have undertaken participation training each year.
- **survey** staff on their knowledge, skills and confidence in patient participation and its impact on their work.
- **evaluate** how we are doing against the intended cultural shift, via additional questions in existing surveys.

## 2

## We will establish processes and practices to make patient participation systematic across the whole of the trust.

Alongside developing the skills and capabilities of staff to enable them to feel comfortable with patient participation, we will systematise participation by introducing new checks and balances to ensure it is happening. It is important that patients are considered and involved appropriately in all our key decisions; whether that is for service or quality improvement projects, business as usual or larger-scale projects such as our long-term plan to relocate City Road facilities to a new centre of research, education and clinical care.

### We will:

**Introduce a new requirement for business cases** of future projects to state what patient participation will be, or has been undertaken in the development of that business case.

**Add a section to service change proposals** outlining how patient input has been sought for the project or paper being discussed.

**Review organisational evaluation criteria** to include patient participation as a divisional key performance indicator (KPI).

**Clearly define role descriptions** for patient participants, managing expectations of the level of involvement, time commitment and participation required.



### How will we know we are successful?

#### We will:

- **evaluate** the impact of patient participation via patient-centred outcome measures and by evaluating our patient involvement activities.
- **monitor** patient awareness of available participation opportunities via existing channels and if appropriate, via new surveys.
- **publish** as part of our quarterly and annual quality, safety and experience report the number of patients who have been involved in our activities each year, and the impact of these on the ambitions in 'Our Vision'.

## 3

## We will create a pool of patient participants to support our work, and invite every patient to get involved.

Although we want to engage with as wide a group of patients, carers and families as possible, we are often restricted in our efforts by existing mechanisms and current data systems. We will make participation opportunities more visible to patients, in order to grow the number of active participants getting involved in our work, from volunteers to fundraisers and patients giving feedback on their experience to help support service and quality improvement.

### We will:

**Create a focused** and prominent area for patient participation on our website, listing all patient participation opportunities from clinical, education, service design and research.

**Invite patients to participate** in the hospital environment by distributing leaflets in the patient information hub, and providing information on patient information screens.

**Use the changes to data protection legislation** (GDPR) as an opportunity to write to Moorfields' members to outline participation opportunities.

**Review our data strategy** and improve data capture methods to help identify patients' interests and demographics and promote relevant and meaningful participation.

**Celebrate participation actively** via our communications channels, in order to encourage greater participation from a wider group and signify the change that is happening.

**Scope the infrastructure** required to build an online patient participation hub as part of Moorfields' future.



### How will we know we are successful?

#### We will:

- **monitor** traffic to the patient areas of the website and monitor the increase in numbers of participants via the patient pool database.
- **monitor** the number and diversity of patients in particular segments and run mini-recruitment campaigns for seldom-heard groups.
- **track** and report numbers of patient participation actions.

# What will we do to implement this strategy?

A year 1 action plan has been developed to implement our three key commitments to participation as outlined in the previous section. Divisional management teams will include patient participation in day-to-day running of services, projects and business cases, including plans and key milestones as required. These activities will be reported through the patient participation and experience committee, to foster mutual support and trust wide learning.

## We will:

- adopt the language of patient participation used in this strategy and be clear on the distinctions between experience, engagement and involvement.
- implement the 'quick wins' derived from working with patients and staff in the process of developing the strategy. This will signal our new way of working and enable us to start immediately working towards the cultural shift.
- develop a communications plan to disseminate the strategy to all staff and patients.



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