

Strategic lay forum

 Wednesday 26th April 2023, 09:30 - 12:00

In-person and via Microsoft Teams (online)

Strategic lay forum attendance:	
Trish Longdon	Chair
Shanaka Dias	Co-chair
Graeme Crawford	
Jane Wilmot	
John Black	
Sonia Richardson	
Phayza Fudlalla	
Agnes Seecoomar	
Other organisations and Trust attendance:	
Bob Klaber	Director of strategy, research, and innovation
Michelle Dixon	Director of engagement and experience
Linda Burridge	Head of patient and public partnerships
Meera Chhaya	Community engagement manager
Darius Oliver	Associate director of communications
Michelle Knapper	Clinical review and elective patient experience lead
Maria Piggins	PERC (Patient Experience Research Centre) partnerships and training manager
Daniel Codesal	Customer experience manager
Linda Watts	Associate director of digital transformation & general manager for outpatients & patient access
Tanya Hughes	Communications strategist
Anna Lawrence-Jones	Patient and public involvement and engagement lead, Helix Centre
Lea Tiernan	Patient safety engagement manager
Raashi Shah	Patient safety partner
Ben Glampson	Research informatics programme manager
Deidra Orteu	Head of redevelopment design
Apologies:	
Ed Lowther	Co-chair
Oliver Freeman	Lay partner
Ian Lush	Director of imperial health charity
Peter Jenkinson	Director of corporate governance and trust secretary

1.	Welcome and time to remember John Norton - Trish Longdon, chair, strategic lay forum	Action
	<p>Trish welcomed attendees and explained the first part will be spent remembering John Norton; a very long-standing lay partner. John collaborated with Imperial as well as several other places for many years. John was a committed lay partner for over 10 years.</p> <p>Trish said she worked with John on creating the whole system integrated care tool kit. John made many valuable points and was committed to making care connected and integrated around patients rather than patients fitting with providers. At the strategic lay forum away day in January, we had the privilege of celebrating John's 95th birthday and Trish said she would remember John as smart, active, and hugely involved and if anyone asked how old he was, none of us would have said 95!</p> <p>Bob mentioned that when the news was shared the immediate moment goes to a sense of shock and sadness. However, this quickly moved into celebration and what an extraordinary man he was. John was kind, very generous with his time and had great insights that would never disrupt thinking. John was very curious and constantly trying to learn.</p> <p>Anna worked with John since 2016. The general sentiment was that he was a true gentleman with a great sense of humour. John was a real champion for co-production, meaningful involvement for the staff and people he worked for, and he will be really missed.</p> <p>Ben said John joined the data access committee early in the pandemic. John also stayed on to support new lay partners to ensure a smooth transition and to increase diversity. John approached everything with a great attitude and sense of humour; he will be sorely missed.</p> <p>Tanya first met John when she worked as a lay partner and he rebelled against every cliché about what you should or should not do during retirement, i.e., relaxing, winding down or gardening. One of the tasks they were presented with was to write about what the future of St Mary's could be. John wrote the most brilliantly, innovative piece about how care should be delivered. Tanya plans to use this at some point during comms.</p> <p>Sonia worked with John for a few years and was very fond of him. Sonia said that the committee needs to ensure his legacy is carried forward both in what we do and how we approach it. John was interested in future generations coming into healthcare so perhaps this would be an area to remember him by. Sonia remembers that at the last meeting he discussed how he had got an air fryer and how we would be cooking several new meals. John could put his heart and soul into everything and for that Sonia has a huge amount of respect.</p> <p>John Black mentioned John was enormously generous and giving of his time. Beyond this gentleman exterior was a persistent man in seeking change. John applauds and thanks him for all his kindness. John was an absolute joy to work with and an inspiring mentor for so many people.</p> <p>Linda remembered being at the Western Eye hospital with John and they were about to go upstairs to support an event. Linda didn't know how old</p>	

	<p>John was but thought it best to wait for the lift. John suggested to take the stairs. He was very open, and you could talk to him about anything and have healthy debates. Linda complimented him on how well he aged. He acknowledged it was partly down to luck and said the most important thing is to keep active, not just the body but the mind too (as well as drinking green tea). Linda added that she has been very grateful her work life has involved knowing someone like him.</p> <p>Michelle mentioned John was incredibly optimistic and positive; he never gave into moaning or negativity. Michelle recalled the 95th celebration at the away day and how lovely it was to celebrate a milestone and for him to recall stories about his life.</p> <p>Maria works for the college and recalls working with John on a committee meeting. He was a champion for research and public involvement. Technology did not phase John and there was an opportunity to take part in a tweet chat for an organisation called 'data saves lives'; he loved this experience, and it illustrated John's ability to get involved and try new things as he didn't have a Twitter handle. This is an example of how positive he was.</p> <p>Michelle Knapper met John once but recalled a conversation where he mentioned he got so much more out of volunteering than the organisation gets out of him.</p> <p>Trish thanked everyone for their kind words and will make sure everyone's thoughts are put together which will then be shared with his family and the forum.</p>	
2.	<p>Patient safety partners - Raashi Shah, trust patient safety partner</p>	
	<p>Trish welcomed Agnes who will be observing a couple of the strategic lay forum meetings with a view of joining.</p> <p>Trish also welcomed Raashi Shah, the patient safety partner who is here to create a link between the strategic lay forum and patient safety partners.</p> <p>Raashi explained she is one of six patient safety partners: all of whom are from different backgrounds. The role is to engage with patients and staff to obtain the patient perspective. In doing so, the patient safety partners provide relevant knowledge to help develop patient safety resources. The patient safety partners are involved in different steering groups for the Trust's safety priorities. Raashi's role focuses on supporting families and patients with the incident investigation process as well as improvement.</p> <p>Michelle welcomed Raashi and mentioned it is important not to feel like you must represent all the voices or questions into these meetings.</p>	<p>Raashi to speak at the next team meeting to outline what they are doing and how we can build synergies between the two groups</p>
3.	<p>Minutes, action log and brief updates on projects - Linda Burridge, head of patient and public partnerships</p>	

<p>Minutes reviewed and agreed were correct. They will be edited in future to reduce the length.</p> <p>Action Log reviewed: Forum involvement in redevelopment communication and engagement plan The re-development plan at St Mary’s Hospital has been paused but there is planned work for Charing Cross and Hammersmith Hospital. There was an early draft business case which the forum has commented on. The sense is that we did some brilliant work around co-designing however this piece of work is on-going with a strong user focus lens.</p> <p>Develop policy and plan for reimbursing lay partners/patient reps We have started the reimbursement process and to check regularly whether people do require reimbursement.</p> <p>Patient interpreting The next step is updating the policy and improving the communication around patient interpreting as well as working on a job description as this project requires resource. An update can be presented at the next forum.</p> <p>End of life care End of life care has been flagged as one of the user focused projects we want to develop (supported by Rachel Watson). A session will be provided on this at the next forum. There is research taking place which is focusing on engagement with underrepresented communities.</p> <p>Research briefing document for Trust management This action has been on the list for a while. As Phayza is involved in the BRC governance there is a suggestion to re-visit this action in the summer to identify whether this is still a project as some of the solutions may already be in place with the DNA work.</p> <p>Lay partner networking session to be set for lay partner feedback and collaboration The next lay partner networking session has been scheduled for Thursday 22nd June. The last session was well-received; great feedback was received which will be implemented in the next lay partner networking session. We are also working on an overall plan for how many lay partners we want to recruit and how we are going to promote this.</p> <p>Outpatient transformation board and lay partner involvement The programme is currently being reviewed to ensure user-focus elements are co-ordinated. The project team is checking to ensure everyone understands what the project is, how it’s structured and how we can work together to launch the vision.</p> <p>Community engagement At the beginning of the year, we were committed to doing five community engagement events. The good news is that seven have been completed. The plan is to set a process on how we engage with community groups as well as inviting clinical staff to go to these events. The aim is to set up a network of colleagues who are confident, open, and able to have these conversations and then have a mechanism to capture and share the information. The intention is to have the same people go to these meetings. Linda is keen to build this piece of work slowly because it will be incredibly damaging if we start to talk to community organisations and stop.</p>	<p>An update on patient interpreting to be presented at the next forum meeting</p> <p>An update on end of life care to be presented at the next forum meeting</p> <p>Remove the research briefing document for Trust management from the action log for now</p> <p>The equity diversity and inclusion statements to be scheduled for the June meeting</p>
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	<p>Community engagement has also extended to the Imperial Charity re: art support, Imperial College (Maris Piggins) and The Institute of Global Health Organisation re: patient safety (Anna Lawrence-Jones). Trish suggested that it would be useful to have feedback from these groups to increase learning and understand what is being said. Linda explained a brief content report is completed after each community event and perhaps a summary of these could be provided.</p> <p>Annual strategic lay forum report to the Trust management This will be discussed during the meeting.</p> <p>Trish mentioned whether the complaints report is worth noting. Having read the annual complaints report, one of the striking figures was the increase in neuro scan complaints. It was agreed that Trish and Linda will review whether we regularly review the complaints reports. Jane also suggested it would be important to look at our vision of how we want to operate as lay partners, as this will help us understand our engagement with communities and learning from complaints.</p>	<p>Review the lay partner vision of how we want to operate as lay partners, as this will help us understand our engagement with communities and learning from complaints</p>
<p>4.</p>	<p>Discussion and next step to build the patient voice and user-insight into digital experience - Trish Longdon, chair, strategic lay forum, Shanaka Dias, co-chair, strategic lay forum</p>	
	<p>Trish said that Kevin and Sanjay presented at the last strategic lay forum and were very open about wanting feedback on the apps and user-involvement. The consensus from the group was that this was great however we need that the patient voice is enshrined in the governance and way of doing things before the apps were released rather than after. This was outlined in our business priorities in terms of having input in some sort of user strategy. The next step is to have a meeting with Michelle, Bob and other colleagues involved including Kevin and Sanjay.</p> <p>It is important to have a conversation first to start building an overarching framework rather than one off input at some point in the process. John mentioned he is a member of the patient reference group where he feels the Care Information Exchange (CIE) has not been co-designed with patients. John wrote to Paul Harrison to address his concerns where Paul agreed and said CIE can be more information driven rather than being designed for intuitive patient use.</p> <p>Agnes stated the more complicated this gets, the more people this excludes from receiving their information.</p>	<p>Trish to meet with Kevin and Sanjay to explain lay partner involvement in digital experience</p> <p>Trish to connect with Paul Harrison re: user strategy. John Black to forward correspondence to Trish</p>
<p>5.</p>	<p>Health equity update - Bob Klaber, paediatrician and director of strategy, research, and innovation</p>	

Bob presented the paper that he and Hannah wrote for the executive management board which was held the day before. He explained one of his key points to his executive colleagues was that equity is a domain of quality and noted there is pressure from national bodies to focus on this and an opportunity for the Trust to lead in this area of work.

To start with, the focus is on patients and how we improve and make more equitable the do not attend to outpatients. Bob, Michelle and Amrish are discussing how this can be embedded in the out-patient transformation work. Amrish is very keen to contribute to discussions specifically on health equity as there is real worry around the people who do not attend appointments, i.e., 50 percent more likely to be from black community and 55% likely to be from a deprived community. There is real focus on the user insights work with an equity lens and how we can use the work around complaints and smoking to improve this area.

There is work around community engagement and how we try to tackle some of these issues where historically communities have not been good at engaging, i.e., patients may work zero hours contract, the cost to travel to the appointment. Thus, we must think differently about the offer and the service.

One of the lay partners asked whether vaping is identified as smoking. Bob mentioned this is an interesting area of work and is unsure of the answer. Vaping requires at least 10 years of experience before the real impact can be identified. There is real worry that people who stop smoking switch to vaping without the knowledge or understanding of the dangers associated with this. There is not enough research in this area.

John mentioned there was a suggestion in the paper that obesity will be addressed. Why was smoking chosen over obesity? Bob explained smoking was chosen first as there was national funding for this. In the future, there may be funding for obesity.

One of the lay partners asked whether there is a plan on how to facilitate patient and community engagement. Bob mentioned there is lot of research why patients 'do not attend' (DNA) their appointments. There have been 2,700 papers published about how to reduce DNA's all with limited patient engagement. Thus, the aim is to take a different route and to review the waiting lists to identify where the issues are and then sense check this via engagement and user insights.

Agnes mentioned whether you are more likely to stop smoking if you attend your appointments, e.g., if you weren't waiting a long time for your appointment or surgery, you are less likely to stress and thus not smoke. Bob mentioned there is a piece of work he and Michelle are working on which focuses on what actions can be done to help people psychologically manage their healthcare, i.e. if you stop smoking, get a little fitter, be mentally prepared, your outcomes will be better.

Trish met with Tim to discuss the lay partners' commitment to 'what matters to you' as part of their priorities. Tim was very positive about this and mentioned two things:

- Outlining the methodology as 'what matters to you' means different things to different people.

Bob and Michelle to provide an update on DNA and user insights

	<p>➤ Understanding how the pilot will be evaluated if no-one knows what it means.</p> <p>Trish and Michelle discussed culture change as this is for everybody, not just nurses and doctors. Trish asked whether Bob can support with the methodology so at the end the forum have something which demonstrates it made a difference and that it should be rolled out everywhere.</p> <p>Bob mentioned he has commitment to keep working with Trish and Michelle on this piece of work and can provide support from the Improvement Team and Eric Mayer regarding the research around how we utilise the neuro linguistic programme.</p> <p>Trish mentioned Michelle's great piece of work around waiting lists with the acute collaborative and setting some time at a later meeting to share the work that has been done.</p>	Michelle to share work around waiting lists with the acute collaborative
6.	Developing a user insights function and establishing user-focused metrics - Michelle Dixon, director of engagement and experience	
	<p>Linda circulated a paper which outlined our programme for this new insights and experience function. Resource and roles are working together on joint projects to prove the value of user-insights.</p> <p>The focus is on how we get hold of this data or insights i.e., complaints to make the most of the insights and act on them in pragmatic way to set achievable objectives.</p> <p>There is also focus on what needs to be done at board level to create this change and combine the programmes that support this overall goal from the various teams - quality improvement, PALS and patient safety team.</p> <p>Darius said that more hearing loops have been implemented and that several staff colleagues didn't know what they were or how to use them, demonstrating that there needs to be a greater understanding around disabilities.</p> <p>In terms of data, Agnes mentioned that it takes a lot for somebody to get to the stage where they go to PALS to raise an issue and there must be a larger number of people that want to, but do not get in touch with PALS. She asked what is being done to gather this information and data. Darius mentioned 'what matters to you' is addressing this where structured feedback can't be obtained.</p> <p>Another suggestion was to have boxes in the wards so people can anonymously complain or provide feedback, which can be analysed and reviewed.</p>	<p>Any further comments from the user insight paper to be circulated by Monday</p> <p>Date to be confirmed of the next Quality Committee.</p>
7	AOB	
	<p>Trish said that we will now start to plan and write the strategic lay forum's annual report. In past years this was presented at the Trust board but as there is now a Trust in common which the four acute trusts attend, we will share our report at the Quality Committee which is attended by some non-executive directors. Linda will create the plan and provide an update on this at the next meeting.</p>	