

## Strategic lay forum

Wednesday 5th June 2024, 09:30 - 12:00  
In-person and via Microsoft Teams (online)

<b>Strategic lay forum attendance:</b>	
Ed Lowther	Co-chair
Shanaka Dias	Co-chair
Stephanie Nash	Deputy co-chair
Phayza Fudlalla	Deputy co-chair
Olivia Freeman	
Sonia Richardson	
John Black	
Graeme Crawford	
<b>Other organisations and Trust attendance:</b>	
Michelle Dixon	Director of engagement and experience
Bob Klaber	Paediatrician and director of strategy, research, and innovation
Linda Burridge	Head of patient and public partnerships
Meera Chhaya	Community engagement manager
Darius Oliver	Associate director of communications
Hannah Franklin	Strategy, research, and innovation programme manager
Sharon Jheeta	Consultant paediatrician and working on AI
Rachel Watson	Head of user insights and user experience design
Tori Martin	Lead Nurse for palliative and end of life care
Stuart Forward	Strategic communications
Faye Oliver	Strategic communications
Deirdra Orteu	Redevelopment clinical design director
Charlene Rajaratnam	Project manager
Clare Robinson	Associate director of service development and commissioner relations
Maria Piggins	Patient Experience Research Centre partnerships and training manager
Anne Middleton	Deputy chief nursing officer
Katherine Buxton	Consultant palliative medicine
Raashi Shah	Patient safety partner
Victor Chamberlain	Redevelopment communications
Jan Palmer	Elective care delivery manager
David Woollcombe-Gosson	Divisional head of productivity and development
Mark Robson	Deputy general manager, theatres, anaesthesia, pain, and pre-assessment
Steve Hart	Director of operations for surgery, cancer and cardiovascular

<b>Apologies:</b>	
Jane Wilmot	
Agnes Seecoomar	
Lorraine Brown	Head of the patient advice and liaison service
Shona Maxwell	Chief of staff
Raymond Anakwe	Associate medical director
Ian Lush	Chief executive of Imperial Health Charity
Peter Jenkinson	Director of corporate governance and trust secretary
Michelle Knapper	Clinical review and elective patient experience lead
Iona Twaddell	Senior advisor to CEO
Lea Tiernan	Patient engagement manager
Christina Walters	Programme director - outpatient transformation programme
<b>Observing</b>	
Mariya Stoeva	
Zohra Davis	
Bridget Harris	
Candice Savary	

<b>1.</b>	<b>Welcome and apologies - Shanaka Dias, co-chair, strategic lay forum</b>	<b>Action</b>
	Shanaka opened the meeting, and the apologies were noted.	
<b>2.</b>	<b>Minutes and action log, Linda Burridge, head of patient and public partnerships</b>	
	<p><b>Minutes</b> One amendment was noted in the minutes. In the 'emerging projects: acute provider collaborative strategy' section, Shanaka requested an important point to consider is how the Trust make use of the patients time.</p> <p><b>Action log</b> Linda ran through the action log.</p> <p>The group discussed the online collaborative space and agreed to ensure accessible options such as paper copies and training for colleagues that are not confident using digital devices. Michelle Dixon suggested the use of team engine, an app to access and mark up papers. Linda explained the next step is for everyone to complete their training and paperwork and to set out and agree the structure of the space. More information on this will follow soon. Shanaka questioned what measures are being taken against these actions.</p>	<p>Action: Amend April minutes with the below comment - 'how the Trust make use of the patients time'.</p> <p>Action: Consider team engine for forum use</p> <p>Action: Share final steps, training and structure of online collaborative space</p>
<b>3.</b>	<b>Returning item: End of life care, Dr Katherine Buxton, consultant in palliative medicine and clinical lead of end of life care, Tori Martin, lead nurse for palliative and end of life care</b>	
	<p>Tori shared the end of life strategy which is used within the organisation.</p> <p>This is a three-year strategy which started in April 2022 and runs till 2025. The strategy is underpinned by three key commitments:</p>	

- Vision: Providing care at the end of a person's life is seen as everyone's business and all staff and volunteers will work collaboratively to ensure individuals receive compassionate, holistic, and well-planned care, which strives to continuously meet their needs and the needs of those close to them
- Commitment one: To deliver Trust-wide service improvements, reducing variation in care delivery and making best use of quality frameworks
- Commitment two: To augment trusted partnerships with allied teams and align end of life with Trust-wide strategic and operational business as usual
- Commitment three: To work collaboratively across organisational boundaries to provide the best possible care at the time it is needed, in the place it is required

Tori and Katherine explained the main challenges for the team are recruiting the transformation role, agreeing the governance structure and role of the senior reporting officer, and the challenge associated with accessing data.

Progress over the last six months include:

- The development of an End of Life Care (EoLC) Education and Improvement Team, January 2024
- Participation in National Audit for Care at the End of Life (NACEL)
- End of Life steering group and governance refresh
- Data dashboard journey
- End of Life Big Room
- Co-design with bereaved relatives

Over the next 12 months, EoLC Education and Improvement Team will be launching the purple butterfly model of care and symbol. This is an approach to giving patients and their carers the right support. A purple butterfly symbol is visible and used as a way of letting others know a patient is near the end of their life.

The purple butterfly symbolises:

- The provision of dignity, respect, and compassion in care
- Awareness that end of life care is everyone's responsibility
- An openness of culture around end of life
- A willingness for staff to go the extra mile in supporting the needs of patients and those important to them at the end of life

Rashi asked how the purple butterfly will be used. Tori said it will be used in training material and visible on wards - on trolleys and on the side of beds, as a pin badge, on written information and items patients will use.

Katherine and Tori updated that the team will measure their success through how smoothly they can reconfigure the EoL steering group, develop projects with lived experience representatives, launch the purple butterfly model of care and continue with the NACEL.

Next steps for the EoL programme are their education and improvement priorities, the monthly clinical governance meeting, continue to improve the service user feedback strategy, explore the use of volunteers and review and refresh the overall EoL strategy.

	<p>Katherine highlighted the engagement for the end of life strategy for 2025 will begin in autumn where the 2024 workstreams will be reviewed. Michelle commented on the importance of keeping the lay voice on-going in this programme of work. Katherine agreed and mentioned a lay partner was on the steering group and when engagement begins in the autumn there will be another opportunity for lay partner involvement.</p> <p>Phayza questioned whether the end of life champions are bi-lingual as this will ensure the voices of patients/relatives whose first language is not English are heard. Tori welcomed the comment and explained that although this has not been made an essential criteria when recruiting for the role, a number of staff members are bi-lingual. Michelle suggested a helpful action would be for Tori to connect with the interpreting improvement programme to discuss how the end of life care programme can access interpreters.</p> <p>Sonia was keen to understand whether the purple butterfly concept can be shared with other Trust hospitals. Michelle explained that this is a campaign also used by our partners. Other trusts use different symbols and we have adopted the purple butterfly to align with other hospitals in north west London.</p> <p>The strategic lay forum supported the programme and concluded:</p> <ul style="list-style-type: none"> <li>• The need for further lay partner involvement</li> <li>• Consideration for cultural differences and interpreting needs</li> <li>• Unified approach across north west London Hospitals</li> </ul>	<p>EoL team to link up with Lorraine Brown, the patient interpreting improvement lead on how EoL care can better use patient interpreting services – Tori/Lorraine</p> <p>Forum conclusions to be shared with EoL and set date for update - Meera</p>
<p>4.</p>	<p><b>Deep dive: how to improve the appointment and booking process, including waiting Presenters:</b></p> <ul style="list-style-type: none"> <li>• Steve Hart, director of operations for surgery, cancer and cardiovascular</li> <li>• Jan Palmer, elective care delivery manager</li> <li>• David Woollcombe-Gosson, divisional head of productivity and development</li> <li>• Mark Robson, deputy general manager, theatres, anaesthesia, pain and pre-assessment</li> <li>• Rachel Watson, head of user insight and experience design</li> <li>• Michelle Dixon, director of engagement and experience</li> </ul>	
	<p><b>Planned surgery and diagnostics</b> Steve introduced the team, gave an overview of the overall approach to planning operations and explained the improvement work they have been leading on. There is a theatre improvement programme oversight board to manage the improvement work. It is a Trust-wide forum and includes clinical and operational colleagues working across six key work streams, all with a focus to maximise patient experience and mitigate and manage risks:</p> <ul style="list-style-type: none"> <li>• Scheduling</li> <li>• Pre-operative optimisation</li> <li>• Utilisation</li> <li>• Workforce</li> <li>• Estates</li> <li>• Financial efficiency</li> </ul> <p><b>Scheduling prioritisation</b> - surgeries are booked by clinical priority and urgency, and then by chronological order by weeks waiting.</p> <p><b>Prioritisation of lists</b> - operating theatre lists are prioritised in the following order:</p> <ol style="list-style-type: none"> <li>1. Emergency (trauma/booking lists)</li> </ol>	

2. Cancer/urgent (cancer/liver donor/transplant)
3. Long waiters
4. Routine (non-urgent, pre-assessment)

Steve outlined some of the challenges regarding anaesthesiologist vacancies and targets for theatre use.

**Waiting list management and patient-led validation** – accurate lists are a vital part of making sure that the right patients are treated in the right order, and that clinical time and resources are effectively used.

Waiting list guidance set by NHSE intends to support clinicians and enable them to prioritise patients based on their individual needs. It also sets out regular communication to discuss any changes to their condition and there are three levels of patient validation:

- Technical validation - focused on identifying data inaccuracies and ensuring the data is accurate.
- Administrative validation - focused on identifying patients who may no longer require care. The team contact all patients to discuss any changes in their condition or circumstances.
- Clinical validation - Patients' records are reviewed by a clinician to identify those whose symptoms have resolved and who no longer require treatment or need different care.

National Patient Choice Programme PIDMAS (Patient Initiated Digital Mutual Aid) is a national initiative aimed at reducing overall waiting times. This is where a patient has the option to use another provider to reduce their waiting time. The team explained there was limited uptake of this initiative and suggested this was due to possible increased distance from the hospital and trust and comfort they feel with their existing medical team.

There have been several key actions to reduce 'do not attends' DNA's, examples include:

- Patients receive a text reminder for their upcoming surgery date at seven days prior.
- 24 - 48 hours prior to surgery patients receive a call from a qualified nurse to confirm surgery date, fitness, and escort arrangements (if a day procedure).

The presentation was well received by the forum members who were keen to learn more. John questioned what the percentage of DNA's on the day of surgery were due to sickness. It was difficult to provide a clear figure but sickness certainly is a factor to consider. DNA rates can be difficult to quantify as when patients are followed up, some do not answer, or their contact details are incorrect; the unaccounted figures skew overall figures.

Ed was keen to understand how far in advance patients are aware of their surgery (i.e. before pre-assessment/date of surgery). The process was explained as being ad hoc where at a minimum patients are contacted every 12 weeks. It is important to highlight that within the patient's treatment pathway, they would be contacted at several points (to provide an update or answer any questions).

Michelle said that the mapping and review that is currently going on as part of the outpatients transformation work would be really valuable to do for inpatient bookings and she will look to link the two programmes together.

The lay partners recognised the process from start to finish is hugely complex as there are a number of key factors to consider, i.e. safety of patient, pre-assessment, ensuring the patient is at the right place at the right time. At times, this can become dis-jointed due to the lack of communication between the pathways. It is important communication happens in the appropriate way.

Olivia questioned how many hours/days the theatres are opens where it was explained the emergency department is open 24/7. The rest of the 44 theatres are open 08:00-18:00, five days a week and 25% on a Saturday. The intention is to create longer working days across a six day week (Monday to Saturday - 08:00-22:00).

Mariya reflected on the pre-assessment phase, highlighting the importance of having a conversation with the patient to understand their needs as opposed to assuming this information. This would mitigate any issues further along the pathway.

With regards to PIDMAS, the forum were keen to understand whether the patient gets a choice in what hospital they can go to should they wish to switch. It was explained patients get a choice of a hospital within a 50- or 100-mile radius but not a specific hospital. This makes patients reluctant to switch as they have already built a relationship with the consultant, some want their family/friends nearby and to be treated within reach of their home/community. The forum challenged that perhaps patients didn't want to risk disrupting an already protracted process and would stay with their original hospital.

Phayza was keen to explore the health inequity issues around using a digital platform as it can create a barrier for several vulnerable groups. The speakers agreed and shared this feedback with the relevant teams. For those who were unable to use the platform, a 24/7 helpline with an interpreting service is provided.

To conclude, the forum shared their support of the work and agreed to combine any points with those that come from the following session on outpatient bookings.

**Outpatients and diagnostics - Rachel Watson, head of user experience and user experience design**

To share information on outpatients appointment bookings Rachel started by giving an overview of her role and the workstreams of the outpatients transformation programme – models of care, standardising the booking process and another looking at technology.

She summarised the various projects that have informed this work – outpatients research informing us of principles and recommendation on what patients want, outpatient pathway mapping and letter design for cardiology and work to reduce the number of patients that do not attend their appointment. She also summarised the waiting well service evaluation study which aimed to understand the challenges faced by people living in

<p>more deprived areas while waiting for orthopaedic treatment and to design tailored support initiatives that might help them to live well while waiting. This identified four key support needs: medical support to help with pain and mobility, practical support to assist with daily tasks, informational support to help patients understand what to expect and emotional support to help patients stay positive.</p> <p>Rachel mentioned several hospitals have implemented a 'one strike and out' rule where patients are contacted once and if they do confirm or miss an appointment, they are removed from the waiting list. The team is currently seeking further funding to continue developing and implementing the support ideas with patients and staff.</p> <p>The forum raised concerns about this approach to remove patients from waiting lists following one missed appointment and gave examples of how this would adversely affect many patients or those that have additional needs. i.e. blind, mental health needs, unfamiliar with digital platforms or individuals where English is not their first language.</p> <p>Michelle advised she would escalate this as a concern and feedback to the forum.</p> <p>Conversation focused on different modes of communication, i.e. letters, text messages, phone calls where it was agreed different methods would suit different cohorts of people. One possible reduction in DNAs would be to tailor the communication style to suit the patient. Phayza worked with Imperial Health Charity to implement the Health Navigator tool; an AI-powered solutions that identifies patient risks, enabling preventative care. Phayza suggested this would be a useful tool to embed in the Trust.</p> <p>Taking all this information and recent mapping into account, Rachel shared a slide on current issues and recommendation for the outpatient's transformation. It includes unmet needs and insights that we know patients want such as multiple ways to confirm appointments (text, phone call, online). She said that a number of these recommendations have been selected and will be designed and implemented carefully with different operational teams. She noted that booking appointments is very fragmented and in the past was not purposefully designed. At present there is little flexibility in the booking process and we want to implement functionality to give patients ability to book appointments at the time/date they want. There is also rigour on how these benefits are prioritised through ranking and testing with stakeholders. Rachel said that the improvements are also interdependent and sometimes need to be viewed as a set.</p> <p>She also said a very good or 'near perfect' appointment booking process has been mapped and there is opportunity to standardise this approach in different services.</p> <p>GP referrals were also discussed and the importance of involving them in these improvements. Rachel said that it is crucial to continually get feedback from staff, patients and GPs on any improvements so they can develop. She also flagged there are inefficient work arounds such as 'grey space' slots that enable multiple patients that must be seen, be booked into the same slot. It enables patients to be cared for but they can end up waiting a long time and this work hopes to address this.</p>	<p>Action: Michelle to escalate the 'one strike and out' rule and feedback to the forum</p>
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	<p>Rachel ended by saying that the team are also looking at improving the patient letters and considering metrics that we can measure the experience and if it has improved. E.g. Would these metrics be waiting times, time in a queue or ability to get the most convenient appointment for you?</p> <p>The group discussed how to ensure care if a patient was discharged and how this must involve the GP more. They also covered how text messages are simply not suitable for some patients.</p> <p>To conclude the forum felt the work is in the right direction and supported the need for further lay partner and user insight involvement. Shanaka highlighted the key points.</p> <ul style="list-style-type: none"> <li>• It's important to understand the reasoning behind the DNA and whether vulnerable groups are being targeted. Health Navigator was seen as an interesting tool to explore as well as ensuring communication to patients is tailored to their needs and preferences.</li> <li>• There is opportunity to interrogate and understand the entire life cycle of care, from GP to final treatment from the patient side, capture insights and realise better approaches to all aspects including communications, expected timelines and maximising patient experience and efficiencies. This is already happening in outpatient transformation and it can be extended to inpatients and surgery.</li> <li>• We can engage GPs more in this process so they can support their patients.</li> <li>• There is scope for more involvement and co-design as part of the theatre efficiency programme.</li> <li>• Health inequities and greater support for patients who miss their appointments is required. Significant concerns at current North West London 'access policy' where patients can be discharged back to their GP for one missed appointment.</li> <li>• Technology should be accessible to all patients and in situations where this is not possible providing an alternative method is crucial.</li> </ul> <p><b>BREAK (five minutes)</b></p>	
<p><b>5.</b></p>	<p><b>Biomedical research centre update, Phayza Fudlalla, community member, BRC and deputy co-chair strategic lay forum, Maria Piggin, partnerships and training manager, PERC, Imperial College London</b></p>	
	<p>Maria provided an update on the Imperial BRC patient public involvement engagement and participation strategy. The goal of the Imperial biomedical research centre is to research and develop for the benefit of the patients, the public and the health care services in North West London. This includes new treatments, diagnostic tests and medical technologies and she ran through the public involvement, engagement, and participation strategy objectives.</p> <p>She explained the role of community partner and they found the experience really rewarding to provide a lived experience and gave them confidence to participate in broader more involvement roles.</p> <p>The community partners in research event took place on the 20<sup>th</sup> November 2023. This was attended by 77 BRC researchers/staff and community partners and provided a great space for networking, Presentations on public involvement was co-delivered by researchers and public contributors and two departments of health and social care staff attended.</p>	



	<p>Maria touched on several challenges as well as key actions and recommendations. An example includes the need for PPI training at all researcher levels. An action for this would be to implement BRC funded pilot projects/fellowship to undertake online PPIE in research course as condition of funding/appointment.</p> <p>Future plans include the appointment of a second community partner to attend relevant meetings to report/discuss PPIEP progress as well as regular community outreach sessions to build trust and research involvement.</p> <p>Due to time constraints, the forum members were requested to gather any comments/questions which can then be feedback.</p> <p>To conclude, Shanaka highlighted BRC approached patients from the beginning and is a great initiative. There are several actions the lay partners can get involved in and embed within the Trust.</p> <p>Michelle said this work in really important and took an action to set a date for this presentation to be shared with the executive team.</p>	<p>Action: Michelle to set a date for the BRC presentation to be shared with the executive team</p>
<p><b>6.</b></p>	<p><b>Emerging projects: Artificial intelligence (AI), Bob Klaber, Paediatrician and director of strategy, research, and innovation, Sharon Jheeta,</b></p>	
	<p>Bob Klaber provided an overview of the draft AI strategic narrative and principles where we are committed to the responsible use of artificial intelligence (AI).</p> <p>Bob explained that through existing relationships with Imperial College London, Paddington Life Sciences and the NIHR Imperial BRC, we are working on better use of our data and shared expertise to better understand our local and wider community populations.</p> <p>Researchers across our partnerships have also been exploring the use of AI in healthcare for several years. This combined with our understanding of population health and equity as an anchor institution means we have the potential to be a community-focused leader in this area.</p> <p>The focus of healthcare will always be our patients, staff and communities and we will prioritise maximising the impact of AI for real-world application that benefits the population. To realise this ambition effectively we must bring our existing AI and data research and applications together under a coherent strategy.</p> <p>This focus is to co-produce the strategic approach with our patients and staff, considering their unique experiences and challenges to ensure equitable access to the benefits of AI for all.</p> <p>There is work to be done to fully understand the potential of AI across healthcare; from automating routine administration to analysing scans and supporting diagnosis or extracting trends from large datasets. There are three key areas where we believe AI can deliver the most benefit for our people – clinical care, clinical and patient administration and corporate functions.</p>	

	<p>Providing the right support for developing our use of AI and increasing capability is just as important as the technology and research. Providing equity of access and training for staff, sourcing robust platforms and systems and supporting our patients to contribute to our work is a priority.</p> <p>Sharon Jheeta highlighted that in order for AI to be ethical it must also be kind and fair for everyone (young and old), show empathy (was this expressed in a friendly way?) and not include any bias.</p> <p>The presentation was met with great enthusiasm from the forum members. The need to focus on patient needs and target communities who may not be digitally equipped was highlighted as a key concern as well as the cost implications. Bob echoed the above comments and mentioned investment was needed to deliver the programme efficiency. Bob suggested a helpful action would be to come back to a later forum to discuss the AI strategy in more detail.</p> <p>Shanaka wrapped up the conversation and said a few lay partners have experience in this area. He agreed approaching this ethically and with kindness is very important.</p>	<p>Action: Bob to come back to a later forum to discuss the AI strategy in more detail</p>
	<p><b>Meeting close</b></p>	